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The Introduction of a Legal Framework for Advance Directives in Irish Mental Health Care

This thesis is submitted to the National University of Ireland Galway in fulfillment of the requirement for the degree of

Doctor of Philosophy

by

Fiona Morrissey, BA, LL.B, LL.M, DLIS

Supervisor: Dr. Mary Keys, School of Law, NUI Galway

Head of School: Professor Donncha O’Connell
Abstract

Advance directives (ADs)\(^1\) are legal statements or documents, which allow a person to outline treatment preferences and other life choices prior to a mental health crisis. This thesis examines the issues arising in relation to the introduction of a legal framework for ADs in Irish mental health care from an international, comparative and national perspective. Ireland currently lacks legislative provisions for ADs, but it is proposed to incorporate legislative provisions into the Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill) in the near future. This thesis reviews the literature on ADs and considers the legal, ethical and implementation issues associated with their use under international, comparative and domestic frameworks and from the perspective of key stakeholders. The views and preferences of Irish stakeholders are addressed through an original empirical study. The international research considers the introduction of ADs under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD requires a new approach to decision-making in mental health care and the development of a range of support strategies. The thesis will consider the implications of the CRPD on the conceptual foundation of ADs and their role under new human rights frameworks. The thesis also includes a comparative study into an innovative approach to the implementation of ADs in the State of Virginia in the United States. The aim of the empirical research is to determine the views and preferences of Irish service users and consultant psychiatrists towards the proposed use of ADs and the extent to which they will be supported in Ireland. The empirical research found broad support for ADs among Irish stakeholders, but varying implementation preferences. The research makes recommendations for the introduction and implementation of an appropriate legal framework for mental health ADs in Ireland and other jurisdictions under international human rights frameworks.

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\(^1\) The term advance directive (AD) is used to refer to a legal document or statement, which allows individuals to state treatment preferences and other life choices prior to a mental health crisis.
Declaration of Originality

24th March 2014.

The substance of this thesis is the original work of the author and due reference and acknowledgement has been made, when necessary, to the work of others. No part of this thesis has been accepted for any degree and is not concurrently submitted for any other award. I declare that this thesis is my original work except where otherwise stated.

Name of Candidate

____________________________

Signature of Candidate

____________________________
Acknowledgements

I would like to profusely thank my supervisor Dr. Mary Keys for her relentless support and encouragement. She went beyond her call of duty at every stage of the process and is a shining example to the School of Law at NUI Galway. She is an amazing supervisor and person.

I would especially like to thank my loving husband Mark for his continuous support and help throughout this journey. I couldn’t have done it without you. I would also like to thank my parents for their support throughout my life and education.

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The visit to Virginia and the National Resource Centre for Psychiatric Advance Directives was a pivotal turning point in this research. I would like to especially thank Professor Richard Bonnie at the University of Virginia and the National University of Ireland Travelling Studentship in the Humanities and Social Sciences for making this possible. I would like thank all the stakeholders in Virginia for so generously sharing their time and expertise with me during visit and a special thanks to John Oliver for his comments on the draft legislation in Ireland and to Dr. Jeffrey Swanson for ongoing support.
I also wish to thank Charles O’Mahony for his ongoing encouragement and our long PhD chats! It is impossible to list everybody who helped in small ways and provided moral support throughout this journey, but I would to thank everybody who made it possible.
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Table of Cases

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_Croke v Smith (No. 2) [1998]_ 1 IR 101.

_Fitzpatrick v FK (No. 2) [2008]_ IEHC 104.

_EH v Clinical Director of St Vincent’s Hospital [2009]_ 3 IR 774.

_JH v Lawlor [2008]_ 1 IR 476.

_JM v The Board of Management of St Vincent’s Hospital [2002]_ 1 IR 321.

_KC v St. Loman’s Hospital [2013]_ IEHC 310.


_MR v Byrne [2007]_ 3 IR 211.

PL v Clinical Director of St Patrick’s Hospital [2012] IEHC 15.


Re a Ward of Court (No.2) [1996] 2 IR 79.


RT v Director of Central Mental Hospital [1995] 2 IR 65.

2. United States


Cruzan v Director, Missouri Department of Health 497 US 261 (1990).


Schindler v Schiavo (In Re Schiavo), 780 So 2d 176, 180 (Florida District Court App 2001).


3. England and Wales

A Local Authority v E [2012] EWHC 1639 COP.

B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449.


Re C (Adult: refusal of treatment) [1994] 1 WLR 290.

Re F (Mental Patient: Sterilization) [1990] 2 AC 1.


In the matter of Re P (A Child) [2013] EW Misc 20 (CC).


4. Canada


5. Germany

6. Judgments of the European Court of Human Rights
AK and L v Croatia, Application No 37956/11, Judgment 8 January 2013.

Bayatyan v Armenia, Application No 23459/03, Judgment 7 July 2011.

Croke v Ireland, Application no 33267/96 (struck out 21 December 2000).

DD v Lithuania, Application No 13469/06, Judgment 14 February 2012.

Glor v Switzerland, Application No 13444/04, Judgment 30 April 2009.

Herzegefalvey v Austria (1992) EHRR 437.

HL v United Kingdom (2005) 40 EHRR 761.

Lashin v Russia, Application No 33117/02, Judgment 22 January 2013.

Jehovah’s Witnesses of Moscow v Russia, Application No 302/02, 10 June 2010.

MS v Croatia, Application No 36337/10, Judgment 25 April 2013.

Keenan v United Kingdom (2001) 33 EHRR 913.


Pretty v United Kingdom, Application No 2346/02, Judgment 29 April 2002.


Salontaji-Drobnjak v Serbia Application No 36500/05, Judgment 13 October 2009.

Shtukaturov v Russia, Application No 44009/05, Judgment 27 March 2008.

Stanev v Bulgaria, Application No 36760/06, Judgment 17 January 2012.


Winterwerp v the Netherlands, Application No 6301/73, Judgment 24 October 1979.

X and Y v Netherlands (1986) 8 EHRR 235.
Table of Legislation

1. Ireland


Criminal Lunatics (Ireland) Act 1838.

Disability Act 2005.


Health Act 2004.

Health Identifiers Bill 2013.

Lunacy (Ireland) Act 1826.

Lunacy Act 1821.

Lunacy Regulation (Ireland) Act 1871.

Mental Capacity Bill 2008.

Mental Health Act 2001.
Mental Health Act 2001 (Approved Centres) Regulations 2006, Article 15, 16 of Statutory Instrument No 551.

Mental Treatment Act 1945.

Private Lunatic Asylums (Amendment) Act 1842.

2. International Human Rights Law


Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (IACPD).


UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (New York, 10 December 1984)


3. Soft Law
Council of Europe Recommendation No R (99) 4 of the Committee of Ministers to Member States Concerning the Legal Protection of Incapable Adults, adopted on 23 February 1999.


Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012).

Council of Europe, Recommendation 1993, Protecting Human Rights and Dignity by taking into account Previously Expressed Wishes of Patients (Council of Europe 2012).


UN Declaration on the Rights of Mentally Retarded Persons, GA res 2856 (XXVI) 26 UN GAOR Supp (No 29) at 93, UN Doc A/8429 (1971).


4. **Canada**


   Decision-Making Support and Protection to Adults Act, SY 2003.


   Health Care Consent Act SO 1996 (Ontario).

5. **England and Wales**

   Mental Capacity Act 2005.

   Mental Health Act 1983.

   Mental Health Act 2007.
6. United States

Human Rights Regulations 12VAC35-115-70, Virginia.

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List of Abbreviations

AD  Advance Directive
ADA  Americans with Disabilities Act
AI  Amnesty International Ireland
ANH  Artificial Nutrition and Hydration
ARI  Advancing Recovery in Ireland
CAT  Convention Against Torture
CMHT  Community Multi-Disciplinary Mental Health Teams
CDBI  Council of Europe Steering Committee on Bioethics
CPT  European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment
CRPD  United Nations Convention on the Rights of Persons with Disabilities
CSO  Central Statistics Office
DCU  Dublin City University
ECHR  European Convention on Human Rights and Fundamental Freedoms
ECtHR  European Court of Human Rights
ECT  Electroconvulsive Therapy
EPA  Enduring Powers of Attorney
ESC  European Social Charter
EU  European Union
F-PADs  Facilitated Directives
HSE  Health Service Executive
IACPD  Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities
ICCPR  International Covenant on Civil and Political Rights
ICESCR  International Covenant on Economic, Social and Cultural Rights
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<td>IMG</td>
<td>Independent Monitoring Group</td>
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<td>Irish Medical Organisation</td>
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<td>ImROC</td>
<td>Implementing Recovery through Organisational Change</td>
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Dissemination of Research

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Book Chapters

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Lectures related to research
2013: Department of Psychology, National University of Ireland Galway, PhD
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Policy Submission to the Department of Health on the Draft General Scheme for
Advance Healthcare Directives for Incorporation into the Assisted Decision-Making
(Capacity) Bill 2013, 7th March 2014

Prepared the Mental Health Commission Response to the Public Consultation on
the Draft Scheme for Advance Healthcare Directives, March 2014

Individual response to the Public Consultation on the Draft Scheme for Advance
Healthcare Directives, March 2014
“Imagine if someone else was making decisions for you. They could decide to take you away, lock you up, not listen to you, give you medication, block you from doing your work and living your life with your body and mind the way they are.

WOULD YOU WANT THIS TO HAPPEN TO YOU?

Wouldn't you have the feeling that you have lost your dignity and want it back?”

CHAPTER 1
1. Introduction

The introductory quote to the chapter prompts us to reflect on the dehumanising impact of decisions being made on our behalf or being forced upon us. This is a reality for many thousands of individuals when they enter the mental health system for treatment and care and may happen to any one of us during the course of our lives. Mental health conditions affect approximately 450 million people worldwide and have a profound impact on individuals, families and society. Mental distress is a universal feature of all societies. It is found in men and women at all stages of the life course and among people from varying backgrounds in different countries. The treatment of mental distress is a growing human rights issue both in Ireland and internationally. This thesis examines the issues relating to the introduction of a legal framework for advance directives (ADs) in mental health care. Advance directives (ADs) are legal statements or documents, which allow a person to outline treatment preferences and other life choices prior to a mental health crisis when decision-making autonomy may be vulnerable. The measure serves to restore the voice of the person during periods when it is so often disregarded. Ireland currently lacks legislative provisions for ADs, but it is proposed to incorporate them into the

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1 Quotation from the International Disability Caucus’ advocacy paper during Ad Hoc Committee on a Comprehensive and Integral International Convention on and Promotion of the Rights and Dignity of Persons with Disabilities, Nothing about Us without Us, January 31, 2006.
4 Life course refers to the sequence of events, roles and age categories that people pass through from birth until death, all of which are culturally defined. <https://www.boundless.com/sociology/definition/life-course/> [accessed 17 March 2014].
5 The term advance directive (AD) is used to refer to a legal document or statement, which allows individuals to state treatment preferences and other life choices prior to a mental health crisis.
Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill) in the near future. The draft Irish legislation for advance healthcare directives was published and opened for public consultation in February 2014. This thesis includes seven chapters that analyse the use of ADs from the perspective of international, comparative law and domestic law and the views of Irish service users and consultant psychiatrists. The research will serve to inform the introduction and implementation of a national legal framework for ADs in Irish mental health care and under international human rights law.

2. Study Overview

The inclusion of ADs in mental health settings is part of an international impetus towards promoting human rights for persons with mental health conditions. The measure has gathered momentum in the past decade and is increasingly recognised as an important decision-making tool. Individuals with mental health conditions have been traditionally excluded from decisions involving their treatment and care and have had little influence over their destiny. ADs provide a novel solution to this dilemma by enabling treatment and other life choices to be articulated prior to a mental health crisis. The measure aims to preserve the legal capacity of the person and to ensure his/her wishes are known to providers and carers. The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) requires State Parties to develop support measures, which respect the ‘will and preferences’ of the person. ADs are increasingly recognised as strategies for giving individuals with mental health conditions more say in the management of their treatment and their lives.

A broad fundamental consensus exists on the appropriateness of ADs in the mental health context. However, the debate reveals a myriad of ethical and policy issues requiring further exploration. The use of mental health ADs raises conflicts in

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9 Peter Lack, Nikola Biller-Andorno and Suzanne Brauer, Advance Directives (Springer 2014) v.
relation to self-determination and the state desire to protect the individual and other citizens. ADs are viewed as symbolising a cultural shift away from paternalism towards care based on the needs and the preferences of the person. The thesis presents an overview of the issues from an international and Irish perspective. While much has been written internationally concerning ADs, there is a dearth of Irish research on the topic. Empirical research addressing stakeholder views of ADs is currently lacking in Ireland and has never been addressed in any detail prior to this study. The limited research has focussed on ADs for end-of-life care. Few empirical studies have been conducted on ADs in mental health care. The application of research from other jurisdictions is useful, but limited by the context. It is therefore necessary to consider the feasibility of implementing ADs from an Irish and a CRPD perspective. In order for mental health ADs to be effectively implemented in Ireland, it is important to understand the views of service users and consultant psychiatrists. This thesis addresses the views of national stakeholders through an empirical study.

A number of theoretical frameworks underpin the use of ADs in mental health care. In this thesis, ADs are examined using five theoretical approaches. These include human rights; autonomy; the social model of disability; therapeutic jurisprudence and the recovery approach. The theoretical framework provides a conceptual map for the thesis and will synthesise AD knowledge in the subsequent international, comparative, Irish and empirical chapters. The CRPD requires the consideration of ADs from a new human rights perspective and a re-evaluation of traditional approaches to legal capacity. This thesis expands current knowledge of ADs both in Ireland and internationally, by examining the supported decision-making requirements of the CRPD and effective implementation strategies. One of the central arguments of this thesis is that individuals with mental health conditions have a right to exercise their legal capacity through the development of an AD and have those choices respected on an equal basis with others. Capacity and mental health legislation will have to be reformed to ensure equal access and a culture of respect for preferences. The thesis highlights the importance of considering ADs in the broader context of supporting the exercise of legal capacity and enhancing recovery.

10 In this thesis, the term ‘service user’ is used to refer to those with a lived experience of mental unwellness and involved with mental health services for treatment. The term ‘consumer’ is often used in the U.S. The World Network of Users and Survivors and Psychiatry use the term ‘survivor’.
outcomes. Krone and Bastami outline the potential for ADs to evolve from a legal document into a person-oriented process emphasising communication and support.\textsuperscript{11} The thesis arguments will be outlined in more detail in chapter 2.

3. Background to the Research in Ireland

The proposal to introduce a legislative framework for ADs in Ireland can be traced back to the Law Reform Commission (LRC) consultation paper on Law and the Elderly in 2003\textsuperscript{12} and the subsequent report in 2006.\textsuperscript{13} The LRC’s second programme of law reform recognised the need for changes in the law in relation to vulnerable adults. The report on Vulnerable Adults and the Law informed the publication of a draft Mental Capacity Bill in 2008 (2008 Bill), which proposed to replace the ward of court system governed by the Lunacy Regulation (Ireland) Act 1871.\textsuperscript{14} This has since been replaced by the Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill). The 2008 Scheme led to the publication of a consultation paper on ADs and a report in 2009.\textsuperscript{15} The final report drew on the research undertaken by the Irish Hospice Foundation\textsuperscript{16} and the work of the Irish Council of Bioethics.\textsuperscript{17} The LRC recommended that the proposed statutory framework for ADs should be facilitative in nature and be viewed in the wider context of healthcare planning.\textsuperscript{18} The 2009 report proposed a legal framework for ADs under new capacity legislation,\textsuperscript{19} but specifically excluded ‘psychiatric advance directives’ from its

\textsuperscript{11} Tanja Krones and Sohaila Bastami, ‘From Legal Documents to Patient-Oriented Processes; The Evolution of Advance Care Planning’ in Peter Lack, Nikola Biller-Andorno and Suzanne Brauer, \textit{Advance Directives} (Springer 2014) 193-200.
\textsuperscript{18} Law Reform Commission, \textit{Bioethics: Advance Care Directives} (LRC 94-2009) para 170.
\textsuperscript{19} Department of Justice and Equality, Scheme of Mental Capacity Bill 2008 (Department of Justice and Equality 2008).
scope due to the inherent complexities.\textsuperscript{20} The report recommended a separate review of the Mental Health Act 2001 and the role of the Mental Health Commission for this area.\textsuperscript{21}

Ireland still lacks a legislative framework for ADs, but it is proposed to incorporate them into the 2013 Bill in the near future. An Advance Healthcare Decisions Bill was presented to the Dáil in 2012 and referred to a select sub-committee on health, but was subsequently withdrawn.\textsuperscript{22} The 2012 Bill excluded mental health treatment decisions under the 2001 Act. In the absence of legislation, many Irish hospitals and professional bodies developed guidelines and protocols. The Irish Medical Council and the National Consent Policy provide guidance for health services staff.\textsuperscript{23} The Irish Hospice Foundation launched an advance planning project for end-of-life decisions in 2009 and is currently conducting regional pilots. The development of an AD forms just one part of the wider healthcare planning process in the ‘Think Ahead’ project.\textsuperscript{24}

The law in relation to individuals with mental health conditions has evolved rapidly in Ireland over the past decade. A number of significant developments in mental health law and policy provided the foundation for the current research. Similar to other jurisdictions, Ireland has separate legislative frameworks for mental health and capacity law, which apply to individuals with mental health conditions and those who may need decision-making assistance. The commencement of the Mental Health Act 2001 (2001 Act) in 2006 marked a major reform in mental health law and practice in Ireland. The 2001 Act moved towards a rights-based approach to mental health law and was a significant departure from the Mental Treatment Act 1945.

\textsuperscript{20} Law Reform Commission, Bioethics: Advance Care Directives (LRC 94-2009).
\textsuperscript{21} The Mental Health Commission is an independent statutory body, which was established in April 2002 under the provisions of the Mental Health Act, 2001. The principal functions of the Commission are to promote, encourage, and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services and to take all reasonable steps to protect the interests of persons detained in approved centres.
(1945 Act), which was considered to be paternalistic in nature. The 2001 Act was influenced by the procedural rights approach under the European Convention on Human Rights (ECHR). The mental health policy framework, ‘A Vision for Change’, was also published in 2006 and provided a blueprint for the modernisation of mental health services in Ireland. The new policy proposed significant changes and improvements for Irish mental health services including recommendations for empowerment, advocacy and recovery. The policy promotes the involvement of service users at every level of service provision and explicitly supports the use of ADs. It identified the need for a shift within mental health services from one dominated by the biomedical model to a recovery orientation. The policy formally introduced the recovery approach into the Irish mental health services along with the ‘Quality Framework for Mental Health Services in Ireland’. Significant improvements had been achieved in deinstitutionalisation and the focus was shifting to community based services. While the number of individuals in institutions decreased five-fold during this period, the prison population increased five-fold, suggesting a significant correlation between the number of individuals in psychiatric units and prison figures. The importance of participation also emerged in a number of Irish health policy documents during this period culminating in the ‘National Service User Involvement Strategy’ in 2008. The 2001 Act required each service user to have an individual care plan, to participate in the admission process and have regard for autonomy in making decisions. The dignity, autonomy of the person and right to self-fulfilment was viewed to be enshrined most strongly in the individual

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26 Ibid 30.
27 Mental Health Commission Ireland, Quality Framework: Mental Health Services in Ireland (Mental Health Commission 2007).
28 The number of individuals in public psychiatric hospitals had fallen to 3,389 in 2006 from a peak of 21,075 in 1961.
32 Mental Health Act 2001 (Approved Centres) Regulations 2006, Article 15 of Statutory Instrument No 551; Mental Health Act 2001, s 4(2), s 4(3).
care plan. The Disability Act 2005 and the National Disability Strategy also promoted the social inclusion of persons with disabilities.

A service user movement also developed in Ireland during this period with the establishment of the Irish Advocacy Network in 1999 and the emergence of organisations such as Mind Freedom Ireland and the Critical Voices Network over the past decade. A National Service Users Executive (NSUE) was established in 2007. In 2003, AI began an influential campaign on mental health in Ireland with a series of reports and the establishment of an ‘Experts by Experience Advisory Group’. These reports outlined criticisms of Irish mental health treatment, and measured it against international human rights standards. The next two phases of the campaign focused on the implementation of ‘A Vision for Change’, the review of the 2001 Act, the introduction of new capacity legislation and CRPD ratification. The Centre for Disability Law and Policy at NUI Galway were also instrumental in lobbying for reform of capacity legislation in line with CRPD standards. Other lobby groups such as, Mental Health Reform, have now been established to call for improvement in mental services and the implementation of human rights standards and government policy.

At international level, the first UN human rights treaty of the new millennium was opened for signature in early 2007 and entered into force in 2008. The CRPD was the first human rights treaty to explicitly apply to persons with disabilities and to be ratified by the European Union (EU) in its own right. Ireland signed the CRPD in 2007, but has not yet ratified its terms. The CRPD is expected to be ratified as soon as the ward of court system governed by the Lunacy Regulation (Ireland) Act 1871 is replaced with new capacity legislation. The Committee on the Rights of Persons with

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35 The function of NSUE is to inform the National Health Service Directorate and the Mental Health Commission on issues relating to service user involvement and participation in planning, delivering, evaluating and monitoring services and to develop and implement best practice guidelines between the service user and provider interface.

36 Mental Health Reform promotes improved and prioritised mental health services in Ireland. The lobby group works with its members through education, information, support and training to help bring about structural and cultural changes in mental health matters.

37 A/RES/61/106.

38 The EU became the 97th party to the treaty when it ratified it on the 23rd of December 2010. Twenty four of the 28 EU Member States have ratified the CRPD to date.
Disabilities has repeatedly stated that States Parties must review laws allowing for guardianship and replace substitute decision-making regimes.\(^3^9\) The CRPD is now a key driver of Irish law reform, along with the ECHR. In 2011, the new Irish coalition government committed to ratifying the CRPD and to enacting new capacity legislation.\(^4^0\) The CRPD requires the abolition of substitute decision-making regimes to one based on supported decision-making.\(^4^1\) It requires State Parties to develop a broad range of measures to support the exercise of legal capacity including ADs.\(^4^2\)

ADs were also formally recognised at European level during this period. The Council of Europe first recognised ADs in the Convention on Human Rights and Biomedicine (Oviedo Convention)\(^4^3\) in 1997. ADs and continuing power of attorney were subsequently recognised as the principal means of self-determination for individuals anticipating future impairment in decision-making in a Council of Europe Recommendation in 2009.\(^4^4\) The Council of Europe further built on the 2009 recommendations by adopting a further Parliamentary Assembly resolution on ADs in 2012.\(^4^5\) The resolution states that it is essential for member states to enact and fully implement legislation on ADs. ADs have also been referred to in the case law of the European Court of Human Rights (European Court).\(^4^6\)

The new Fine Gael/Labour coalition government began the process of capacity law reform in 2011 on foot of a commitment in the Programme for Government and claims that the 2008 Scheme did not comply with international human rights standards. The government also committed to reviewing the Mental Health Act, 2001. The Department of Health is currently undertaking a review of the 2001 Act,


\(^{4^1}\) Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention-Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 46

\(^{4^2}\) Ibid para 24.

\(^{4^3}\) Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Council of Europe 1997). Ireland did not sign or ratify the Oviedo Convention.


\(^{4^5}\) Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012).

\(^{4^6}\) Jehovah’s Witnesses of Moscow v Russia, Application No 302/02, Judgment 10 June 2010.
following the publication of an interim report in 2012. \textsuperscript{47} The Oireachtas Justice Committee conducted a series of hearings on the proposed capacity legislation in 2012 and advocacy groups hosted a number of conferences and seminars. Many of the changes to the 2013 Bill were attributed to engagement with civil society groups. The 2013 Bill published in July 2013, proposes to provide a modern statutory framework for those who need assistance in making decisions in Ireland and is viewed as a key step towards CRPD ratification. It is planned to incorporate legislative provisions for ADs into the 2013 Bill at the Committee stage of the legislative process in 2014. A draft general scheme of legislative provisions for advance healthcare directives was published and opened for public consultation by the Department of Health in February 2014. \textsuperscript{48} The scheme proposes a single legislative framework, which encompasses ADs for general and mental health care.

\section*{4. Aims and Objectives}

In the context of the preceding discussion, this thesis aims to investigate the introduction of an Irish legal framework for mental health ADs and to propose an appropriate implementation model. The evolving human rights framework and the recovery approach show the need for measures that support the exercise of legal capacity and provide for increased participation in mental health treatment. ADs are proposed as an innovative and effective way to support the exercise of legal capacity and to reduce the need for coercion. This research will examine the legal and ethical issues associated with ADs and propose effective implementation strategies. The thesis will review the literature on ADs; assess the impact of international human rights agreements; examine the Irish legal, policy, mental health system and cultural context; consider comparative models; and the views of Irish stakeholders. In order for ADs to be effectively implemented, it is important to understand whether such documents will be supported at national level. The objective of the empirical research is to determine the views of Irish service users and consultant psychiatrists. These views will help inform Irish legislation and policy. The international, comparative and empirical research will provide a theoretical basis in which to discuss the introduction and implementation of a legal framework for ADs in


\textsuperscript{48} Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.'
Ireland. In order to address the aims and objectives, the thesis will pose the following specific research questions:

1. What are the theoretical frameworks underpinning ADs?
2. What are the legal, ethical and implementation issues associated with ADs?
3. What is the status of ADs under international and European human rights frameworks? Which model is suited to implementation under the CRPD?
4. What are the potential issues for the implementation of ADs in the Irish context?
5. To what extent are comparative legal frameworks suited to Ireland?
6. What are the views and preferences of Irish service users and consultant psychiatrists towards their proposed use? To what extent are they willing to support them?
7. What are the perceived barriers and benefits to the use of ADs in Ireland?
8. Which legal framework, if any, is appropriate for implementation in Ireland?

This thesis aims to investigate the introduction of an Irish legal framework for ADs and propose a suitable implementation model under the CRPD. This will be achieved by:

- Describing the various theoretical frameworks underlying ADs;
- Discussing the different forms of ADs and the legal, ethical and implementation issues associated with their use;
- Examining the status of ADs under international human rights frameworks and assessing the requirements under the CRPD and European instruments;
- Considering the legal, policy, mental health system and cultural context in which ADs will operate in Ireland;
- Analysing the introduction and implementation of a comparative legal framework in the State of Virginia in the United States (U.S.) with a view to making recommendations for Ireland;
- Conducting empirical research to determine the views and preferences of Irish service users and consultant psychiatrists towards ADs and the extent they will be supported;
• Proposing the introduction of a suitable legal framework for ADs under the CRPD and effective implementation strategies.

The research seeks to provide an alternative response to mental health crises, to restore the capacity of the individual, to provide equal recognition of mental health treatment decisions and to inform legal and policy makers when contemplating the introduction of legislative provisions in this area. It is necessary to limit the scope of this thesis to the analysis of law and policy relating to ADs for individuals with mental health conditions. The use of ADs in other contexts is considered, where it is related to their overall development and implementation.

5. Chapter Outline
The introduction of legislative provisions for ADs requires consideration of the theoretical and human rights framework underpinning their use. Chapter 2 sets out the various theoretical frameworks underlying the use of ADs in mental health care and reviews the issues that arise in the literature in relation to their use. The chapter begins with a review of the historical development of ADs and an examination of the theoretical frameworks underlying their use. These frameworks include human rights, autonomy, the social model of disability, therapeutic jurisprudence and the recovery approach. The various legal, ethical, logistical and operational factors associated with ADs and the views of stakeholders will also be discussed. This will provide a foundation for exploring the views and preferences of Irish service users and consultant psychiatrists and the status of ADs under Irish, international and comparative legal frameworks in subsequent chapters. This chapter also identifies gaps in the international literature and suggests that the developmental impact of ADs and effective implementation strategies require further research.

Chapter 3 addresses the introduction of ADs under international and European legal frameworks. This chapter specifically focuses on the CRPD and European frameworks and recommendations. The ECHR and the CRPD are key drivers of reform in Ireland. The CRPD provides a new human rights framework for the implementation of ADs and requires them to be separated from traditional frameworks predicated on capacity and incapacity. The use of ADs under the supported decision-making model in the CRPD is part of the context in which they
can develop. The literature has yet to consider the implementation of appropriate forms of ADs under the new approach to legal capacity in the CRPD and their role under the supported decision-making model. It is therefore necessary to consider the implementation of ADs from a CRPD perspective. The analysis of the international and European human rights frameworks in this chapter will set the stage for the consideration of ADs in the Irish context. The original foundation for this chapter was published in the European Journal of Health Law in 2012.\(^\text{49}\) A version of this chapter was also submitted for a book chapter publication on the introduction of ADs under the CRPD in 2012.\(^\text{50}\) This is due to be published in the near future.

The introduction of a legal framework for ADs requires consideration of the legal, policy, cultural and other system contexts in which they will operate. Chapter 4 will consider the features of the Irish legal, policy and mental health system framework. The aim of this chapter is to consider the proposed introduction of ADs under the Irish legal framework and the requirements for implementation in Ireland. This will be achieved by examining the history of mental health treatment in Ireland, the legislative and policy framework and the relevant system and cultural context. The features of the Irish framework will set the context for the comparative and the empirical study in chapters 5 and 6.

Chapter 5 will examine the introduction and implementation of a legal framework for ADs in the State of Virginia in the United States and compare it with the CRPD principles, the recovery approach and the provisions of the 2013 Bill. This chapter is based on a research visit by the author to the University of Virginia, State of Virginia mental health services, AD pilot sites and the National Resource Centre for Psychiatric Advance Directives at Duke University in 2012.\(^\text{51}\) This visit included meetings and interviews with key stakeholders and international experts in the field. While ADs have received extensive legislative support internationally, little is


\(^{51}\) The visit was funded by a National University of Ireland, Travelling Studentship Award in the Humanities and Social Sciences. See Appendix.
known about how they can be effectively implemented into practice. The State of Virginia is at the forefront of international efforts to successfully implement a legal framework for ADs into mental health practice. An innovative new healthcare law integrates a broad range of healthcare decisions, including mental health treatment decisions, into a single AD. Virginia is undertaking an unprecedented attempt to successfully implement ADs in mental health settings on a system wide basis and achieve higher levels of participation. The three-phase study focuses on knowledge, attitudes to facilitation, content and completion and will help inform the implementation of ADs in other jurisdictions. Chapter 5 will consider the features of the Virginia legislation and implementation strategy with the features of the CRPD and the 2013 Bill with a view to informing the Irish State at a critical juncture in the legislative process. A version of this chapter was published in the Medico-Legal Journal of Ireland in December 2013 and sent to officials in the Department of Health involved in drafting the AD legislation.

Chapter 6 of the thesis is an empirical study conducted with 111 Irish service users and 100 consultant psychiatrists. The effective implementation of a legal framework for ADs is dependent on the support of key stakeholder groups involved in development and enforcement. Stakeholder research can determine expectations and preferences in relation to implementation. This study examines support for the introduction of ADs, preferences for implementation and the perceived benefits and barriers. The empirical study reveals broad support for ADs in both stakeholder groups, but varying preferences and barriers to implementation. The findings of the study will have significant implications for individuals drafting legislation and will assist them in understanding stakeholder support and preferences for ADs.

Chapter 7 draws on the research in the previous five chapters to make final conclusions and recommendations for the introduction and implementation of a legal framework for ADs. The thesis concludes by integrating the international, comparative, Irish and empirical research to propose an Irish legal framework for ADs and appropriate implementation strategies. The proposals will assist national

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and international legislators, policy makers and mental health professionals to consider the requirements for the introduction of legislative provisions for ADs. In addition, to concluding on the legal framework, strategies for the effective implementation of ADs into mental health practice are also proposed. This research provides a unique contribution to knowledge by providing the first comprehensive study on ADs for individuals with mental health conditions from both a CRPD and Irish perspective. The research provides an unprecedented opportunity to identify a model, which complies with the CRPD and can be successfully implemented under the Irish legal framework. The recommendations for the legal framework and implementation strategies informed by this research are compared with the proposals of the draft scheme for ADs published by the Department of Health in February 2014. The international, comparative and empirical research will inform answers to specific questions posed on the introduction of legislative provisions for ADs as part of the public consultation and included in the conclusions and recommendations. Both the empirical and the conclusions chapters provide directions for future research on ADs in Ireland and other jurisdictions.

6. Contribution to Knowledge

This thesis will add to existing knowledge in several innovative ways:

- Challenge the current lack of a legal framework in Ireland;
- Analyse the legal, ethical and implementation issues associated with ADs in Ireland and internationally;
- Consider the adoption of appropriate forms of ADs under the CRPD;
- Provide an Irish and international perspective on ADs;
- Undertake a comparative study of ADs with a view to recommending an appropriate model for Ireland and other jurisdictions;
- Examine the views and preferences of Irish service users and consultant psychiatrists;
- Contribute to a broader attitudinal shift in the conceptualisation of persons with mental health conditions and their capacity to make decisions.

53 Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.”
CHAPTER 2
A Theoretical Framework and a Review of the Literature on Advance Directives in Mental Health Care

1. Introduction
The aim of this chapter is to set out the various theoretical frameworks that inform the use of ADs in mental health care and to identify the issues, which arise in the literature in relation to their use. This will be achieved by defining ADs and their scope; examining their historical development; outlining the theoretical frameworks underlying their use; identifying the comparative legislative approaches and synthesising the issues in the literature. The first part of this chapter will define ADs, describe their historical development, and outline the theoretical frameworks underpinning their use. This will be followed by a discussion of the varying forms of ADs, the associated benefits and barriers and the views of clinicians, families and service users. The various legal, ethical, logistical and operational factors associated with ADs will also be addressed. This will provide a basis for analysing the use of ADs under international and national frameworks and exploring the views and preferences of Irish service users and consultant psychiatrists in subsequent chapters. This chapter will help inform the implementation of an appropriate legal framework in Ireland in conjunction with the international, Irish, comparative and empirical chapters.

1.1 Advance Directives in Mental Health Care v End-of-Life Directives
ADs were originally developed to allow individuals to communicate their wishes regarding end-of-life care. The human rights activist and lawyer, Luis Kutner, first proposed the ‘living will’ or end-of-life directive as a way for individuals to state their healthcare desires when they were no longer able to express them. The aim of the measure was to maintain the individual’s ‘voice’ in medical decision-making and empower individuals to dictate end-of-life care. The ‘living will’ was then extended to the mental health context, allowing treatment and other life choices to be

expressed in advance of a mental health crisis. While both directives share the goal of autonomy, the context by which this objective is realised varies. The goal of general ADs is usually to increase dignity and autonomy at the end-of-life, whereas the objective of mental health ADs is often to maximise recovery, minimise unwanted interventions and treatment, while also enhancing dignity and autonomy.  

Mental health ADs can be distinguished from end-of-life directives in two ways. The end-of-life directive is often based on a situation the person may not yet have experienced, whereas the mental health AD is usually based on personal experience of a recurring condition.  

The end-of-life directive is only used once, whereas an AD for mental health may be used many times. Backlar describes the distinction succinctly, “one directive attempts to guarantee for those who so desire, a good death; while the other endeavours to secure, for a specific population of individuals a good life.”

1.2. Development

ADs developed with the social movements in the United States (U.S.) in the 1960s and 1970s. The service user and the international human rights movement raised questions in relation to traditional mental health treatment and institutionalised care. Mental health ADs originated in both the end-of-life and the anti-psychiatry movement. A series of high profile cases in the U.S. drew public attention to the issues around life-sustaining treatment for individuals who were unable to communicate their wishes. The ground breaking decision in *Cruzan v Director of Missouri Department of Health* extended the right to refuse medical treatment to

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7 *Re Quinlan* 355 A 2d 647 (1976); *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990); *Schindler v Schiavo (In Re Schiavo)*, 780 So 2d 176, 180 (Florida District Court App 2001).
8 *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990). Nancy Cruzan was a young woman who was left in serious vegetative state after a serious car accident. Justice O’Connor was prepared to protect advance directives under the 14th amendment of the U.S. Constitution.
incompetent patients who were unable to express a choice. The *Cruzan*\(^{10}\) decision had a monumental impact on the development of ADs in the U.S and resulted in the enactment of the Patient Self-Determination Act 1990 (PSDA). The PSA requires federally supported healthcare providers to ask every adult patient if he/she has an AD and give them the opportunity to complete one. This social and legal environment laid the foundation for the use of mental health ADs.\(^{11}\) Appelbaum mooted the idea of using ADs for mental health treatment in the *New England Journal of Medicine* in 1979 when he asserted:

““The idea’s undoubted appeal in medical settings is exceeded only by its potential utility on the psychiatric ward.””\(^{12}\)

Thomas Szasz first suggested the notion of a ‘psychiatric will’ in the early 1980s.\(^{13}\) This involved taking a patient’s express refusal or consent to future mental health treatment into account. Szasz argued that individuals should be legally empowered to forgo unwanted psychiatric interventions and that ADs were equally applicable in the mental health context. The critiques of coercive interventions and social control in mental health fuelled further interest in ADs.\(^{14}\) The AD movement gathered support from advocacy organisations, consumers, lawyers and clinicians. The first reported court decision occurred in the U.S. in 1991, when a New York court upheld a written directive refusing electroconvulsive treatment (ECT) in the case of *Rosa M*.\(^{15}\) The court referred to the prior competent wishes of the patient expressed in a brief signed statement. It was held that the hospital must respect a patient’s competent rejection of certain medical procedures in the absence of an overriding state interest. The U.S. Supreme Court subsequently held that individuals with

\(^{10}\) *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990).


Mental health conditions have the equivalent right to refuse treatment even when subject to involuntary commitment.\textsuperscript{16}

Mental health ADs have since received extensive legislative support internationally and are currently available in 26 U.S. states. The debate on ADs has advanced in a number common law countries and resulted in legislative reform in some cases.\textsuperscript{17} The dearth of case law on ADs for mental health decisions is reflective of difficulties accessing the legal system and inherent stigma in the courts.\textsuperscript{19} The failure of advocacy organisations to pursue litigation is viewed as a major barrier to their success in the U.S.\textsuperscript{20} Mental health ADs have lagged behind the broader advance planning movement and remained somewhat isolated. The international legislation and case law reflects a desire to limit the use of ADs through exceptions to enforcement and revocability.\textsuperscript{18} The de facto only area where advance decisions can be overridden. Atkinson and Reilly argue that the key issue is whether mental health legislation can override an AD and the circumstances in which this is permissible.\textsuperscript{22} Few jurisdictions fully respect the directive during involuntary commitment, permit the refusal of all treatment or allow advance authorisation of hospitalisation. No jurisdiction allows a person to refuse involuntary admission to hospital, even if they cannot be treated. Jamison highlights how stigma embeds itself into policy decisions resulting in institutional discrimination.\textsuperscript{24} Human rights campaigners claim discriminatory standards reinforce stigma and diminish

\begin{itemize}
\item \textsuperscript{16} Riggins v Nevada 504 US 127 (1992).
\item \textsuperscript{17} Vitek v Jones 445 US 127 (1992).
\item \textsuperscript{18} Australia, New Zealand, England and Wales, Scotland, Canada and the United States.
\item \textsuperscript{19} Stigma is a socially constructed mark of disapproval, shame or disgrace that causes significant disadvantage through the curtailment of opportunities. Jennifer Martin, ‘Stigma and Student Mental Health in Higher Education’ (2010) 29 (3) Higher Education Research & Development 259.
\item \textsuperscript{20} The low uptake of the habeas corpus remedy, whereby individuals with mental health conditions can challenge the legality of their detention, in Ireland highlighted the access barrier. Mary Keys, ‘Challenging the Lawfulness of Psychiatric Detention under Habeas Corpus’ (2002) 24 Dublin University Law Journal 26.
\item \textsuperscript{21} Meeting communication by expert (National Resource Centre for Psychiatric Advance Directives, August 2012).
\item \textsuperscript{23} Jacqueline Atkinson and Jacquie Reilly, ‘Limitations to the Scope and Binding Force of Advance Directives: The Conflict between Compulsory Treatment and the Right to Self-Determination’ in Peter Lack, Nikola Biller-Andorno and Suzanne Brauer, Advance Directives (Springer 2014) 91.
\item \textsuperscript{24} Kay Redfield Jamison, ‘The Many Stigmas of Mental Illness’ (2006) 367 (9520) The Lancet 533.
\end{itemize}
citizenship. In *Hargrave v Vermont*, the U.S. Court of Appeal held that a state law that allowed mental health professionals to override advance refusals of psychiatric medication for detained patients was discriminatory under the Americans with Disabilities Act (ADA) 1990. After filing a legal challenge for differential treatment, Nancy Hargrave asserted:

“It seems fundamentally unfair that I choose or refuse chemotherapy which is saving my life, but I don’t have the same right to choose or refuse psychiatric medication.”

While the decision has not been followed in all states, ADs are an accepted part of the mental health landscape in the U.S. Despite the difficulties, ADs are considered one of the most significant developments in mental health law and policy in recent years. The analysis requires an examination of the theoretical frameworks underlying the use of ADs.

2. Theoretical Frameworks for Advance Directives in Mental Health Care
The theory underlying the phenomenon to be researched should be addressed at the start of a research study. A number of theoretical frameworks underpin the use of ADs in mental health care. This chapter will discuss the use of ADs under international human rights frameworks; the social model of disability; autonomy; therapeutic jurisprudence and the recovery approach. The theoretical framework will provide a conceptual map for the thesis and will synthesise AD knowledge in the international, comparative and Irish research. The framework will be reviewed and developed at each stage of the research process to further develop or confirm relationships and inform the development of an appropriate Irish legal framework.

27 Ibid.
2.1. Human Rights Frameworks

The intersection between mental health and human rights provides a theoretical framework for ADs. The principles of autonomy, self-determination, freedom, respect and dignity place ADs in a human rights approach to mental health law. The incorporation of ADs into domestic law generally follows the adoption of international human rights legislation. The formal recognition of ADs coincided with the rise of the human rights movement in the U.S. and with the articulation of the right to the highest standard of health by the international community. ADs are not explicitly acknowledged in international instruments relating to mental health, but they are widely recognised as vehicles for the principles of participation, non-discrimination, acceptability and accessibility. ADs have generated widespread support from service users and survivors of psychiatry. The first National Summit of Mental Health Consumers and Survivors developed a consensus statement for ADs in 1999 and the World Network of Users and Survivors of Psychiatry (WNUSP) endorsed the use of ADs to prevent coercion. WNUSP recognises that ADs are a valuable tool in enhancing user autonomy.

The CRPD provides a new human rights framework for ADs. It extends the application of human rights to persons with disabilities within the UN system and represents the most recent set of international standards. It has been embraced widely by the disability movement as the universal standard for the human rights of all persons with disabilities, including those with mental disabilities. The CRPD provides for the realisation of human rights through the overarching principles of equality and non-discrimination and aims to ensure respect for persons with

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31 Sofia Gruskin and others, Perspectives on Health and Human Rights (Routledge 2005).
34 Tina Minkowitz, No-Force Advocacy by Users and Survivors of Psychiatry (Mental Health Commission Wellington 2006).
disabilities in all aspects of life. Participation is a critical objective of the CRPD\(^\text{36}\) and allows persons with disabilities to make choices with or without support. Legal capacity is the ability to hold and exercise rights and is key to meaningful participation in society.\(^\text{37}\) Historically, individuals with mental health conditions have been denied their legal capacity to make decisions through mental health laws that permit non-consensual treatment and declarations of incapacity, but the CRPD does not permit forced treatment.\(^\text{38}\) The right to equal recognition before the law requires that legal capacity is a universal attribute, which applies to all persons with disabilities on an equal basis with others. The CRPD requires State Parties to provide access to supports for the exercise of legal capacity\(^\text{39}\) and the abolition of legislative provisions that allow or perpetuate forced treatment.\(^\text{40}\) It can be interpreted as promoting various forms of supported decision-making measures including the use of ADs.\(^\text{41}\) Under the CRPD, involuntary treatment by psychiatric and other professionals is considered to be a violation of the right to legal capacity, the right to personal integrity and freedom from torture and violence.\(^\text{42}\) ADs can address the contradiction between involuntary treatment and autonomy by facilitating choice and enabling clinicians to respect human rights.\(^\text{43}\) The measure has an important role in reorienting mental health systems towards recovery, participation and supporting legal capacity from a CRPD perspective.\(^\text{44}\)


\(^{38}\) Ibid para 38.

\(^{39}\) Ibid para 30.

\(^{40}\) Ibid para 38.


\(^{42}\) Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 38.


2.2. **Biomedical Model of Disability**

The disability models underlying different human rights frameworks must also be considered in the context of ADs. Disability was originally conceptualised as a problem that lay with the individual. The biomedical approach assumes that disability is primarily caused by an impairment or deficit that is abnormal. The critical feature of the biomedical model is the identification of pathology as a deviation from normal functioning.\(^{45}\) Under this model, medical practitioners are considered to be the experts in relation to the cause and appropriate response to disability. The narrow biological focus of medical knowledge in conjunction with paternalism and professional dominance are argued to have profound social effects.\(^{46}\) Supports or benefits are provided on the basis of charity and persons with disabilities are treated as objects in need of protection rather than equal subjects bearing rights.

Mental health services in Ireland are largely defined by the biomedical model of psychiatry as discussed in chapters 3 and 6. The critique of the biomedical model and the relationship between authority, paternalism and empowerment informs the social model of disability in the CRPD.\(^{47}\)

2.3. **Social Model of Disability**

The concept of disability has undergone a significant shift in the past fifty years.\(^{48}\) In the 1960s, disability activists and theorists began to develop new conceptualisations of disability recognising the restrictions of existing models, which focused on functional limitations.\(^{49}\) The new framework focused on attitudes and limitations within society rather than the individual. Under the social model, disability is caused by socially constructed barriers that serve to exclude the individual. The model focuses on the social context in which disability occurs and concentrates on altering limitations, changing attitudes and advancing human rights. It points to the need to change or alter social structures and processes that create disability\(^{50}\) and emphasises the role social attitudes and systems play in perpetuating disadvantage. The social

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\(^{46}\) Ibid.
\(^{49}\) Ibid.
model also recognises the unique perspective of those with a ‘lived experience’ of disability and promotes participation. The features vary according to the country or context. Functional impairment is only recognised to the extent it is needed to achieve substantive equality.

The social model of disability forms the basis of the CRPD. It is referred to in the preamble and Article 1 which sets out the purpose. Disability is considered to be an evolving concept resulting from interaction between individuals and attitudinal and environmental barriers. The CRPD focuses on abilities rather than deficits and suggests prevailing norms should change to accommodate individual attributes. The social model of disability focuses on the full and equal participation in society as a vehicle by which human rights can be realised. ADs can further the social model of disability and embed values such as equality, autonomy and inclusion through participation in mental health decisions.

2.4. Autonomy

The main theoretical rationale behind ADs is the enhancement of user autonomy. Autonomy derives from the Greek words *auto* and *nomos* meaning self-law or self-control and is considered one of the foundational principles of Western society. Terms such as independence, choice, control or freedom are often used to refer to the concept of autonomy. The notion that freedom should be specifically understood as

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54 Article 1.
autonomy was promoted by the German philosopher Kant.\textsuperscript{59} The Kantian concept of autonomy is not merely an occasional self-directed force within a person and is ever present in an internally generated way.\textsuperscript{60} The Oxford English Dictionary defines autonomy as “the right of self-government, of making its own laws and administering its own affairs”\textsuperscript{61} or the “liberty to follow one’s will, personal freedom.” Autonomy also refers to the person’s ability and opportunity to make decisions according to his or her own wishes and preferences.\textsuperscript{62} It can be used to make choices and to resist choices others make on our behalf including the right to make decisions that others may not agree with or understand.\textsuperscript{63} Free choice permits individuals to select from multiple options, but autonomy is more akin to an internal psychological state. The exercise of autonomous choice may also require support.\textsuperscript{64} Relational autonomy recognises that autonomy is not exercised in a vacuum, but in an interconnected process with others.\textsuperscript{65} The relational approach to autonomy requires consideration of the impact of social and cultural factors on the decision-maker.\textsuperscript{66} The importance of supported autonomy and social inclusion are also recognised in the CRPD.\textsuperscript{67} The emphasis on autonomy and freedom to make one’s own decisions is infused in the preamble and runs throughout the CRPD. Article 12 affirms the importance of autonomy, independence and freedom of choice and recognises the right of persons with disabilities to make decisions on an equal basis with others in all aspects of life.\textsuperscript{68}

\begin{thebibliography}{99}
\bibitem{Amers} Karl Americks, \textit{Kant and the Fate of Autonomy: Problems in the Appropriation of the Critical Philosophy} (Cambridge University Press 2000).
\bibitem{Oxford} Ibid.
\bibitem{Rosin} Arnold Rosin and Yehuda Van Dijk, ‘Subtle Ethical Dilemmas in Geriatric Management and Clinical Research’ 31 Journal of Medical Ethics 355.
\bibitem{Re} \textit{Re T (Adult: Refusal of Treatment)} [1992] 4 ALL ER 649.
\end{thebibliography}
The literature provides a variety of justifications for ADs. The moral and legal validity of ADs is based on the right to autonomy and is one of the most commonly cited values.\textsuperscript{69} ADs are an extension of the principle of autonomy by allowing individuals to express future treatment preferences when they may be unable to communicate a choice.\textsuperscript{70} The general principle of the law requires consent to medical treatment.\textsuperscript{71} Exceptions are provided for in emergencies; where a person is unable to consent or is detained under mental health legislation. In the absence of an AD, a person deemed incapable of consenting can be treated in their ‘best interests’ under Irish law. The exercise of precedent autonomy is of increased significance in mental health due to the invasive nature of psychiatric treatment.\textsuperscript{72} The prolonged use of psychiatric medication may even be more harmful than physical restraint due to the impact on the psyche of the person and the harmful side effects. Respect for autonomy is one of the fundamental aspects of clinical ethics, but coercive treatment erodes this. The ethical justifications for overriding autonomy include non-maleficence i.e. the prevention of harm, and beneficence i.e. treatment that will benefit the individual. Mental health legislation overrides autonomy and provides for involuntary treatment in certain circumstances. The severity of the condition, lack of insight and societal interest in risk of harm to self or others are frequently used to deny autonomous choice.\textsuperscript{73}

The failure to respect autonomy is irreparable in health due to the inescapable nature of the body and the connection to dignity, well-being and security.\textsuperscript{74} In a multi-nation analysis of involuntarily detained persons, it was found that the right to refuse treatment was routinely ignored and staff rarely provided information about

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\item \textsuperscript{70} Cristiano Vezzoni, Advance Treatment Directives and Autonomy for Incompetent Patients: An International Comparative Survey of Law and Practice, with Special Attention to the Netherlands (Edwin Mellen Press 2008) 8.
\item \textsuperscript{71} Re F (Mental Patient: Sterilization) [1990] 2 AC 1.
\item \textsuperscript{72} Paul Appelbaum, ‘Advance Directives for Psychiatric Treatment’ (1991) Hospital and Community Psychiatry 983.
\item \textsuperscript{73} Amita Dhanda, ‘Universal Legal Capacity as a Universal Human Right’ in Michael Dudley, Derrick Silove and Fran Gale (eds), Mental and Human Rights: Vision, Praxis and Courage (Oxford University Press 2012) 181.
\item \textsuperscript{74} Deirdre Madden, Medicine Ethics and the Law (Butterworths 2002) 413.
\end{itemize}
treatment. Weller states that the provision of treatment in an emergency or under mental health legislation should be governed by the person’s wishes, a proxy decision maker or an AD to meet CRPD standards. The CRPD Committee states that decisions involving the physical or mental integrity of the person should only be taken with the free and informed consent of the person.

Proponents of autonomy have always accepted that the right is not absolute, but the risk of harm does not justify a total disregard for choice in mental health care. The research suggests the increased risk of harm is low and violence occurs very rarely. In the absence of substance abuse, the risk of violence is no greater than the general population. The numbers of persons killed by individuals with mental health problems has been falling since 1970. Between 1999 and 2009, only six per cent (33) of homicides in the U.K. were committed by individuals with psychosis and only 7 assailants had refused treatment prior to this. The MacArthur studies found that previous history of violence, personality disorder or substance abuse were more robust predictors of violence. Involuntary treatment is sometimes justified as a form of liberation, which restores autonomy by giving the person the capacity to make decisions and choices. However, the psychological effect of the loss of

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77 The CRPD Committee is authorised to interpret the CRPD and to review the reports made by countries that have ratified the treaty. After reviewing a country’s report, they make Concluding Observations. These observations, along with the committee’s views on individual complaints, along with general comments from the committee, constitute the most authoritative interpretation of the treaty.
80 Ibid.
81 National Confidential Inquiry into Suicide and Homicide by People with Mental Illness 2012, Annual Report July 2012 (University of Manchester Press 2012).
82 Tables 21, 25.
autonomous control and the non-consensual invasion of the body is significant.\textsuperscript{85} Consistent findings suggest that individuals are increasingly likely to engage in treatment and to experience better outcomes when given the opportunity for autonomous choice.\textsuperscript{86} The threat of coercion is pervasive in the mental health system and impacts on both voluntary and involuntary patients. ADs can decrease the need for coercion by allowing the person to clearly express choices in advance of crisis and increase engagement with treatment.

The ability to exercise autonomous choice and control over life decisions is pivotal to social and mental well-being.\textsuperscript{87} The desire to make choices is fundamental to being human and is arguably both innate and learned from birth.\textsuperscript{88} Individuals with mental health conditions have been traditionally treated in a paternalistic manner and deprived of the opportunity to participate in treatment decisions. The presumption that they are unable to guide their own lives and need to be controlled, protected and limited in the scope of their decision making is common.\textsuperscript{89} According to Winick the incompetence label forces people to learn helplessness and non-participation in decisions, which are an integral component of living a full life.\textsuperscript{90} A determination of incapacity in some or all respects removes a person’s authority over their lives and vests this authority in another.\textsuperscript{91} The sense of helplessness can further accentuate feelings of stigmatisation, lack of control and demotivation.\textsuperscript{92} When individuals are no longer considered persons in their own right and their capacity to act is restricted, their status is diminished in the eyes of society.\textsuperscript{93} This contributes to stigmatisation and other forms of social exclusion which can increase powerlessness and

\begin{footnotesize}
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\item Larry Davidson and others, ‘If I Choose it: Am I more Likely to Use it?’ (2012) 2 (3) The International Journal of Person-Centred Medicine 577.
\item The Roeher Institute, Social Well-Being (Roeher Institute 1993).
\item Sheena Iyengar, The Art of Choosing (Hachette Book Group 2010).
\item Paul Longmore ‘Medical Decision Making and People with Disabilities: A Clash of Cultures’ (March 1995) 23 (1) Journal of Law, Medicine and Ethics 82.
\item Mary Donnelly, ‘From Autonomy to Dignity: Treatment for Mental Disorders and the Focus of Patient Rights’ (2008) 26 (2) Law in Context 49.
\item Michael Bach, Jane Anweiler and Cameron Crawford, Coming Home-Staying Home, Legal Research: Supported Decision Making and the Restriction of Guardianship (The Roeher Institute 1994).
\end{itemize}
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vulnerability. Individuals with mental health conditions are often socially isolated and economically excluded resulting in the lack of opportunity to develop a vision. The traumatising impact of lack of choice and coercion is reiterated by users and survivors of the mental health system. The negative impact of coercion and incapacity determinations are not always considered by policy makers when developing responses.

A number of clinical outcomes have been associated with autonomy including enhanced self-esteem and treatment satisfaction. Respect for treatment preference is reported to increase perceptions of autonomy and empowerment. ADs are perceived by individuals with mental health conditions as giving greater control and choice. Autonomy is not just about independence, it can help improve therapeutic relationships, enhance communication and facilitate the sharing of ideas to make realistic choices. ADs support the autonomy of the individual in the context of other relationships. The opportunity for individuals to reveal their value system to others can help build autonomy and the articulation of choice.

2.5. Therapeutic Jurisprudence

The broader therapeutic impact of the law is apt when considering the introduction of ADs. ADs offer several therapeutic benefits including the facilitation of preventative care, empowerment, the reduction of stress and anxiety, enhanced self-esteem and decision-making capacity, improved negotiation with clinicians and

94 Timothy Stainton, Autonomy and Social Policy (Ashgate 1994); Roeher Institute, Harm’s Way: The Many Faces of Violence and Abuse against Persons with Disabilities (Roeher Institute 1995).
96 World Network of Users and Survivors of Psychiatry (WNUSP) and Bapa Trust, First Person Stories on Forced Interventions and Being Deprived of Legal Capacity (Bapu Trust 2006).
98 Empowerment involves the reciprocal exchange of information between two or more persons, which may lead an individual to feel more autonomous. Anna Scheyett and others ‘Psychiatric Advance Directives: A Tool for Consumer Empowerment and Recovery’ (2007) 31 (1) Psychiatric Rehabilitation Journal 70.
100 Jacqueline Atkinson, Advance Directives in Mental Health: Theory, Practice and Ethics (Jessica Kingsley 2007) 187.
Therapeutic jurisprudence envisions the construction of law as a therapeutic agent, which positively impacts the emotional life and psychological well-being of individuals. When mental health law policies are drafted in this framework, service users are more likely to assume an active and meaningful role in negotiating and designing treatment programmes, collaborating with mental health professionals, and recovery. The biomedical model provides for involuntary hospitalisation and defers to medical opinion, while the procedural approach applies strict legal standards and requirements, which focus on the protection of civil liberties. Therapeutic jurisprudence aims to achieve a balance between these two approaches. Winick describes therapeutic jurisprudence as:

“An interdisciplinary approach to legal scholarship and law reform that sees law itself as a therapeutic agent … it seeks to ascertain whether law’s anti-therapeutic effects can be reduced and its therapeutic effects enhanced without subordinating due process and other justice values.”

It focuses on the underpinnings and rationale for mental health legislation, ensures the involvement of stakeholders prior to the enactment of legislation and offers procedural safeguards to protect and promote long term health outcomes for the individual. Therapeutic jurisprudence provides an appropriate theoretical framework for ADs. Legislative provisions for ADs can have a therapeutic impact helping individuals build self-esteem, gain a sense of control over treatment and a perception of respect. The concern with the outcomes of the law for the psychological well-being of the individual also aligns with the recovery approach.

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104 Kate Diesfeld and Ian Freckleton, Involuntary Detention and Therapeutic Jurisprudence (Ashgate 2003) 5.
2.6. Recovery Approach

ADs are conceptualised as part of the recovery approach in mental health care. The approach envisions a process by which service users take control of their lives and plan for crises with the support of trusted persons. The personal and social conception of recovery emerged from the service user movement in the U.S. during the late 1980s and early 1990s, which called for equal treatment. Both the recovery approach and the CRPD arose from challenges by persons with disabilities to traditional views and the need for more affirmative responses to their experiences. The recovery approach has been explicitly adopted as the guiding principle of mental health policies in Ireland, the U.S., England, Scotland, New Zealand and Australia. Recovery-oriented services have advanced significantly in the U.S. and New Zealand and have been incorporated in the National Institute for Clinical Excellence (NICE) guidelines for schizophrenia in the United Kingdom (U.K.). The recovery ethos is central to mental health policy and service planning in Ireland, having first appeared in the discourse in 2005. Recovery can be defined by the individual within the context of his or her personal wishes. A recovery approach identifies the importance of involving service users in their own care and respects the expertise of the individual. It includes planning practices with strong involvement of the individual. O’Hagan contends that recovery can be viewed through the lens of personal experience, as a set of workforce practices, or as a

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110 Shari McDaid, Recovery ... What you should Expect from a Good Quality Mental Health Service (Mental Health Law Reform Ireland 2013) 13.
112 National Institute for Clinical Excellence, Schizophrenia Core Interventions in the Treatment of and Management of Schizophrenia in Adults in Primary and Secondary Care (NICE 2009).
115 Ibid.
whole system. It challenges the ‘bedrock of beliefs’ found in the mental health system of the institutional era.\textsuperscript{116}

Critics of the recovery approach claim it lacks support for individuals with severe mental health conditions, and those living in poverty.\textsuperscript{117} Fernando contends that the recovery approach is overly focused on the individual and tends to ignore the political and social context of mental distress.\textsuperscript{118} The U.S. model focuses more on the individual than the social, economic and political processes that enable recovery.\textsuperscript{119} Some service users have criticised the concept of recovering from an event rather than accepting mental distress as part of the human condition.\textsuperscript{120} O’Hagan contends that two versions of the recovery approach exist i.e. the service user and psychiatric rehabilitation models.\textsuperscript{121} The rehabilitation model is mainly driven by professionals. In New Zealand, service users claimed ownership of recovery.\textsuperscript{122} The New Zealand blueprint defines recovery as ‘living well in the presence or absence of ill health’ and refers to the importance of hope, personal, social responsibility and actively participating in recovery with support.\textsuperscript{123} The blueprint states that discrimination is the biggest barrier to recovery.\textsuperscript{124} The emphasis on social and personal responsibility for recovery fits with New Zealand’s tradition of egalitarianism and collective responsibility.

\textsuperscript{116} Mary O’Hagan, ‘An Update on Recovery’ (2009) Mental Health Today
\textsuperscript{117} Mental Health Recovery Study Working Group, Mental Health ‘Recovery’: Users and Refusers (Wellesley Institute 2009); Jennifer Poole, ‘\textit{Behind the Rhetoric of Hope}: A Critical Analysis of Recovery Discourses in Ontario’ Unpublished Doctoral Dissertation (University of Toronto 2007).
\textsuperscript{118} Suman Fernando, ‘Recovery Approach Limited to White Middle Classes’ (European Centre for Migration & Social Care 2008).
\textsuperscript{120} Peter Campbell, Mind ‘It does not Ring my Bell’
\textsuperscript{121} Mary O’Hagan, ‘An Update on Recovery’ (2009) Mental Health Today
\textsuperscript{122} Mental Health Commission, \textit{The Blueprint for Mental Health Services in New Zealand} (Mental Health Commission 1998); Mental Health Advocacy Coalition, Destination: Recovery (Mental Health Advocacy Coalition 2008).
\textsuperscript{124} Mental Health Commission, \textit{The Blueprint for Mental Health Services in New Zealand} (Mental Health Commission 1998).
Human rights are at the core of the recovery process by supporting individuals to participate fully in society.\textsuperscript{125} The four tenets of recovery are described as hope and belief in the potential of the person, self-determination, choice and equal participation.\textsuperscript{126} The recovery approach encapsulates many of the CRPD principles by focusing on strengths and support rather than symptoms. The main parallel between the CRPD and the recovery approach is the shift away from deficits towards a life of full citizenship.\textsuperscript{127} The recovery approach reflects the social model of disability acknowledging the wider social, attitudinal and economic barriers to participation.\textsuperscript{128} The concepts of voice, confidence, control and person-centred care are reflected in many of the CRPD provisions.\textsuperscript{129} The emphasis on listening to the ‘voice’ and ‘choice’ of the person under the recovery approach can be linked to the CRPD principles of autonomy, participation and freedom of choice.\textsuperscript{130} The CRPD can assist the implementation of the recovery approach by providing a new international human rights framework that supports many of the principles. Moreover, the integration of the recovery approach into human rights frameworks such as the CRPD can help guarantee rights, increase staff familiarity and service user awareness and empowerment.\textsuperscript{131}

The recovery approach supports the introduction of laws that respect a person’s treatment choices, avoid coercion and promote the use of advance planning.\textsuperscript{132} The AD development process yields recovery and capacity building benefits beyond the
legislative aspects. Advance planning can assist individuals towards recovery by enabling them to express treatment preferences, develop insight, acquire information and become empowered by the process. ADs provide service users with a structure for recovery and the discussion of values, concerns and wishes with families and clinicians. The directive also provides a forum for regular evaluation and discussion whether a mental health crisis has taken place or not. This allows ADs to act as vehicles for learning in future mental health experiences. The AD can promote autonomy during crisis periods by placing the person’s values at centre stage and decrease the likelihood of relapse. ADs have the potential to reorient mental health systems towards recovery, engage people with treatment, assist early intervention and reduce the use of involuntary treatment to that of last resort. The use of ADs provides a measure for the implementation of a recovery-based system.

The recovery approach, autonomy, the social model of disability, therapeutic jurisprudence and the CRPD provide appropriate frameworks for ADs. The theoretical frameworks provide an opportunity to promote ADs under new approaches to decision-making for individuals with mental health conditions. The reconceptualisation of ADs as measures that promote recovery and support the exercise of legal capacity, with accompanying therapeutic benefits are part of the context in which they can develop. ADs can promote participation, the implementation of a recovery-oriented system, the social model of disability and the supported decision-making model under the CRPD. The use of ADs can assist the

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140 Ibid.
paradigm shift espoused in the CRPD and give effect to the new vision of human rights and recovery in mental health care.

3. Review of the Literature on Advance Directives in Mental Health Care

The literature surrounding ADs will be discussed under various themes. A review of the qualitative literature identified seven main themes: different forms of ADs; effectiveness; practical use; service user views; clinicians’ views and economic and legal aspects. The links between these themes will inform some of the proposed outcomes of ADs after consideration of the quantitative and qualitative research.

3.1. Literature Search Methodology

The AD literature was reviewed in order to define their scope, identify the various forms of the measure and to examine the perceived benefits and barriers associated with their use. The first step of the review included retrieving references through ISI Web of Knowledge, Medline, CINAHL, the Cochrane library, the legal journals index on Westlaw UK, the Index to Legal Periodicals and Google Scholar using the terms ‘advance directives’ OR ‘psychiatric advance directives’ OR ‘advance statements’ OR ‘advance agreement’ OR ‘joint crisis plan’ OR ‘crisis card’ OR ‘Ulysses directives’ OR ‘advance crisis planning’ AND ‘mental health’ OR ‘psychiatry’. A selected bibliography on psychiatric advance directives compiled by the National Resource Centre for Psychiatric Advance Directives at Duke University was also identified. The bibliography compiled by experts in the field identified 60 articles from the research literature on psychiatric advance directives and related topics. Two systematic reviews of ADs for individuals with mental health conditions and a review of the qualitative literature were identified. The search also identified two trials and an economic assessment.

abstracts of the retrieved papers to identify the relevant research. Some references were outside the scope of the review and related to end-of-life directives or ADs for physical conditions. The third step involved applying limits to restrict the sample of references. Date restrictions were applied to the search strategy. The first research papers on ADs appeared after the Patient Self Determination Act 1990 was introduced in the U.S. in 1991. Both quantitative and qualitative research studies were included. According to a ‘realistic review methodology’, multiple methods are required for studies to gain a comprehensive picture of the intervention. Other Irish and international sources were consulted including the Irish health information repository (Lenus), Westlaw IE and the Irish Legal Information Initiative (IRLII.org). The Irish mental health literature is addressed separately in chapter 4. Most of the international empirical studies involved service users, and mental health clinicians such as psychiatrists, social workers and mental health nurses. Other studies involved families and carers. Most studies focused on the early stages of the AD development process, while two studies considered access and compliance. Many studies consider key stakeholders’ views on ADs and features that facilitate use. Whilst the review attempts to identify the main themes in the literature relating to ADs, it does not claim to deal with all literature and perspectives on the subject.

4. Function of ADs
ADs have a range of functions in mental health care. ADs were originally adapted to the mental health context as a way for service users to exert more control over treatment and avoid coercion. The emphasis on recovery and person-centred care has expanded the focus to implementation and efficacy. The measure has fuelled increasing interest from groups promoting recovery, empowerment and self-directed...
The process of developing an AD can facilitate engagement in treatment, communication and help avert mental health crises by assisting the identification of relapse triggers reducing the need for involuntary admission or hospitalisation. The potential for empowerment and treatment engagement provides a meaningful alternative to traditional responses to crises. The four basic functions of ADs in the literature include: providing treatment choice; refusing certain treatments; appointing a proxy decision-maker and providing for wishes to be irrevocable during a crisis through a Ulysses clause. A Ulysses clause can be used by individuals who wish to override their own refusals in advance of a future mental health crisis. Both the granting and denying of consent to treatment are important functions of ADs.

5. Types of Advance Directives

ADs can take varying forms, enabling different decisions to be made. Several types of ADs have emerged across comparative jurisdictions in recent decades. Terms frequently used to describe ADs include: psychiatric advance directives (PADs); Ulysses clauses; advance statements; advance decisions; joint crisis plans; self-binding directives and facilitated directives. Some directives are legally binding whereas others are accorded due respect and consideration. Significant differences exist between countries concerning the legal status of ADs, or the particular situations in which they can be developed. A directive can be either positive or


negative in that it includes advance consent or refusal of treatment. Preferences can be expressed through an instructional directive, which provides directions regarding treatment or a proxy directive where the authority to communicate preferences is given to a designated person. Some jurisdictions provide for a third form of hybrid directive, where the proxy and instructional directive are combined. The law often stipulates that the AD has to be in writing, but allows oral revocation. Other jurisdictions accept oral ADs, with witnesses. In some jurisdictions, they specifically relate to healthcare decisions, but can be broadly or narrowly interpreted. Typically, mental health ADs are used to request or refuse specific treatment, describe symptoms of relapse, respond to crisis, specify emergency contacts and to make suggestions for hospitalisation. The research shows that service users are also interested in including personal life management choices e.g. childcare, visitor preferences, care of pets. The findings of the empirical study (in chapter 6) found Irish consultant psychiatrists were more interested in including life choices in the directive than service users. The inclusion of non-treatment choices in the directive is considered particularly beneficial to autonomy. Up to 20 per cent of joint crisis plans in the U.K. included non-treatment choices. The different types of ADs are used to limit the adverse consequences of relapse in conjunction with other goals.

The type of AD adopted and the strength of the legislative framework will influence their utility. ADs vary in the extent to which they are legally binding and whether providers and families are involved in their development. Directives may stand alone

155 See chapter 5 Virginia.
or be used in conjunction with a healthcare power of attorney i.e. an individual designated by the person to make decisions. Each jurisdiction has different legal requirements in relation to enforceability with some adopting a more formalised approach. Comparative models range from a paternalistic approach, to one based on shared decision-making to an independently completed AD. The range of stakeholders involved in completion is also a key variable in development. The various forms of ADs are based on diverse models of care and the legal and service context in which they operate.

5.1. Instructional Directives
Instructional directives provide specific directions and are more supportive of autonomy. However, future events can be difficult to anticipate and compliance may be lower in the absence of a proxy decision-maker. The instructional directive informs family, friends and treatment providers of preferences, while retaining decision-making control. Individuals with different mental health conditions often choose varying forms of ADs if it is perceived they promote greater autonomy and control. Those who are more autonomous or who lack a trusted person to act may choose an instructional directive. In one study, individuals who chose instructional directives had greater knowledge of their condition and wanted to include details that gave them control. The specificity of the instructions are more important in this form of directive.

The inclusion of reasons for treatment decisions can help ensure instructional directives are respected. This was demonstrated in a previous study where instructional ADs with reasons were followed in 74 per cent of cases, while those

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without reasons were followed in 53 per cent of cases.\textsuperscript{165} Compliance was over three times higher where clinicians considered the reasons to be ‘rational’.\textsuperscript{166} An explicit definition of ‘rationality’ and ‘irrationality’ is not provided in psychiatry, but it is often defined by social conformity and concurrence with medical opinion.\textsuperscript{167} e.g. a woman with lymphoma who refused medical treatment and chose to die was deemed irrational.\textsuperscript{168} The decision to forgo treatment is often viewed as an irrational decision rather than an informed choice and used to deny the capacity to make decisions.\textsuperscript{169} However, choices and decisions are dependent on a multitude of complex factors and are seldom purely ‘rational’.\textsuperscript{170} The denial of legal capacity based on the rationality of the decision is discriminatory and disproportionately affects individuals with mental health conditions.\textsuperscript{171}

5.2. \textit{Proxy Directives}

A proxy directive allows an individual to designate another person to communicate preferences during periods when he/she may be unable to do so. The appointment of a proxy decision-maker is an important component of ADs in mental health care. Proxy directives are less constrained by unpredictable events, the difficulty anticipating future circumstances and are more likely to be respected.\textsuperscript{172} The proxy has an important role in alerting providers and in ensuring compliance.\textsuperscript{173} The appointment of a proxy is the most frequently used component of ADs and attracts a


\textsuperscript{166} ADs with reasons deemed to be ‘irrational’ were only followed in 22 per cent of cases. Christine Wilder, ‘Effect of Patients’ Reasons for Refusing Treatment on Implementing Psychiatric Advance Directives’ (2007) 58 (10) Psychiatric Services 1349.


\textsuperscript{169} Patrick Corrigan and others, ‘From Adherence to Self-Determination: Evolution of a Treatment Paradigm of People with Serious Mental Illnesses’ (2012) 63 (2) Psychiatric Services 169.


\textsuperscript{171} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 21.


\textsuperscript{173} Patricia Backlar, ‘Anticipatory Planning for Psychiatric Treatment is not quite the same as Planning for End-of-Life Care’ (1997) 33 Community Mental Health Journal 261.
higher level of support from clinicians.\textsuperscript{174} The majority of service users are also interested in appointing a proxy decision-maker.\textsuperscript{175} In a study of AD preferences, 74 per cent of service users were interested in a proxy decision-maker.\textsuperscript{176} There is an increasing move towards a model whereby a trusted proxy understands the person’s values and makes decisions based on these beliefs.\textsuperscript{177} Sabatino argues that having a trusted decision-maker is far more valuable than an instructional directive, but only if the person is informed and educated.\textsuperscript{178} He suggests that the most important trait in a proxy is the desire to want to understand the person’s values and a drive to research these relentlessly.\textsuperscript{179} A close loving relationship does not necessarily translate into good proxy decision-making due to emotional involvement. The proxy directive helps resolve the issue of preferences changing over time. Instructional directives may need to be regularly reviewed to ensure any changes are incorporated.\textsuperscript{180} The end-of-life research suggests that preferences for life-sustaining treatment remained relatively stable within a two-year period.\textsuperscript{181} Another study suggested mental health treatment preferences were relatively stable in the short term.\textsuperscript{182}


\textsuperscript{176} Ibid.

\textsuperscript{177} The Physician Orders for Life-Sustaining Treatment (POLST) form translates treatment preferences into medical orders. The POLST model represents the next frontier, beyond traditional executed ADs, in the quest to assure patients who are unable to speak for themselves receive exactly the kind of care they want and is consistent with their own values and preferences. There are approximately fourteen states in the US with established POLST programs, Center for Ethics in Health Care, Oregon Health & Science University, POLST <http://www.ohsu.edu/polst/> [accessed 11 March 2014].

\textsuperscript{178} Charles Sabatino, ‘Eight Advance Care Planning Lessons that took me Thirty Years to Learn’ 34 (6) Bifocal 115.

\textsuperscript{179} Ibid.


\textsuperscript{181} Peter Ditto and others, ‘Stability of Older Adults’ Preferences for Life-Sustaining Medical Treatment’ (2003) 22 (6) Health Psychology 605.

\textsuperscript{182} Daniel Ambrosini, Anne Crocker and Eric Latimer, ‘Preferences for Instructional or Proxy Advance Directives in Mental Health: An Exploratory Mixed Methods Study’ (2012) 6 Journal of Ethics in Mental Health 1.
Proxy directives are generally viewed as less autonomous than instructional directives. The appointment of a proxy decreases the likelihood that the person’s wishes will be reflected in the decision. The literature suggests that proxies are more likely to use a ‘best interest’ standard than the person’s wishes. Proxy decisions have been shown to poorly correlate with the individual’s treatment preferences in general ADs. Empirical studies have shown that healthcare proxies often do not correctly interpret the person’s wishes for end-of-life care even, when the proxy is very familiar with the person. The proxy decision-maker should thus be a trusted person with whom the individual discussed his/her preferences and has a clear understanding. The legislation should place a duty on the proxy to make decisions based on the person’s will and preferences and provide training. In the State of Virginia in the U.S., the proxy is bound by the person’s known ‘values and preferences’ if an instruction does not exist. In the Canadian province of Alberta, proxies have an on-going duty to consult the person regarding decisions. The duty to consult with the person when decision-making capacity may be reduced respects the dignity of the individual and his/her current wishes. In order to meet the concerns in relation to proxy directives, individuals should be given the option to develop specific instructions. The legislation should ensure that the physician is not entitled to make decisions, in the absence of a designated proxy, instructional AD or decision-making representative outside of defined emergencies.

188 See chapter 5. Va Code s 54.1-2986.1 (b).
189 Personal Directives Act, RSA 2000, s 13.
192 Ibid.
5.2.1. Designating a Proxy

The relationship of trust with the treating doctor and social network with family and friends may impact on the appointment of a proxy decision-maker. Some service users lack a trusted person to act or may not want to burden family or friends. Individuals with mental health conditions often receive less support from family and friends in times of crisis due to stigma. A recent study in the U.K. found service users experienced higher levels of discrimination from family members. Some service users may not be able to rely on family members if strained relationships exist. The lack of a trusted proxy decision-maker was identified as a barrier to the implementation of ADs in Virginia. In a previous study in North Carolina, 20 per cent of participants lacked a trusted person to act. The law in many jurisdictions prohibits the appointment of a treatment provider due to the conflict of interest. This issue suggests a need to provide a choice of instructional and proxy directives in the legal framework and to build support networks. Poor levels of social support are strongly associated with higher levels of mental distress. ADs can assist the building of relationships between family members through communication. Some clinicians have expressed concerns in relation to potential conflicts between the individual and his/her proxy. The designation of a proxy chosen by the person should always take precedence over appointed representatives.

198 See chapter 5.
In some jurisdictions, multiple proxies can be appointed for different decisions where one person is not appropriate. The CRPD provides that persons with disabilities may appoint one or more trusted persons to assist them with various decisions. Separate directives may be necessary to protect confidentiality in general health settings. In the Canadian province of British Columbia, individuals can appoint more than one proxy provided each person has authority over different areas. In another Canadian province, two proxies can act successively or jointly. The first proxy makes a decision where a majority decision cannot be reached. The authority of the proxy was overridden in one Canadian jurisdiction where they were no longer considered mentally capable of fulfilling the role. One of the distinctive features of proxy directives in the Canadian Yukon territory is the requirement for the proxy to sign the document. The person can also authorise the proxy to physically restrain them during a mental health crisis if legal advice has been obtained before signing the directive. Supported decision-making agreements allow individuals to appoint trusted friends or relatives to act as assisted decision-makers, obtain relevant information and explain it in a manner that the person understands. Other jurisdictions provide for punishment by fine or imprisonment or both if a proxy wilfully destroys, conceals or alters a directive. The benefits offered of combining instructional and proxy directives will be now be considered.

5.3. **Hybrid Directives**

The analysis suggests that both instructional and proxy directive have strengths and limitations. The hybrid directive combines the specificity of the instructional directive with the flexibility of a proxy. Winick suggested the combination of the

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204 See State of Virginia, United States, chapter 5.
206 Representation Agreement Act, RSBC, ch 405, pt 3, 26 (1996), s 5 (2).
209 Care Consent Act, SY 2003, s 28 (1)(e).
210 Care Consent Act, SY 2003, s 30 (1)(a), s 30 (2)(a).
211 Decision-Making Support and Protection to Adults Act, SY 2003, c 21, ss 4, 5, 6.
212 Alberta, Saskatchewan, Canada.
two directives may be the most enforceable. The hybrid directive confers decision-making power on the proxy with the advantage of specific instructions. The instructions increase the likelihood that the person’s wishes will be reflected in the decision. In the event that a treatment decision is made without a specific instruction, the proxy can be bound by the person’s values. This form of directive protects autonomy, ensures the provider is aware of the instructions and provides a trusted decision-maker to communicate the decisions on behalf of the person.

Brown suggests that stronger evidence is needed in relation to the choice of instructional or proxy directives before reforming legislation. A Canadian study suggested both instructional and proxy directives have an important role and several participants were interested in both documents. The CRPD requires an informal and flexible approach to support measures to suit various needs and preferences, suggesting a need for a choice of instructional and proxy directives in the legislative provisions. The various legislative frameworks used for ADs will now be considered.

6. Forms of Advance Directives
The provisions for ADs are dependent on the characteristics of the legal, system and cultural context in which they operate. Comparative jurisdictions have a range of legal frameworks for mental health ADs, with some adopting provisions under mental health legislation and others providing for them under general capacity and healthcare decisions laws. Some jurisdictions have integrated all types of health care decisions into a single directive eliminating the need for separate ADs. ADs may be developed along a continuum of formality from legally binding to non-legally

Each jurisdiction has different legal requirements with some adopting legally binding directives and others providing for non-legally binding statements and joint crisis plans. The enforceability of ADs often depends on the strength of the legal framework in which they are introduced so the different forms of AD need to be considered. The analysis will consider psychiatric advance directives (PADs); facilitated directives (F-PADs); advance statements; individual care plans and WRAP plans.

6.1. Psychiatric Advance Directives (PADs)

The legally binding ‘psychiatric advance directive’ (PAD) promotes user autonomy and choice. The document was designed to be developed independently and is common in U.S. jurisdictions. It states the circumstances in which the AD may be overridden and is legally enforceable. This form of AD typically offers three ways for individuals to plan for future mental health crisis by providing consent to future treatment; by giving instructions on treatment preferences and by appointing a proxy decision-maker. Treatment providers generally have an obligation to follow legally binding ADs, but they can be generally overridden for involuntary admission; if the treatment request is not feasible or appropriate or conflicts with practice standards. Case law in the U.S., Germany and Canada has found that legally binding ADs are enforceable during periods of involuntary detention. In Germany, ADs are legally binding during involuntary detention under legislation. The German law provides legal certainty, emphasises autonomy and flexible legal regulations. ADs do not require certification or specific periods in which they have to be updated and can be revoked informally. The independently completed PAD is less likely to be respected without provider input, but facilitated support and the appointment of a proxy can help address this issue. The AD may also be discussed with the provider.

220 Scotland, England and Wales.
after it is developed. Although provider involvement is associated with increased compliance and usage, it may undermine some of the autonomy ADs are designed to protect.225

6.2. Facilitated Advance Directives
The low uptake of ADs in the U.S. led to the introduction of facilitated support for completion.226 Facilitated directives (F-PADs) were found to achieve higher completion rates, were more responsive to user needs and contained more valuable information.227 In a study of individuals with persistent or severe mental health conditions, the majority needed support to develop ADs, but all the participants were capable of completing them.228 Some participants needed help articulating preferences, while others simply needed help with reading.229 More than half needed technical support, while under half needed clarification of information, and nearly a third needed both forms of support.230 In addition, some service users needed encouragement, rest breaks and assistance proofreading the final document.231 Peers provided support in the study, but approximately a third of participants expressed a preference for assistance from their case manager. Service users have reported a lack of information and the need for support in previous studies of unfacilitated ADs.232

229 Ibid.
230 Ibid.
231 Ibid.
The technical aspects of writing or typing the form may require assistance. Facilitated support also assists identification of the person’s values and increases the likelihood that the document is valid and the instructions are feasible. The facilitator can support the person to distribute the document and upload it to an electronic medical record or registry. A study of crisis cards (a form of AD) in the U.K. showed that all of the patients chose to make a joint card instead of an independent card.

The support to complete a facilitated AD can be provided by a peer, mental health professional or other person. While clinicians may provide support, they may not be the most appropriate person under an autonomy based framework. The balance of power in the clinician facilitated directive raises concerns in relation to undue influence. Service providers may also feel burdened by the amount of time required to develop an AD. The user is supported to complete the document without the involvement of clinicians in the independently facilitated AD. The formal integration of trained peer support workers into mental health services in the U.S. and other jurisdictions has expanded the role to ADs. The research suggests peers may provide appropriate support, because of their independence from the treatment relationship, unique knowledge and shared experience. Georgia and Arizona were among the first U.S. states to provide certified peer specialists and other states have followed suit. Minnesota provided for certified peer specialists under legislation in 2007. Peers are now being used to support the development of ADs in Georgia and Virginia and certification programmes have been introduced. Peers have also

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238 Minnesota Statute 256B.0615
240 See chapter 5.
241 Plans are underway to introduce an official certification programme in Virginia and in house programmes are already in place.
provided AD education programmes in the New York Resource Centre and workshops in Washington State. A previous study found veteran consumers were more comfortable with facilitators from outside the mental health system with no stake in their treatment preferences. The research is consistent with suggestions that family, friends or other trusted individuals should support AD completion. A key component of the successful Gundersen Lutheran programme for end-of-life directives in Wisconsin includes the provision of trained facilitators in a range of settings. A model for personal advocacy in Australia showed advocates improved the outcomes of individuals who were involuntarily detained and led to a significant reduction in readmission to hospital and increased treatment engagement. The peer facilitated directive supports the statement of treatment preferences without clinician involvement, thereby maintaining autonomy.

6.3. Advance Statements

The use of non-legally binding forms of ADs must also be considered. Advance statements can be used to describe treatment preferences and other life management choices. The statement is non-legally binding and can include positive treatment choices. This form of directive is used in Scotland. The State of Victoria in Australia is also considering legislating for advance statements in proposed reforms to mental health legislation. Non-binding statements can be integrated on an informal basis without the need for legal formalities. Accountability mechanisms can

249 Mental Health (Care and Treatment) (Scotland) Act 2003 s 275.
250 Department of Health, A New Mental Health Act for Victoria: Summary of Proposed Reforms (Department of Health 2012).
be put in place requiring providers to comply with the statement, but they are not legally obliged to follow them. In cases where the AD is overridden outside of emergencies, legal safeguards should be provided. This requires the establishment of an independent public authority with oversight responsibility.

The Scottish Mental Health (Care and Treatment) Act 2003 provides a comprehensive framework for advance statements, which require the clinician to provide reasons for overriding the directive to the service user, the proxy decision-maker, legal representative and the Mental Welfare Commission.\textsuperscript{251} The AD can be overridden to provide urgent life-saving treatment, prevent serious deterioration; alleviate serious suffering or in cases where the person is a danger to him/herself or others. The non-binding advance statement is automatically invoked if the person is subject to involuntary detention. While this may be beneficial, it can create an assumption that those subject to involuntary admission lack decision-making capacity and limit the use of ADs to avert the need for detention.\textsuperscript{252} The mental health tribunal also has to consider the content of the advance statement when making decisions. The Scottish framework shows the value of linking innovative legislation to independent accountability and oversight mechanisms.\textsuperscript{253} Figures from the Scottish Mental Welfare Commission show the vast majority of advance statements are adhered to and very few are overridden.\textsuperscript{254} The Scottish legislation includes a comprehensive set of ethical and human rights principles which promote good practice. The other form of non-legally binding AD is the joint crisis plan (JCP).

\textsuperscript{251} Mental Health (Care and Treatment) (Scotland) Act 2003 ss 275, 276.
\textsuperscript{254} The Commission received 25 notifications of overrides in 2013 but only 18 of these were valid overrides. No figures exist on how advance statements have been made. Mental Welfare Commission for Scotland, \textit{Mental Health Act Monitoring 2012/2013} (Mental Welfare Commission 2013) 44. Among 62 people visited who had made advance statements, only one statement had been overridden without the required notifications. Mental Welfare Commission for Scotland, ‘Not Properly Authorised: Unannounced Visits to People Receiving Treatment Under the Safeguards of Part 16 of the \textit{Mental Health} (Care and Treatment) (Scotland) Act 2003’ (Mental Welfare Commission Scotland 2011).
6.4. Joint Crisis Plans (JCPs)

Individuals can also express treatment preferences outside of the legal framework through joint crisis plans (JCPs). This form of AD is used in the U.K and Germany. The JCP forms part of the shared decision-making model and grants partial autonomy to the individual.\textsuperscript{255} Shared decision-making generally involves both parties agreeing on future treatment.\textsuperscript{256} The JCP involves a discussion between the service user, provider, family members, care co-ordinator and an independent facilitator regarding acceptable forms of future treatment.\textsuperscript{257} It aims to empower service users, while facilitating early identification of relapse and treatment.\textsuperscript{258} The goal is to produce a plan agreeable to both parties; to improve the therapeutic alliance\textsuperscript{259} and to reduce the need for involuntary admission.\textsuperscript{260} The evidence suggests that the JCP is the most effective type of AD in reducing involuntary admissions.\textsuperscript{261} In previous studies, JCPs were found to reduce involuntary readmission rates\textsuperscript{262} and were more cost effective than standard service information in preventing hospital admissions.\textsuperscript{263} However, a recent U.K. trial found that JCPs were not significantly more effective than treatment as usual.\textsuperscript{264} The findings differ from the two previous studies, but the trial had several limitations.\textsuperscript{265} JCPs were not

\textsuperscript{258} Claire Henderson and others, ‘A Typology of Advance Statements in Mental Health Care’ (2008) 59 (1) Psychiatric Services 63; Graham Thomnicaft and others, ‘Clinical Outcomes of Joint Crisis Plans to Reduce Compulsory Treatment for People with Psychosis: A Randomised Controlled Trial’ (2013) 381 The Lancet Published online March 26 2013.
\textsuperscript{260} Graham Thomnicaft and others, ‘Clinical Outcomes of Joint Crisis Plans to Reduce Compulsory Treatment for People with Psychosis: A Randomised Controlled Trial’ (2013) 381 The Lancet Published online March 26 2013.
\textsuperscript{264} Graham Thomnicaft and others, ‘Clinical Outcomes of Joint Crisis Plans to Reduce Compulsory Treatment for People with Psychosis: A Randomised Controlled Trial’ (2013) 381 The Lancet Published online March 26 2013.
fully implemented on all sites, and were combined with routine clinical review meetings.\textsuperscript{266} The failure to consider the views of clinicians and undertake adequate staff and organisational preparation was considered to be a critical limitation of the trial. In cases where the JCP was effectively used, service users reported feeling respected and clinicians referred to how the service user ‘came alive’ as an individual.\textsuperscript{267} The CRIMSON trial provides important lessons for other jurisdictions considering the implementation of ADs. The trial suggests provider support and organisational preparation are crucial for successful implementation.

The JCP may impact on user autonomy due to the power imbalance in the clinician/service user relationship.\textsuperscript{268} The potential loss of autonomy resulting from provider involvement may make the JCP incompatible with human rights frameworks. The threat of coercion can be also be used as a leverage to limit autonomous choice.\textsuperscript{269} The completion of an AD without support or with the support of non-clinicians is underpinned by user autonomy, whereas the JCP may be more appropriate under a therapeutic alliance framework.\textsuperscript{270}

6.5. \textit{Individual Care Plans}

Treatment plans or individual care plans are distinctive from ADs in that they are not legally binding and can be developed without the involvement of the person.\textsuperscript{271} Individual care plans have become a key component of mental health services and may contain details of future treatment. The plan may provide the foundation for developing an AD or form one of the recovery goals.\textsuperscript{272} The development of the care plan also provides the opportunity to introduce ADs to the service user. The requirement to complete an individual care plan means they often have a higher rate

\textsuperscript{266} Graham Thornicraft and others, ‘Clinical Outcomes of Joint Crisis Plans to Reduce Compulsory Treatment for People with Psychosis: A Randomised Controlled Trial’ (2013) 381 The Lancet Published online March 26 2013.
\textsuperscript{267} Ibid.
\textsuperscript{269} Paul Appelbaum and Alison Redlich ‘Impact of Decisional Capacity on the use of Leverage to Encourage Treatment Adherence’ (2006) 42 (2) Community Health Journal 121.
of completion than ADs.\(^{273}\) Irish mental health legislation requires that an individual care plan be completed by the multidisciplinary team in consultation with the service user.\(^{274}\) However, successive reports have revealed high levels of non-compliance\(^{275}\) and low levels of service user involvement despite the legal requirements.\(^{276}\) Only half of Irish mental health services were fully complying with their obligations in relation to individual care plans in 2012.\(^{277}\) The integration of legally binding ADs with individual care plans can strengthen the framework for meaningful service user participation. Other non-legally binding tools are also being used to increase service user participation and enhance recovery outcomes.

6.6. WRAP (Wellness Recovery Action Plan)

Wellness Recovery Action Plans (WRAP) are being used to empower individuals towards recovery in mental health care.\(^{278}\) The WRAP programme originated in the U.S., but has been successfully implemented into recovery systems in a number of jurisdictions including Ireland.\(^{279}\) A randomised control trial has confirmed the importance of WRAP as an evidence-based recovery intervention.\(^{280}\) The main goal of WRAP is to increase empowerment and recovery through self-management. The plan involves identifying recovery strategies, trusted supporters, relapse triggers and the development of a crisis plan. The crisis plan is not a legal document, but may provide instructions in relation to treatment preferences, life management choices and trusted supporters. In some jurisdictions, the WRAP plan can act as a legally binding AD if it is appropriately signed and witnessed. Many jurisdictions do not

\(^{273}\) Ibid.

\(^{274}\) Mental Health Act 2001 (Approved Centres) Regulations 2006, Articles 15, 16 of Statutory Instrument No 551.


require a specific format for the AD to be valid e.g. Virginia. However, this may result in provider recognition and access problems. The crisis plan in WRAP is preceded by a reflective self-management process and provides instructions in the event of relapse. The structure, self-reflection, crisis planning and support provide a natural foundation for the development of a legally binding directive. WRAP is being used to support the development of ADs in mental health settings in some U.S. states. The crisis plan in WRAP is preceded by a reflective self-management process and provides instructions in the event of relapse. The structure, self-reflection, crisis planning and support provide a natural foundation for the development of a legally binding directive. WRAP is being used to support the development of ADs in mental health settings in some U.S. states. Other holistic life planning tools used under the recovery approach include the Recovery Star.

The research evidence suggests service users have a sense of self-determination and empowerment when completing any form of AD. While there is no evidence that one form of AD is more effective for enhancing user autonomy, the facilitated directive significantly increases completion rates and is more responsive to the person’s needs. Individual care and WRAP plans are being used to facilitate completion and to introduce ADs to service users. A number of different forms of legally binding and non-legally binding ADs may co-exist together to give choice and flexibility. WRAP plans and legally binding ADs are used in tandem in the U.S. and treatment agreements and joint crisis plans are used with ADs in Germany and Austria. The use of one document to inform the contents of another can decrease the likelihood of conflict. The evidence in relation to the effectiveness of facilitated ADs and JCPs have resulted in increased convergence between the U.S. and U.K approaches. Ideally, a choice of ADs tailored to the person’s needs and preferences

281 See chapter 5, State of Virginia.
282 The star is being used by many mental health trusts in the U.K. as a tool for optimising individual recovery and gaining the information to create a recovery focused care plan. Outcomes Star, ‘Mental Health Recovery Star’ <http://www.outcomesstar.org.uk/mental-health/> [accessed 13 February 2014].
285 See chapter 5, Virginia.
should be made available under the CRPD. Issues such as whether the person specifically requests the AD to be formally invoked when they are admitted to hospital or during earlier stages of relapse should be addressed within the parameters of the directive. The issue of revocability and consultation with proxy decision-makers should also be set out in the terms of the directive and subject to regular review. Ultimately, the choice of AD should remain with the person with the provision of appropriate information and support.

7. Stakeholder Preferences and Support for Advance Directives

7.1. Service Users

The literature shows discrepancies between psychiatrist, service user and family views in relation to ADs. Most stakeholders supported the idea of documenting treatment preferences, but significant differences were found between service users and clinicians. The majority of service users perceived ADs would promote recovery, but only a small proportion of clinicians believed they would be beneficial in this area. Service users have a preference for legally binding ADs and perceive the document to promote autonomy. Individuals with mental health conditions have a strong interest in developing ADs and report a high level of satisfaction including increased control, respect and value as a person. The literature shows service users perceive ADs as a tool for communicating treatment wishes and avoiding decisional conflict. Individuals with mental health

288 Ibid.
conditions have been shown to be capable of identifying appropriate and effective treatment preferences. The document is viewed as a protection against unwanted side effects and involuntary treatment. Preferences for specific types of ADs were grounded in personal mental health experiences. Coercion was associated with negative perceptions of medication and the desire to retain control. The demand for ADs was significantly higher among individuals who feel coerced into taking medication and lower among individuals who reported a higher level of personal autonomy. The relationship of trust with treating doctors and communication were common themes underlying AD preferences. One participant did not complete an AD because it was perceived as part of the healthcare system she did not trust.

7.2. Clinicians

The literature suggests that clinicians are less supportive of ADs. Several studies have found a high level of ambivalence and varying levels of support. Clinicians are critical at two stages of the process: when an individual creates an AD and when it is invoked. The research points to an association between clinician support and service user interest in directives. Clinicians generally support service user
involvement, but significant variations exist between professions. The literature suggests approximately half of clinicians endorsed ADs. A number of studies have shown support for ADs to be associated with knowledge of their legal status, particularly the ability to override the document.Clinicians may be more comfortable with ADs when they do not feel constrained by the measure. In a previous study, psychiatrists’ knowledge of ADs was linked to increased support, suggesting a need for education.

7.3. Family Members

Family members generally support the idea of empowering service users and involving them in treatment decisions, but are more supportive of coercive treatment than clinicians. They also support the irrevocability of the directive during a crisis and the role of the proxy decision-maker. The views of family members are more oriented towards their role as decision-makers. The literature suggests that family and carers of those who are involuntarily detained often do not feel involved in the care and treatment of their relatives. In a national survey of patients in acute units, over a third of Irish service users did not want families or carers involved in treatment. Individuals with mental health conditions often experience higher levels

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309 Lieuwee de Haan and others, ‘Preferences for Treatment during a First Psychotic Episode’ (2001) 16 European Psychiatry 83.


312 Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2011’ (Mental Health Commission 2012).
of discrimination from family and carers. ADs can facilitate communication and help rebuild family relationships. Family and carer involvement is promoted in several mental health policy documents in Ireland. Some organisations suggest family members can play a positive role in supporting recovery when they have a good understanding. The Irish Mental Health Commission has stated that community mental health teams should provide support to family members, including education. ADs are proposed to improve service user, provider and family relationships and reduce conflict in relation to the person’s wishes.

8. Benefits of Advance Directives

The potential benefits of ADs are described extensively in the literature. ADs are multifaceted measures that confer a variety of benefits at the development and invocation stage of the process. The measure is proposed to enhance autonomy, decrease coercive treatment and promote recovery. The research has focused on improved clinical outcomes and empowerment. The conceptual discussions are divided into two areas: the benefit of creating and of invoking an AD.

8.1. Creating an AD

The benefit of creating an AD is particularly apt under the recovery approach and the supported decision-making model. The AD confers many benefits in terms of daily wellness even if the person never legally invokes it. ADs can have capacity and recovery building benefits beyond the legislative aspects. Individuals with mental health conditions have self-experience of crises so ADs can be used to improve

future outcomes. One of the most significant benefits of developing an AD is that it can provide users with a sense of control over treatment. The increased sense of choice, being listened to, respected and ownership can improve treatment engagement, self-efficacy and hope for recovery. The development of an AD can also assist the identification of relapse triggers, treatment preferences, contact persons and effective crisis responses. In one study several participants stated “just knowing the document was there provided ‘peace of mind’.”

8.2. Invoking an AD

ADs can also direct care during a mental health crisis. Invoking a directive can give individuals the opportunity to have their choices respected and decrease the need for coercive treatment. The document also provides valuable information regarding the person and effective treatment. Service users who believe their wishes will be followed are more likely to engage with treatment. The AD increases autonomy, decreases the need for involuntary admission, hospitalisation and contact with the criminal justice system. The provision of ADs can also contribute to a broader attitudinal shift towards individuals with mental health conditions and how they are treated.

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326 Robert Calsyn, Joel Winter, and Gary Morse, ‘Do Consumers who have a Choice of Treatment have better Outcomes?’ (2000) 36 Community Mental Health Journal 149.
327 Leslie Campbell and Steven Kisely, ‘Advance Treatment Directives for People with Severe Mental Illness’ (2012) 8 The Cochrane Library (Wiley and Sons).
The AD research, to date, has focussed primarily on improved clinical outcomes and enhanced empowerment329 and is limited by the paucity of the data.330 A systematic review suggests more trials are required to investigate the impact of various types of ADs.331 While much is known about the types and function of ADs and completion, more research is needed in relation to implementation issues such as accessing the document, respecting its contents and effective use. The improvement of the therapeutic relationship is also a benefit of ADs in the literature.

8.3. Therapeutic Alliance
The original rationale behind ADs was the enhancement of autonomy, but the measure is also beneficial under a therapeutic alliance framework.332 ADs can promote trust and respect in the doctor-patient relationship and lead to enhanced outcomes.333 The results of a trial suggested service users who completed ADs had a greater working alliance with clinicians and were more likely to have their preferences respected.334 The trial suggested a number of positive outcomes including increased functioning, treatment satisfaction and decreased crises. The document provides a way of harnessing service user expertise and improving decision-making quality.335

The therapeutic relationship may impact on demand and the type of AD the service user wishes to create. The degree to which individuals want their treating psychiatrist involved in the AD will partly depend on the level of trust.336 A higher level of trust

330 Leslie Campbell and Steven Kisely, ‘Advance Treatment Directives for People with Severe Mental Illness’ (2012) 8 The Cochrane Library (Wiley and Sons).
331 Ibid.
and empowerment allows individuals to discuss their treatment preferences openly in a safe environment. Individuals with higher levels of empowerment displayed significantly lower desire for physician involvement. A number of studies highlight the impact of coercion on the therapeutic relationship. Involuntary admission had a negative impact on the therapeutic relationship for 27 per cent of patients in a previous Irish study. Another study found individuals in more secure wards had the lowest working alliance and least interpersonal trust in clinicians. A pilot for an end-of-life planning tool with Irish GPs found ADs enhanced the relationship with patients and reduced the potential for family conflict. Individuals who believe their choices will be respected are more likely to engage and benefit from treatment than those who feel coerced and disrespected.

8.4. Empowerment

The development of an AD is frequently associated with empowerment. The perception of respect for choice can lead to an increased sense of empowerment and well-being. Empowerment involves the sharing of knowledge with the goal of increasing autonomy. The research suggests that the AD completion process

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337 Ibid.
342 Sarah Murphy and Brendan O’Shea, ‘Think Ahead: An Irish Care Planning Tool’ 3 (2) BMJ Supportive and Palliative Care 270.
provides a sense of empowerment and security.³⁴⁷ The sense of control can empower individuals towards recovery and reduce the need for hospitalisation and involuntary admission. The World Health Organisation (WHO) statement on user empowerment in mental health refers to the need to offer service users the opportunity to be involved in the development of shared crisis plans, recovery plans and ADs.³⁴⁸ Social exclusion and disempowerment can discourage the use of ADs, suggesting a need for encouragement and support in mental health care.³⁴⁹ The establishment of a legislative basis for ADs was viewed as enhancing autonomy and empowerment in the Irish mental health policy framework.³⁵⁰

8.5. Reduced Involuntary Detention and Treatment

ADs are at the forefront of contemporary measures to reduce involuntary admission and treatment.³⁵¹ Winick argues that ADs have a therapeutic value, making service users more responsive to treatment and self-compliant, thereby reducing the need for involuntary admission.³⁵² The MacArthur Research Network studies showed that individuals who believe they have a ‘voice’ experience less coercion during the hospital admission process.³⁵³ The research consistently suggests that individuals are increasingly likely to engage in treatment and to experience better outcomes when given a choice.³⁵⁴ Treatment engagement was increased and coercive interventions were reduced by half for individuals who completed facilitated ADs in a previous study.³⁵⁵ A previous trial found decreased use of mental health legislation and lower

³⁴⁸ WHO Europe, User Empowerment in Mental Health: A Statement by the WHO Regional Office for Europe (WHO 2010) 7.
readmission rates for those who used joint crisis plans (JCP) in the U.K. The Irish mental health system is characterised by high hospital readmissions and involuntary admission rates have been increasing again since 2010. Prior research found a negative correlation between involuntary admission and engagement with treatment after discharge.

Involuntary admission is a traumatic experience depriving the person of their liberty and basic human rights. The ethical issues involved in admitting and treating individuals against their will are at the centre of personhood. The experience of coercion has been explored in previous research. Coercive treatment can be anti-therapeutic, negatively impact on self-esteem and induce feelings of apathy, distrust, submissiveness, dehumanisation and frustration. The core themes in one study included lack of respect as a human being and involvement. Individuals with mental health conditions are often abhorrent to the depersonalisation and loss of control that accompanies the involuntary admission process rather than being totally opposed to treatment itself. Many individuals perceive involuntary treatment to be a negative experience and view it as unjustified. Even those who viewed their

358 Involuntary admissions accounted for 11 per cent of all admissions in Ireland in 2012, a slight increase from 2011.
360 The Oxford English Dictionary defines personhood as the quality or condition of being an individual person. Richard Hull, ‘Involuntary Commitment and Treatment of Persons Diagnosed as Mentally Ill’ in Biomedical Ethics Reviews (Springer 1983) 131.
362 Andrea Blanch and Jacqueline Parrish, Report on Roundtable on Alternatives to Involuntary Treatment, (Rockville, Maryland, National Institute of Mental Health 1990).
365 Christina Katsukou and others, ‘Psychiatric Patients’ Views on why their Involuntary Hospitalisation was Right or Wrong: A Qualitative Study’ (2012) 47 Social Psychiatry Psychiatric Epidemiology 1169; Stefan Priebe and others, ‘Patient’s Views and Readmissions 1 Year after
detention as justified were still angry about the admission.\textsuperscript{366} Gardner and others believed this was a result of the injury caused by the coercive nature of detention and the loss of autonomy.\textsuperscript{367} A review of the qualitative studies on involuntary admission and treatment experiences found a number of negative themes, including restrictions on autonomy, lack of participation in treatment decisions, quality of care, the emotional impact of involuntary treatment and feeling devalued.\textsuperscript{368} Higher levels of dissatisfaction with staff care were reported among individuals who were detained.\textsuperscript{369} A Norwegian study found that the mental health service the person had been in contact with was a better predictor of involuntary admission than diagnosis.\textsuperscript{370}

Katsakou found the perception of coercion was more important than the admission status under mental health legislation.\textsuperscript{371} The perception of coercion is associated with the experience of force or threats and the belief that one’s views are not taken into consideration in the admission process.\textsuperscript{372} The lack of respect for choice extends beyond the realm of involuntary detention.\textsuperscript{373} Individuals who are not subject to involuntary admission may also perceive a threat of coercion. A series of studies have found that even where individuals are admitted on a voluntary basis, many believe that they are not free to leave due to the implicit or explicit threat that they

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\textsuperscript{367} Ibid.
\end{footnotesize}
can be detained.\textsuperscript{374} This was illustrated in a recent Irish case where a voluntary patient, who was refusing treatment, but did not indicate a wish to leave, was changed to an involuntary patient so she could be treated without her consent.\textsuperscript{375} When service users perceive that their opinions are heard and taken into account, they feel less coerced, even if they are subject to involuntary admission. Individuals who perceived less coercion on admission and while receiving treatment in hospital, were reported to be more satisfied with their treatment.\textsuperscript{376} Those subject to mental health legislation often have limited involvement in their care.\textsuperscript{377} The way in which the involuntary admission is handled can impact on a person’s future engagement with treatment.\textsuperscript{378}

The need to decrease the perception of coercion and increase the sense of control provides a strong justification for ADs in mental health care.\textsuperscript{379} ADs can give individuals a sense of informed consent during mental health crises and decrease the need for coercive responses. The measure allows treatment to be provided in accordance with the person’s wishes.\textsuperscript{380} Some directives allow individuals to give advance consent to hospitalisation through a proxy decision-maker for a limited period, thereby avoiding the need for involuntary admission.\textsuperscript{381} The directive can inform the administration of treatment during involuntary hospitalisation. By allowing individuals to describe the circumstances under which they wish to be hospitalised and their preferred treatment, ADs can avert the need for involuntary admission and expedite treatment. ADs provide an opportunity to redefine the model of care from one of coercion to participation.\textsuperscript{382}

\textsuperscript{375} \textit{KC v St. Loman’s Hospital} [2013] IEHC 310.
\textsuperscript{381} Oregon. Virginia allows for advance authorisation to hospital admission for ten days.
8.6. Economic and Organisational Benefits

ADs are associated with a reduced need for readmission and involuntary detention conferring economic and other benefits. In an economic valuation of joint crisis plans found a 78 per cent probability that they were more cost effective than standard service information in preventing admissions. In addition to increased costs, high readmission rates can block the admission of new patients and impact the quality of care. Evidence suggests that non-compliance with aftercare may contribute to increased risk of readmission. ADs have a role in increasing engagement with treatment and promoting self-directed care. The measure has also been hypothesised to reduce hospitalisation lengths by providing more expeditious care. The increased use of ADs also resulted in substantial cost savings in other studies. The economic evaluation of the CRIMSON trial in the U.K. showed JCPs had no significant effect on compulsory admissions. However, the findings suggested a higher probability that JCPs are the more cost-effective option. The limitations of the study impacted the overall findings, but the results were sufficiently striking to warrant further investigation into the potential gain of JCPs among ethnic patient groups.

9. Barriers to Advance Directives

Although the literature shows a range of benefits associated with ADs, the barriers must also be considered. Opponents believe mental health ADs present a wide range of legal and ethical challenges, making them difficult to implement into practice.

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385 Fiona Keogh and others, ‘We have no Beds ... ’An Enquiry into the Availability and Use of Acute Psychiatric Beds in the Eastern Health Board Region’ (Health Research Board 1999).
386 Health Research Board, Community Treatment Orders and Readmissions (Health Research Board Ireland 2004-2009).
391 Ibid.
The issues requiring consideration include: the circumstances in which they can be overridden or revoked; the refusal of treatment; involuntary treatment; the right to request treatment; capacity; unforeseen circumstances and collaborative decision-making. Several clinical and operational barriers to ADs have been identified in the literature including lack of clinician familiarity, legal uncertainty and provider reluctance to support them. Lack of information amongst stakeholders has also been identified as a barrier. The literature shows high demand for ADs amongst service users, but low use in practice. The gap between service user interest and completion rates can be partly attributed to the barriers. Service users cite difficulties in understanding ADs, scepticism about the benefits and provider respect, lack of trusted proxy decision-makers, the complexity of the form and difficulty getting the document witnessed and legally certified. Other barriers include: lack of knowledge or training to implement or honour them; legal liability and ethical issues associated with implementing or overriding the document. The perceived barriers differ between stakeholder groups. Clinicians and family members generally support ADs, but clinicians tend to be concerned about how they will work in practice. Resistance among clinicians can result from lack of awareness, practice pressures, legal defensiveness or discomfort with self-directed care or shared

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394 Ibid.
Clinicians tend to underestimate service user demand for ADs and are more concerned with their ability to complete them. The clinician perception that service users are not interested in ADs combined with the service user perception that providers will not respect the document, can result in low completion rates in practice. A number of strategies have been used to address AD barriers including the use of trained facilitators and involving the treatment team in development.

9.1. Low Completion Rates
The research indicates strong demand for ADs, but low completion rates. Studies suggest one half to two-thirds of mental health service users were interested in completing an AD, if given the choice and necessary support. In a study across five U.S. cities, only 3.9 to 12.9 per cent of mental health outpatients completed an AD, but 66 to 77 per cent reported a desire to execute one with support. Other studies suggest an even higher level of interest amongst service users. The use of facilitated support increased the completion rate to over 60 per cent.

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completion rate for general ADs in the U.S. is approximately 20 per cent. Some commentators have argued that the AD movement should be dismantled because of low completion rates. Aulisio asserts that the AD movement has failed to achieve its primary goal of high completion rates, but has succeeded in bringing about a paradigm shift in the therapeutic relationship.

The high demand for ADs in mental health has been attributed to a desire to prepare for future crises and to ensure treatment preferences are respected. Individuals with mental health conditions usually have prior experience of crisis and treatment allowing them to predict future situations more accurately. The lack of knowledge regarding AD availability may be contributing to the low uptake. The Scottish review suggested low completion rates could be attributed to the fact that most service users had never heard of ADs and, even if they had, they did not think the document was relevant or know how to create one. A study on facilitated ADs found completion was determined by a combination of factors including: the duration of the illness and treatment; past negative experiences; understanding and motivation. Strong support networks have also been associated with increased AD completion. Those who had a close friend were almost four times more likely to complete the document. Service users above the age of 42 were also three times more likely to complete an AD. A number of proposals have been made to increase the use of ADs in end-of-life care including removing the two-witness

411 Ibid.
418 Ibid 104.
requirement; widening the parameters as to who can act as proxy\textsuperscript{419} and making AD forms more readable and user-friendly.\textsuperscript{420} Other commentators suggest that ADs should be placed in the broader context of advance care planning, enhancing communication and participation.\textsuperscript{421}

Low usage may also be attributed to the knowledge and motivation of mental health professionals. ADs are more likely to be completed if providers are supportive of the document.\textsuperscript{422} The qualitative analysis of a randomised trial found that limited provider knowledge and difficulties communicating the value of ADs to inpatient staff limited their utility.\textsuperscript{423} The varying frameworks underlying ADs can also create ambiguity in relation to their purpose e.g. as a crisis planning tool, advance care plan or an alternative to coercion.\textsuperscript{424} Many of the barriers to the use of ADs in mental health care can be overcome through education and service user support for completion. The highest completion rates have been achieved for ADs, which incorporate support e.g. facilitated ADs and joint crisis plans.\textsuperscript{425}

9.2. Clinicians’ Barriers
The views of clinicians are critical to the use of ADs.\textsuperscript{426} The international research suggests the effective implementation of ADs is limited by clinicians’ views and

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\bibitem{419} Lesley Castillo and others, ‘Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care’ (2011) 154 (2) Annals of Internal Medicine 121.
\bibitem{426} Michaela Amering and others, ‘Psychiatric Wills of Mental Health Professionals: A Survey of Opinions regarding Advance Directives in Psychiatry’ (1999) 34 (1) Social Psychiatry and Psychiatric Epidemiology 30; Maria O’Connell and Catherine Stein, ‘Psychiatric Advance Directives: Perspectives of Community Stakeholders’ (2005) 32 (3) Administration and Policy in Mental Health and Mental Health Services Research 241; Marvin Swartz and others, ‘Psychiatrists’ Views and
\end{thebibliography}
knowledge. ADs are perceived less beneficial by psychiatrists than other clinicians.\textsuperscript{427} The literature shows psychiatrists were concerned with a reduction in clinical autonomy, their utility and the refusal of all treatment.\textsuperscript{428} They were also concerned with legal liability and decisional conflict in relation to legal binding ADs and the administrative burden.\textsuperscript{429} These concerns may be more common in jurisdictions where physicians lack ‘good faith’ immunity or do not have a duty to inquire if an AD exists.\textsuperscript{430} Other concerns relate to service user capacity to understand and complete the directive and make statements with adequate and appropriate information.\textsuperscript{431} Concerns have also arisen in relation to ambiguous instructions or inappropriate treatment requests\textsuperscript{432} and pressure from family members.\textsuperscript{433} However, previous studies show the majority of ADs contain clear and valuable information\textsuperscript{434} and are consistent with clinical practice.\textsuperscript{435} Service users are generally interested in helping clinicians to make decisions rather than to refuse all treatment completely.\textsuperscript{436} While they were sceptical about the capacity of the system

\begin{footnotesize}
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\item Good faith clauses are used to protect physicians who treat individuals in their ‘best interests’.
\item Michaela Amering and others, ‘Psychiatric Advance Directives: Qualitative Study of Informed Deliberations by Mental Health Service Users’ (2005) 186 British Journal of Psychiatry 247; Eric Elbogen and others, ‘Effectively Implementing Psychiatric Advance Directives to Promote Self-
\end{itemize}
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to implement ADs, some psychiatrists were interested in using ADs as a reminder of the care plan. The level of knowledge among psychiatrists has been linked to increased support for ADs. Many of the concerns expressed by psychiatrists can therefore be addressed through education. The literature points to the importance of accompanying the introduction of ADs with provider education. ADs are increasingly viewed as tools that enable clinicians to respect human rights while providing the maximum level of care.

9.2.1. Refusal of Treatment

The refusal of treatment is a major source of contention in the literature. A number of studies found a large proportion of clinicians were reluctant to support ADs based on the fear that they will be used to refuse all treatment. In a U.K. survey, psychiatrists were significantly more reluctant than other groups to work with models that allow for refusal of treatment. However, the evidence suggests that ADs are rarely used to refuse all treatment. The document is normally used to

References:


express a preference for particular treatments or to inform providers of concerns. In three empirical studies examining AD content, none were used to refuse all treatment. A Scottish study on 55 advance statements found only one was used to refuse all treatment and 45 per cent of service users named specific medications they were prepared to take. In a review of the qualitative research, AD instructions were consistent with standard treatment and care in nearly all cases. Many service users view medication as helpful when their concerns and preferences were taken into account and exercise reasonableness and restraint. In one study in the U.S., almost three-quarters of participants expressed a preference for refusal of electroconvulsive therapy (ECT), while antipsychotics were the most refused form of medication.

Clinicians also expressed concerns in relation to the unanticipated consequences of refusals. This issue can be addressed by involving a facilitator or clinician in development or appointing a trusted proxy decision-maker to respond. While ADs can be used to refuse treatment, their role has been expanded significantly in recent years. ADs have increasingly focused on enabling individuals to participate in decisions about their future care and recovery, including the ability to consent to

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treatment. The framing of ADs in this context makes them more acceptable to providers and increases utility and support.

9.3. System Barriers
System and operational barriers can hinder the effective implementation of ADs. Clinicians report barriers such as access to the document during a crisis, lack of training, communication between staff in different parts of the system and lack of time to review the document. In order to develop clinician facilitated directives or JCPs, providers and services users need time, which is not always available. In one study it took participants an average of 121 minutes to complete an AD and 94 minutes to complete a proxy directive. Emergency staff also need time to access the AD during a crisis. The implementation of ADs in hospital settings poses barriers including the use of shared decision-making, infrastructure and resources.

9.3.1. Access
The accessibility of ADs has been identified as a barrier to implementation in the literature. Providers are unlikely to invest time in ADs if they are sceptical about accessing the document in a crisis. Concerns have been expressed about accessing the document in emergencies when the individual needs it the most. The AD is more likely to be followed if it is held in a central accessible place and effectively

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documented. Some jurisdictions have employed crisis cards or scanned information to alert providers. Only one empirical study addresses access and compliance in any detail. In the Washington State study, the document was accessed in just 90 out of 450 crisis events despite the use of multiple strategies to alert providers. Results indicated the average compliance rate was 67 per cent in 90 crisis events. The use of ADs requires a shift in provider perception of the document, which is not an end in itself, but a means to an end.

The electronic medical record provides an ideal landscape for accessing ADs and helps build self-directed care into practice. The successful Gundersen Lutheran programme for end-of-life planning in Wisconsin has achieved over 90 per cent participation and compliance through a systematic approach, which includes providing advance planning information in electronic records wherever they need to be accessed. The Gundersen Lutheran application brings together advance care planning practices into one electronic system and guides practitioners through initiating and updating e-plans, patient education, identifying health care proxies and assisting with referrals to facilitators. The programme suggests a well-designed electronic medical record can help make advance planning an on-going, dynamic process where physicians and independent facilitators engage in discussions with patients about their value and goals for future care.

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464 Netherlands, United Kingdom, United States.
466 Service users were provided with crisis cards and bracelets to alert providers, copies were distributed to proxy decision-makers and mental health crisis units, placed in the individual’s medical record and flagged in the electronic registry.
469 Ibid.
The establishment of an electronic registry is important for information storage and access. Electronic registries are being used in a number of jurisdictions. A national ‘living will’ registry was established in the U.S. for storing ADs, organ donor information and emergency contacts. The registry is accessible to healthcare providers with the consent of the person or the proxy decision-maker. Registrants receive reminders to update ADs on an annual basis, ensuring the document is current and up-to-date. During an emergency, and with the prior consent of the individual or a proxy decision-maker, a copy of the document can be forwarded electronically to healthcare providers. The province of Alberta in Canada developed a registry for individuals to store personal directives. However, if the directive cannot be found in an emergency or is not applicable to the situation, treatment can be provided without consent. Electronic registries have also been established in a number of U.S. states. The State of Virginia allows individuals to submit integrated ADs for mental health and other decisions onto the registry. The establishment of an electronic registry confers many advantages and provides access to the AD during a crisis. It also enables reminders for review so the document is current and up-to-date. The registry saves time and can be used in conjunction with the crisis card and electronic medical records to ensure provider awareness and access. Electronic medical records is a key aspect of healthcare reform in the United States.

474 Personal Directives Act, RSA 2000, s 24 (1).
476 Health Service Executive (HSE), National Service Plan (Department of Health 2012).
478 Assisted Decision-Making (Capacity) Bill 2013, s 56 (2)(b).
access raises confidentiality issues in mental health and concern in relation to stigma in general health settings. This suggests a need for safeguards in relation to electronic access to mental health information. The need to establish a national electronic information system is recognised in the Health Service Executive (HSE) service plan in Ireland and a web-based mental health information system was piloted in 2010. The Minister for Health published an ehealth strategy for Ireland in December 2013 and published the Health Identifiers Bill 2013. The Bill will provide for the assignment of a unique number to an individual to whom a health service is being, has been or may be provided. The 2013 Bill proposes to establish a register of decision-making agreements through the Office of the Public Guardian. The draft scheme for ADs does not propose an online registry, but the issue has been raised as part of the public consultation on the legislation. The establishment of a central registry and responsibility for registration should be incorporated into the legislative framework for ADs and include confidentiality safeguards.

9.4. Overriding Advance Directives

The circumstances in which an AD may be overridden can act as a barrier for both service users and clinicians. Mental health legislation often provides grounds for overriding the directive but a single acceptable criterion is lacking. The ambiguity in relation to overriding the AD can contribute to clinician ambivalence. The introduction of legislation for mental health ADs often includes exceptions to enforceability. The provisions vary between jurisdictions, but generally an AD may be overridden for the purpose of involuntary admission, during defined emergencies or where the provider believes the AD was executed in bad faith, under duress or it is

477 Health Service Executive (HSE), National Service Plan (Department of Health 2012).
480 Assisted Decision-Making (Capacity) Bill 2013, s 56 (2)(b).
not clinically appropriate. Compliance is not necessarily an all-or-nothing issue with some aspects of ADs being complied with in certain circumstances.

The law varies as to whether a person detained under mental health legislation automatically loses the right to refuse treatment. In Scotland, an advance refusal of treatment can be honoured even if a person is involuntarily detained. Case law in the U.S., Germany and Canada has found that ADs should be respected during involuntary detention. In Ontario, detained persons have been able to use advance decisions to refuse treatment since the 1980s. A decision of the Constitutional Court of Germany based on CRPD principles found ADs to be binding and to indicate the ‘natural will’ of the person in the context of involuntary treatment.

The court referred to the right to equal recognition before the law and to exercise legal capacity with support. The risk of harm to others was not considered to be a justifiable ground for overriding a valid AD as detention can be used for this purpose. Clinicians fear that this will lead to individuals being left untreated, but the evidence suggests that ADs are rarely used to refuse all treatment. The Bazelon Centre for Mental Health Law urges that mental health ADs operate in the same way as other directives subject only to legitimate emergency situations. The CRPD requires equal recognition before the law and respect for the legal capacity of

485 Jacqueline Atkinson, Advance Directives in Mental Health: Theory, Practice and Ethics (Jessica Kingsley 2007) 73.
487 Health Care Consent Act SO 1996, c 2, SCH A.
488 In current German (civil and criminal) law, ‘natural will’ means any expression of will on the part of a person. Ralf J Jox, ‘Revocation of Advance Directives’ in Peter Lack, Nikola Biller-Andorno and Suzanne Brauer, Advance Directives (Springer 2014) 96.
490 If the risk persists despite a period of detention, treatment may eventually be provided.
all persons, including those detained under mental health legislation.\textsuperscript{493} This requires the abolition of substitute decision-making regimes or any other mechanisms that discriminate against persons with disabilities.\textsuperscript{494}

The potential for ADs to be overridden or ignored by medical staff can lead to low completion rates among service users.\textsuperscript{495} The belief that the directive will be ignored or have limited impact has been identified as a barrier in the literature.\textsuperscript{496} Service users and families need to feel confident that the AD will be respected to use it.\textsuperscript{497} Respect for the AD is a fundamental outcome of development and not just an operational issue that may limit effectiveness.\textsuperscript{498} The dismissal of a person’s choices can cause a sense of worthlessness and diminished sense of self and cause further distrust. Some commentators suggest that the adverse impact is no higher than if the person had not executed a directive.\textsuperscript{499} Some clinicians have overridden valid ADs in the belief that they have a better understanding of the person’s clinical needs. Nonetheless, the failure to recognise individual preferences can lead to a perception of disrespect and damage the therapeutic relationship.

The publication of figures showing the low number of ADs being overridden can help alleviate service user concerns.\textsuperscript{500} The Scottish Commission received 25

\textsuperscript{493} GA Res 61/106. UN Doc A/Res/61/106 (entered into force 3 May 2008), Article 12 provides for equal recognition before the law. Article 14 provides for right to liberty and Article 17 provides a right to physical and mental integrity.

\textsuperscript{494} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 46.


\textsuperscript{500} Jim McManus and others, Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: Report: As Presented to Scottish Ministers March 2009 (Scottish Government 2009).
notifications of AD overrides in 2013, but only 18 of these were valid. Most of the overrides were in relation to the refusal of medication or depot injections, while one was in relation to ECT treatment. Interestingly, four of the overrides were in relation to a request for specific medication. A previous pilot study, based on a small sample, showed that all of the ADs invoked during mental health crisis had been honoured. The establishment of a clear monitoring mechanism whereby treatment in conflict with a valid AD is reported to an independent authority may increase accountability and instil confidence.

AD overrides were found to be higher amongst psychiatrists in emergency departments and those with risk of violence, lack of insight and legal liability concerns. Most statutes provide for an exception to adhering to ADs in emergency situations, but this definition can vary. The Special Rapporteur on the right to health has stated that treatment without consent should only proceed in life-threatening emergencies. In some jurisdictions, an emergency is defined as a situation that requires a person to take immediate action to avoid harm, injury, or death to an individual or to others. The definition needs to be strictly defined in the legislation to ensure the AD is respected outside these limited situations. After reading a hypothetical scenario where the AD was used to refuse hospitalisation or treatment with antipsychotics, 47 per cent of psychiatrists chose to override the directive. Nearly half of psychiatrists reported they would override the directive if the person lacked insight to make a ‘rational’ decision at execution. A trial of JCPs suggested some plans were not followed due to access issues or where the provider believed it

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501 One statement had not been witnessed by an appropriate person and in five cases, the override was superseded by a community treatment order (CTO) imposed under Scottish law. Mental Welfare Commission for Scotland, *Mental Health Act Monitoring 2012/2013* (Mental Welfare Commission 2013) 44-45.
503 The Scottish review recommended requiring responsible medical officers to review any treatment in conflict with an AD and provide a written record of efforts to address the person’s wishes.
506 Human Rights Regulations 12VAC35-115-70, Virginia.
508 Ibid.
was not in the person’s ‘best interests’. Lack of awareness of the AD can also lead to non-compliance. Other cited reasons include vaguely written ADs, but the literature shows service users generally provide clear and unambiguous instructions. Mental health ADs are often clearly written because service users have experience of crisis and treatment.

A number of strategies have been employed to increase AD compliance including involving the psychiatrist in development or executing a legally binding document. However, both strategies create barriers if psychiatrists exert undue influence or are reluctant to discuss the content. Service users may also be uncomfortable with legal documents. Dresser argues the involvement of the clinician can increase paternalism and further decrease liberty. In other studies, clinicians were less likely to override treatment refusals when they were not legally binding; they had longer professional experience; they were aware of the legislation or when a proxy decision-maker was appointed. Psychiatrists were also more likely to follow treatment refusals when they were supported by the family or when mental health professionals were involved in development. The literature suggests the inclusion of valid reasons for treatment choices increases the likelihood that the AD will be respected. ADs are more likely to be upheld if they specify ‘reasonable’ treatment requests and include valid reasons for refusal. In one study, 72 per cent of clinicians stated they would respect the AD if the treatment refusal

was based on concerns about side effects, while only 22 per cent stated they would uphold the AD if the refusal was based on ‘delusions’. 518 The justification for compliance is particularly strong where the choice is based on experience of harmful or ineffective treatment. 519 Provider education can also lead to a high level of compliance with treatment choices. 520 The Gundersen Lutheran programme for end-of-life directives has achieved over 90 per cent compliance through provider training on communicating with patients and families in relation to advance planning. 521

Legislators are generally willing to introduce ADs, but are reluctant to address enforceability. 522 The enforceability of ADs is particularly uncertain in the absence of legislation. The lack of clear guidelines can reinforce stigma and limit usage. In weak legal frameworks, ADs tend to be subordinate to mental health laws. 523 A strong legal model with accountability mechanisms may be required where there is negativity and mental health professionals are influenced by legal uncertainty. 524 Advocates promote strong legislative frameworks that emphasise the enforceability of ADs for mental health decisions. These approaches provide for appeal and review where an AD is overridden or ignored. Strong accountability mechanisms are needed in the legislation until respect for treatment preferences are established in mental health practice.

523 Ibid 160.
524 Ibid 161.
9.5. **Risk Concerns**

The concern with risk has led to widespread perceptions of dangerousness and environments with less respect for choice. The research suggests that AD overrides are highest among clinicians with risk concerns. Bartlett asserts that this is a highly stigmatising stereotype and is discriminatory. The increased risk of harm is relatively low and violence occurs very rarely. In a review of 26 studies in developed countries, individuals with mental health difficulties were ten times more likely to be victims of violence than to be perpetrators. Individuals with mental health disabilities were at a higher risk of violence than other persons with other disabilities, with 24 per cent reporting that they were the victim of some form of violence in the previous year. They are also more likely to struggle with personal relationships, have a greater likelihood of substance abuse, homelessness, being imprisoned or living in poverty and suffer stigma and discrimination in the community.

The perception of risk or dangerousness can be used as a justification for overriding ADs. However, predictions of dangerousness have been found to be weak and inaccurate. Commentators suggest that psychiatrists cannot accurately predict violence using clinical judgement and risk assessment tools are limited. The

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531 Ibid.
532 Ibid.
potential for error in psychiatric risk assessments was illustrated in the *Baxstrom v Herold* case in the U.S. in 1966, which resulted in the release of 966 patients detained on the grounds of dangerousness. In a four-year follow up Steadman and Cocozza found only 20 per cent had been reconvicted, the majority for non-violent offences. The curtailment of choice is often unrelated to risk. The general population is normally not detained under law based on their future dangerousness, but individuals with mental health conditions are subject to preventative detention. Other groups who pose a greater risk of violence such as substance abusers are often exempt from mental health legislation. In referring to the principle of non-discrimination in Article 5 of the CRPD, Bartlett asserts:

“We do not lock up other people on the basis of prospective dangerousness, even when there is cogent statistical evidence of their dangerousness: why would we do so with people with mental disorder?”

The risk of violence may be more effectively addressed through accessible community services and encouraging those who need help to engage with treatment. The management of relapse and engagement are more likely to prevent violence. The small proportion of individuals who are prone to dangerousness often do not seek treatment before committing a harmful act. Individuals who believe their wishes will be followed and respected are more likely to seek and

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538 Mental Health Act (2001), s 8(2) excludes the involuntary admission of persons addicted to drugs or intoxicants only to an approved centre.


engage in treatment. A survey on the impact of involuntary treatment found 28 per cent of individuals reported a fear of coercion as a barrier to seeking treatment. The research suggests coercion is associated with the person’s perception of how they were treated by others and whether their views were taken into consideration rather than the actual involuntary admission. The perception of the interaction is therefore central to the coercive experience. McGuinness argues that mental health professionals need to continually engage with those subject to involuntary admission and help them foster a sense of ownership of their recovery. ADs can provide a perception of respect for the person’s preferences and negate the impact of involuntary admission. The need for coercion can be minimised as individuals engage with their chosen treatment or recovery strategy and consent where needed can be provided by the person.

9.6. Communication
ADs are often viewed as communication tools, providing a forum for dialogue and the exchange of information. The recovery approach proposes ADs as a communicative platform providing for listening in the therapeutic relationship. Some general healthcare programmes teach physicians to communicate, rather than merely using ADs as legal documents. Weller suggests the success of ADs will depend more on the communication skills of mental health professionals and service users than the legal model. Psychiatry is distinct from other branches of medicine in that

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543 Robert Calsyn, Joel Winter, and Gary Morse, ‘Do Consumers who have a Choice of Treatment have better Outcomes?’ (2000) 36 Community Mental Health Journal 149.
the focus is on the therapeutic relationship. Communication is a key aspect of this relationship. Clinicians may lack the listening and communication skills to engage in dialogue. The quality of the conversation between the provider and the person is suggested to be at the centre of all forms of advance care planning. Involuntary treatment can impede the development of communicative skills such as dialogue, persuasion and understanding among mental health professionals. Traditional education curricula do not typically include training on communicating with individuals regarding past treatment experiences. Moreover, practitioners with poor communication skills and those who fail to consider the views of the person are more likely to be the subject of litigation. The CRPD requires all health and medical personnel to use appropriate consultation skills to directly engage with the person and ensure support persons do not have undue influence.

The communication skills of service users may also act as a barrier to ADs. Service users may be inexperienced in making and articulating decisions. The deprivation of autonomy can lead to perceptions of coercion or learned helplessness, making individuals appear unable to make decisions. A study on supported decision-making showed a range of barriers to participation including fear, past trauma, mental health system experience, passivity and literacy levels. In the past, attempts to establish dialogue were frequently interpreted as non-compliance and treatment requests were refused. These experiences can influence the person’s ability to

552 Charles Sabatino, ‘Eight Advance Care Planning Lessons that took me Thirty Years to Learn’ 34 (6) Bifocal 115.
557 Irma Mahone and others, ‘Shared Decision Making in Mental Health Treatment: Qualitative Findings from Stakeholder Focus Groups’ (2011) 25 (6) Archives of Psychiatric Nursing e27.
communicate. The issues of familiarity, uncertainty and disempowerment therefore need to be addressed. ADs have an important role in enhancing the communication skills of both service users and mental health professionals by encouraging active listening and dialogue through open collaborative discussion. The use of ADs can help build communication skills and capacity and act as a platform for the articulation of preferences and the development of trust.

9.7. Service User Barriers
The concerns of clinicians pose significant barriers to ADs, but service user barriers also need to be addressed. The most frequently occurring barriers to completion include a lack of understanding, a belief that the AD will have limited impact and uncertainty as to what to include in the document. Some individuals may be reluctant to complete an AD because: they fear signing a legal document; believe their decision-making capacity will never be impaired; have a low awareness of legal rights; are concerned the document will further stigmatise them; or are deterred by barriers in the legislation or mental health services. Other concerns relate to changing the directive to incorporate new preferences before going into crisis. The difficulty updating the directive and identifying trusted support persons to assist with development has been voiced in a number of studies. The majority of service users expressed a preference to appoint a proxy decision maker, but some did not have a trusted person to make decisions. Service user reluctance to plan for

561 Richard Van Dorn and others, ‘Preferences for Psychiatric Advance Directives Among Latinos: Views on Advance Care Planning for Mental Health’ (2009) 60 (10) Psychiatric Services 1383
readmission and to recall distressing experiences may also act as a barrier.\textsuperscript{566} Other barriers relate to the purpose, limitations and applicability of the document; capacity determinations; logistical issues; uncertainty as to the legal implications and concerns of loss of control and increased mistrust if they are not followed.\textsuperscript{567}

9.8. \textit{Capacity Determinations}

The issue of capacity can pose a barrier to the use of ADs. Capacity is fraught with ethical, legal and pragmatic complexities\textsuperscript{568} and varies by jurisdiction and subject matter. The responsibility for assessing capacity usually lies with physicians and confers significant power. The determination of capacity is particularly problematic in mental health where individuals are vulnerable to findings of incapacity based on the perceived rationality of the decision.\textsuperscript{569} Capacity determinations tend to arise in the context of refusal of mental health treatment.\textsuperscript{570} In general health settings, capacity is often not questioned. Non-compliance with treatment may be due to side effects, values or coping styles.\textsuperscript{571} International research suggests that ADs with ‘irrational’ reasons were only followed in 22 per cent of cases.\textsuperscript{572} Irrational reasons were considered to be ones based on ‘delusions’ and not based on conventional medical explanations for refusal.\textsuperscript{573}

Historically, individuals deemed to lack mental capacity were deprived of their legal capacity to make decisions. Mental capacity and legal capacity are distinct concepts.

\begin{thebibliography}{99}


\bibitem{568} Felicity Callard and others, \textit{Mental Illness: Discrimination and the Law} (Wiley 2012) 47.

\bibitem{569} Michael Perlin, \textit{The Hidden Prejudice: Mental Disability on Trial} (American Psychological Association 2000) 155, 156.


\bibitem{573} Ibid.

\end{thebibliography}
Legal capacity is the ability to hold rights and to exercise those rights.\textsuperscript{574} It enables the individual to choose and to have those decisions respected. Mental capacity refers to individual decision-making skills, which naturally vary and differ depending on the circumstances.\textsuperscript{575} Capacity decisions are often made by judges who interpret legislation and are informed by mental capacity assessments undertaken by medical or other multidisciplinary professionals.\textsuperscript{576} Awareness and insight are often used as criteria for incapacity.\textsuperscript{577} Insight has been defined as the person’s understanding of their condition and how it affects interactions.\textsuperscript{578} According to Winick judicial capacity decisions are inevitably embedded in cultural, social, political and legal values that reinforce stigma.\textsuperscript{579} While there is some evidence that capacity assessments are reasonably consistent in combination with a clinical interview, there is no large scale research on this question.\textsuperscript{580} In Ontario, trained capacity reviewers provide opinions to the court about the individuals’ capacity to make decisions.\textsuperscript{581} O’Reilly found only six cases of judicial support for refusal of mental health treatment over a 15 year period and a finding of incapacity was overturned in only two cases.\textsuperscript{582} In Ireland, the capacity to consent to treatment is determined by the responsible consultant psychiatrist (RCP) without independent review and treatment decisions are made in the person’s ‘best interests’ if the individual is deemed to lack capacity.\textsuperscript{583} The CRPD Committee recently stated, for the first time, that mental capacity cannot be used as a reason for depriving

\textsuperscript{574} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention-Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 12.
\textsuperscript{575} Ibid.
\textsuperscript{579} Bruce Winick, ‘Competency to Consent to Treatment: The Distinction Between Assent and Objection’ (1991) 28 (1) Houston Law Review 15.
\textsuperscript{581} Daniel Ambrosini, ‘PADs and the Role of Autonomy’ (2009) 34 (2) Review Sante Mentale au Quebec 51.
\textsuperscript{582} Richard O’Reilly in Jacqueline Atkinson and Jacquie Reilly, ‘Limitations to the Scope and Binding Force of Advance Directives; The Conflict between Compulsory Treatment and the Right to Self-Determination’ in Peter Lack, Nikola Biller-Andorno and Suzanne Brauer, \textit{Advance Directives} (Springer 2014) 96.
\textsuperscript{583} Mental Health Act, 2001. Ireland.
individuals of their legal capacity for a single decision.\textsuperscript{584} The CRPD prohibits the use of capacity criteria that impose treatment in a person’s ‘best interests’ and provide for substitute decision-making.\textsuperscript{585}

Dhanda argues capacity determinations are discriminatory because they disproportionately affect persons with disabilities and are based on a non-disabled standard of assessment that denies capacity to those who do not meet it.\textsuperscript{586} The selective legal capacity in these assessments designates some individuals as lacking in capacity to make decisions and denies them the opportunity to develop. Models and definitions of capacity are considered over inclusive and reinforce the association between disability and incapacity.\textsuperscript{587} The interpretation of the law is further aggravated by labels of competence and incompetence, which serve to reinforce prejudice and stereotypes.\textsuperscript{588} The use of unconventional reasoning is often viewed as a sign of incapacity and can be used as a ground for invalidating an AD.\textsuperscript{589} The right to equal recognition before the law in the CRPD requires that legal capacity is a universal legal attribute, which is applied to all persons by reason of their humanity.\textsuperscript{590} Universal legal capacity promotes participation and interaction between all members of society and increases understanding.\textsuperscript{591}

The challenge is to break the association between mental health disabilities and incapacity. The MacArthur Treatment Competence Study,\textsuperscript{592} demonstrated that

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\item \textsuperscript{584} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention-Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 12.
\item \textsuperscript{585} Ibid para 23.
\item \textsuperscript{586} Amita Dhanda, ‘Universal Legal Capacity as a Universal Human Right’ in Michael Dudley, Derrick Silove and Fran Gale (eds), \textit{Mental and Human Rights: Vision, Praxis and Courage} (Oxford University Press 2012) 181.
\item \textsuperscript{587} Ibid.
\item \textsuperscript{588} The study found a large number of patients in general health settings lacked competence. Paul Appelbaum, Thomas Grisso, ‘The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments’ (1995) 19 Law and Human Behaviour 149.
\item \textsuperscript{589} Christine Wilder, ‘Effect of Patients’ Reasons for Refusing Treatment on Implementing Psychiatric Advance Directives’ (2007) 58 (10) Psychiatric Services 1349.
\item \textsuperscript{590} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention-Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 8.
\item \textsuperscript{591} Amita Dhanda, ‘Universal Legal Capacity as a Universal Human Right’ in Michael Dudley, Derrick Silove and Fran Gale (eds), \textit{Mental and Human Rights: Vision, Praxis and Courage} (Oxford University Press 2012) 182.
\item \textsuperscript{592} Paul Appelbaum, Thomas Grisso, ‘The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment’(1995) 19 Law and Human Behaviour 105; Paul
\end{itemize}
although decision-making abilities were compromised in some individuals with mental health conditions, more than half had capacity levels similar to their counterparts in general health care. The study rebutted the widespread assumption that individuals with mental health conditions lack decision-making capacity. Okai also showed the majority of mental health inpatients were capable of making treatment decisions.

The research suggests individuals with mental health conditions are capable of completing ADs, but some may require support. The law does not attribute lack of capacity to individuals with physical health conditions, so the capacity to execute or revoke an AD is generally not questioned. The CRPD places an obligation on State Parties to provide access to support to exercise legal capacity. The ability to make decisions can be enhanced by providing information in an appropriate context/format and allowing time for discussion with trusted persons. The side effects of treatment and the episodic nature of a condition should also be considered. Gunn showed a marked improvement in understanding when information was made more accessible. The CRPD requires an exploration of

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593 The MacArthur competence assessment tool (MacCAT-T) is used to measure levels of understanding, appreciation, reasoning and choice for treatment. The Decisional Competence Assessment Tool for Psychiatric Advance Directives (D-CAT-PAD) has been used to determine the person’s ability to understand the impact of an AD and whether they want to execute one. The D-CAT PAD mirrors the structure of the MacArthur Competency Assessment Tool for Treatment. Eric Elbogen, ‘Competence to Complete Psychiatric Advance Directives: Effects of Facilitated Decision-Making (2007) 31 Law and Human Behavior 275.


598 Article 12(3).


600 Ibid.

ways of providing information adapted to the needs of the individual. One of the aims of support measures under the CRPD is to build confidence and skills so individuals can make decisions. The AD can act as a communicative device and augment the decision-making capacity of the person. The use of support measures such as ADs can help build capacity by providing a forum for the articulation of values and choices.

9.8.1. Refusal of Life-Saving Treatment in the Mental Health Context
The refusal of life-saving treatment creates difficult dilemmas in the mental health context. Minkowitz argues that persons without disabilities are permitted to refuse life-saving treatment, so persons with mental disabilities should be equally allowed to do so, with support if needed. Two high profile cases in England and Wales highlight the ethical and practical issues that arise in relation to the refusal of life-saving treatment. In England and Wales, advance decisions can be made under the Mental Capacity Act 2005 and in a limited form under the Mental Health Act 2007. In the case of individuals who are involuntarily detained, such directives do not apply when treatment is authorised under the Mental Health Act 1983, but it may be a factor a doctor may wish to take into account when enforcing treatment. Some exceptions are provided for ECT treatment. In cases where the person is not capable of consenting, ECT treatment can only be given if it is appropriate and does not conflict with the advance decision. The Code of Practice in the Mental Health Act calls for professionals to comply with ‘advance statements of wishes and feelings’ and to document the reasons for non-compliance with the statement. The advance decision can preclude treatment of voluntary patients, or general health

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607 Mental Health Act 2007, s 27.
608 Consent is not required under sections 63 and 58 of the Mental Health Act 1983.
treatments for detained patients. There is relatively little case law in England and Wales relating to advance decisions and existing litigation shows some hesitancy in the courts to uphold such decisions. In two leading cases, the advance decision was held not to be valid.

The E and KW cases also raised controversy in relation life-saving treatment for individuals with mental health conditions. Both cases were decided on the basis of mental capacity, but led to different outcomes. In the KW case, Kerrie Wooltorton, a twenty-seven year old woman, died from deliberate self-poisoning in 2007. She had been receiving support from local mental health services and made several attempts to end her life. She was reported to have drunk anti-freeze on nine previous occasions, but had nonetheless accepted life-saving treatment. In September 2007, she presented to hospital after drinking anti-freeze with a statement written three days earlier clearly refusing life-saving treatment, but consenting to pain relief. The letter was viewed as a statement of KW’s capable wishes. The doctors deemed that she had the mental capacity to refuse medical treatment and was steadfast in her refusals so her wishes were respected. The decision to allow her to die was the subject of considerable debate in the medical profession and the media. Under the current law in England and Wales, if an adult with decision-making capacity refuses life-saving treatment, the doctor cannot override the refusal unless the person is admitted under the Mental Health Act 1983. If KW was deemed to lack mental capacity, she could have been treated in her ‘best interests’ under current English law. The CRPD requires the abolition of substitute decision-making regimes where decisions are based on the person’s ‘best interests’ and requires support for the exercise of legal capacity based on the ‘will and preferences’ of the individual. Under the CRPD approach, KW’s mental capacity would not have affected her right to exercise legal capacity and she would have been provided with support to make

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611 Inquest into the death of Kerrie Wooltorton, 29 September 2009, Unpublished Extracts, Norfolk Coroner Service, Norwich, U.K.
the decision if needed. However, the person can refuse support or end the support relationship at any time.\textsuperscript{613}

The \textit{E} case\textsuperscript{614} also illustrates the dilemmas which may arise in relation to the refusal of life-saving treatment in an AD. In this case, the woman’s refusal of forced feeding, which would have resulted in her death was not respected, and she was forcibly treated. The forcible feeding treatment was estimated to give her only a 20 per cent chance of recovery. \textit{E} was a thirty two year old woman, who had been undergoing treatment for severe anorexia for 17 years, which was treatment resistant. She had frequently expressed a wish not to receive any further forced feeding treatment and written two advance decisions stating that she no longer wished to be treated by compulsion with the support of her family and health professionals. When her death was imminent, an application was made to the English court of protection to determine her mental capacity at the time of the hearing and when she executed the ADs. The court found that \textit{E} lacked capacity at the time of the hearing based on her inability to use and weigh the information. The court also found on the balance of probabilities that \textit{E} lacked capacity when she executed the ADs. The decision appeared to be based on the belief that a person with severe anorexia lacks the capacity to make decisions relating to food. The court erred towards life stating “the balance tips slowly but unmistakably in the direction of life preserving treatment.”\textsuperscript{615}

\textit{E}’s parents had supported her right to refuse treatment and commented on the discriminatory nature of the decision:

“It seems strange to us that the only people who don’t seem to have the right to die when there is no further appropriate treatment available are those with an eating disorder. This is based on the assumption that they can never have capacity around issues connected to food. There is a logic to this, but not from the perspective of the sufferer who is not extended the same rights as any other person.”\textsuperscript{616}

The comments expressed by \textit{E}’s parents raise serious challenges to the judicial reasoning in the case and the right of individuals with mental health conditions to

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\item \textsuperscript{613} Ibid para 25(g).
\item \textsuperscript{614} A Local Authority v \textit{E} [2012] EWHC 1639 (COP).
\item \textsuperscript{615} Ibid para 140.
\item \textsuperscript{616} Ibid para 52.
\end{itemize}
\end{footnotesize}
make fundamental decisions about their lives.\textsuperscript{617} The decision highlights the inherent difficulties that arise in relation to capacity determinations in the mental health context. The discrimination argument alluded to by E’s parents are similar to the ones put forward by Nancy Hargrave in \textit{Hargrave v Vermont} in relation to the right to refuse life-saving chemotherapy, but not psychiatric medication.\textsuperscript{618} The fundamental question, according to Richardson, is whether someone with a mental health disability has an equal right to end his/her life in the same way as a person with a physical health condition.\textsuperscript{619} A person with a terminal physical illness who refuses treatment may be regarded as having mental capacity, but if a person with a mental health condition refuses treatment, which may result in death, he or she will be regarded as lacking capacity. The refusal is seen as a reflection of the condition rather the true self, even if the illness is long term and treatment resistant.\textsuperscript{620} In referring to the \textit{E} case, Bartlett argues that it seems somehow wrong that someone could be found capable if accepting treatment, but incapable when refusing treatment.\textsuperscript{621} The desire to end one’s life due to a mental health difficulty is sometimes viewed as ‘a permanent solution to a temporary problem’. The refusal of life-saving treatment in mental health may warrant longer term engagement and support to ensure the decision truly reflects the person’s ‘will and preferences’. The principle of universal legal capacity in the CRPD removes the distinction between capacity and incapacity and provides support for the person to make his or her own decisions. A recent resolution from the Council of Europe states that the decision should always be in favour of prolonging life where there is doubt as to the person’s preferences in the AD.\textsuperscript{622}

9.9. Revoking an Advance Directive

The circumstances in which an AD can be revoked must also be considered. Revoking an AD means changing certain parts or the whole of the document or

\textsuperscript{617} Peter Bartlett and Ralph Sandland, Mental Health Law Policy and Practice (4\textsuperscript{th} edn, Oxford University Press 2014) 178.
\textsuperscript{618} \textit{Hargrave v State of Vermont} 340 F 3d 27 (2nd Cir 2003).
\textsuperscript{621} Peter Bartlett and Ralph Sandland, Mental Health Law: Policy and Practice (4\textsuperscript{th} edn, Oxford University Press 2014) 178.
\textsuperscript{622} Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012) Principle 7.8.
Some jurisdictions specify the person must have decision-making capacity to revoke the directive, while others allow the AD to be revoked at any time. Other jurisdictions allow the person to choose whether the document is revocable during crisis periods at execution. The general health directive is normally revocable if the person is able to communicate a choice, but ADs are often more difficult to revoke and easier to override in mental health. The literature suggests service user and clinician opinions differ significantly in relation to revocability. Clinicians generally support legislation that requires capacity to revoke an AD, while service users prefer it to be revocable at any time, even though few are fully revoked in practice. Some service users fear they may experience a limitation in treatment not intended in their previously expressed will. In *Rosa M*, a New York court upheld a woman’s revocation of her prior consent to ECT. Sabatino argues that everyone is prone to ambivalence in the context of advance care planning and not only do individuals have a right to change their mind, they often do so. The presumption of capacity in the CRPD implies that an AD can be revoked at any time. The draft general comment on Article 12 states that the person has the right to end or change the support at any time he or she chooses. In Germany, an AD can be revoked informally even with limited decision-making capacity. While this confers autonomy, issues arise in mental health where a person expresses AD preferences in the knowledge that he or she will object to these when unwell, but wishes to override his/her own future protestations to avoid deterioration. The

624 Arizona, Washington.
627 106 clients with ADs and their associated 487 crisis events, a directive has never been revoked as a whole, though in 105 (22%) of the crises, clients changed their minds about some specific instructions in Debra Srebnik and Scott Kim, ‘Competency for Creation Use and Revocation of Psychiatric Advance Directives’ (2006) 34 (4) Journal of the American Academy of Psychiatry and the Law 501.
629 Charles Sabatino, ‘Eight Advance Care Planning Lessons that took me Thirty Years to Learn’ 34 (6) Bifocal 115.
630 Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 25(g).
revocability issue can be resolved by allowing a person to change the AD preferences at any time, unless a Ulysses clause has been executed. Self-binding directives or Ulysses clauses are available in a number of U.S. States, Canadian provinces and the Netherlands.

9.9.1. Ulysses Clause

The Ulysses clause provides for anticipatory consent through a self-binding contract, which can be used to override future treatment objections. The clause presents ethical challenges as the individual elects to be bound to the AD wishes over subsequent objections during crisis periods. The term Ulysses is derived from Homer’s Odyssey where the mythical character asked to be bound to the ship’s mast regardless of subsequent pleas, to stop them being lured aground in the Bay of Sirens. Ulysses limited his future freedom to act by entering into a contract he could not later revoke. Some individuals may want to avoid behaviour they exhibit during mental health crises due to the risk to personal safety, financial security and interpersonal relationships. The Ulysses clause implies that the person cannot revoke the AD during periods he or she specifies. Many individuals self-bind to avoid deterioration and the need for involuntary commitment. Dresser argues the self is equally valid during a psychotic state and that overriding a current preference with one expressed in the past by the capable self is an unethical infringement of a person’s liberty. Concerns have been expressed that this form of directive may result in undue coercion and negate the wishes of the unwell self in favour of the well self. However, service users have requested the provision of such a clause and it has proven popular in some jurisdictions.

632 See chapter 5. Under Va Code s 54.1-2985 (a), an AD can be revoked by signing, dating, writing, physical destruction, revocation by another on the individual’s direction, oral revocation.
635 Alok Sarin, Pratima Murthy and Sudipto Chatterjee, ‘Psychiatric Advance Directives: Potential Challenges in India’ 9 Indian Journal of Medical Ethics 104.
637 Ibid.
638 Approximately 50 per cent of service users in Virginia are executing a Ulysses clause. See chapter 5.
The Ontario legislation provides a Ulysses clause by proxy whereby the representative communicates the previously expressed wishes of the person, which take precedent over contemporaneous refusals of treatment.\textsuperscript{539} The Virginia directive allows the individual to empower a trusted proxy decision-maker to authorise hospitalisation for a limited period to avoid involuntary admission.\textsuperscript{640} The CRPD requires that supports for the exercise of legal capacity must respect the ‘will and preferences’ of the person and should never result in substitute decision-making.\textsuperscript{641} The self-binding directive should be subject to strict safeguards and clear guidance to ensure it reflects the ‘will and preferences’ of the person and apply for only a limited period. Bach suggests individuals should identify the triggering event in an AD and specify guidelines so the parameters are clearly established within the terms of the directive.\textsuperscript{642}

10. Implications of the Barriers in the Literature

The barriers identified in the literature have a number of implications for the introduction and implementation of a legal framework for ADs. The introduction of ADs requires consideration of the barriers at all levels of the development and invocation process from awareness, education, support, activation, revocation and compliance. Some commentators suggest the experience in general healthcare can provide lessons for the implementation of ADs in mental health settings.\textsuperscript{643} Sabatino argues that good advance care planning requires more than just education, it requires fundamental system change.\textsuperscript{644} A culture of respect for preferences and person-centred care must therefore be built into the system. ADs are part of a comprehensive system framework of advance care planning under the recovery approach and the supported decision-making model. The development of an AD is merely one tool in an overall framework of participation. The Gundersen Lutheran

\textsuperscript{539} Ontario.
\textsuperscript{640} Va Code s 54.1-2982.
\textsuperscript{641} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 15.
\textsuperscript{644} Charles Sabatino, ‘Eight Advance Care Planning Lessons that took me Thirty Years to Learn’ 34 (6) Bifocal 115.
health system has built advance care planning into system design ensuring all adults encounter multiple opportunities to engage in the process at different times, in a manner appropriate to their needs. The model demonstrates that it is possible to create effective advance care planning environments in any setting.

ADs are more than narrowly construed legal documents, which are completed at a single point in time but involve an engagement with the person over a longer period. Advocates envisage the very process of creating an AD will enhance service user trust and collaboration with clinicians, improve the therapeutic relationship and engagement with treatment. The document may not only be useful as a communicative platform, but in helping individuals to re-examine their values, develop capacity and build trust. The incorporation of a values history can increase the effectiveness of ADs and support the exercise of legal capacity. ADs should be perceived as documents that can provide “mutual understanding and collaboration between clinicians and patients” rather than being viewed as adversarial documents designed to protect service users.

10.1. Strategies for Overcoming AD Barriers—Education and Support

The strategies for overcoming barriers and increasing AD completion rates highlight the need for education, support and system reform. The perceived barriers were found to increase for groups that were not educated on ADs in previous research. Education is necessary for all stakeholder groups including providers, service users, advocacy organisations and families. The Scottish experience demonstrated the need

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to provide on-going community and professional education. Educating one stakeholder group about the opinions of the other group can also be used to reduce barriers. Provider education is viewed as critical to implementation. The Gundersen Lutheran programme demonstrates that the successful implementation of an advance planning system is dependent on a comprehensive systematic approach in community and other settings, trained facilitators, electronic medical records and provider education. Staff are trained in advance care planning skills and education is provided for members of the community. Providers from all parts of the mental health system at inpatient, community and crisis services should be involved in the education process.

The provision of appropriate support and information for service users to complete ADs can also help address barriers to completion. Support can be provided by a peer, family member, mental health professional or other trained person. A key component of the successful Gundersen Lutheran programme for end-of-life directives includes the provision of trained facilitators in a range of settings. The supported decision-making approach is promoted in the CRPD, which requires State Parties to provide access to appropriate support for the exercise of legal capacity. Other suggested supports to increase completion include the simplification of AD materials to suit individual needs and minimising barriers to execution such as legal certification or limitations on witnesses. Support for legal capacity can also include measures that increase accessibility or unconventional methods of communication. The length and complexity of the form can act as a barrier to completion.

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655 Article 12(3).
software programmes and other resources such as the ‘AD maker’ can also facilitate
development.\(^{658}\) The programme guides the person through the process of creating an
instructional or proxy directive. The CRPD requires the provision of information on
ADs to be adapted to the needs of the individual.\(^{659}\)

11. Conclusions

A wide variation of legislative frameworks for ADs exists across comparative
jurisdictions. The use of ADs in mental health care poses a myriad of practical
issues, most of which transcend jurisdiction.\(^{660}\) Some jurisdictions provide for ADs
in mental health legislation, whereas others have provisions under health care
decisions or capacity legislation. The provisions include legally binding and non-
legally binding options. The approaches range from a paternalistic, to a fully
embedded human rights standard. Both formalistic and flexible approaches have
been adopted. Some jurisdictions provide proxy directives, whereas others provide
for instructional and hybrid directives. Variations exist as to the requirements for
executing, invoking and revoking a directive, individuals who can act as proxy
decision-makers or witnesses, duties of the proxy, support for completion, the
involvement of clinicians, the circumstances in when an AD can be overridden and
accountability mechanisms. Some jurisdictions provide for a Ulysses clause, which
allows the person to make their wishes irrevocable in certain circumstances. Other
jurisdictions place a positive obligation on treatment providers to inquire into the
existence of an AD.\(^{661}\) The theoretical and human rights framework underlying ADs
were also considered including the CRPD, the recovery approach, autonomy and
therapeutic jurisprudence. The CRPD provides a new set of human rights standards,
which challenges the traditional notions of capacity and incapacity on which ADs are
predicated. It forces us to reconceptualise ADs and to separate the measure from
existing legal frameworks, which use capacity as a basis for activation and
deactivation. The CRPD also requires respect for the legal capacity of all persons

\(^{658}\) Paul Sherman, ‘Administrative Update-Computer Assisted Creation of Psychiatric Advance

\(^{659}\) Amnesty International. ‘Essential Principles: Irish Legal Capacity Law’ (April 2012) 4(a),
<http://www.amnesty.ie/sites/default/files/file/MentalHealth/PRINCIPLES_WEB.pdf> [accessed 1
October 2013].

\(^{660}\) Debra Srebnik and Lisa Brodoff, ‘Implementing Psychiatric Advance Directives: Service
Providers Issues and Answers’ (2003) 30 (3) Journal of Behavioural Health Services and Research
253.

\(^{661}\) Patient Self-Determination Act 1990, United States.
implying ADs should be equally available to everyone, including those detained under mental health legislation.662

The introduction of ADs also requires consideration of the international and national context in which they will operate and the views of stakeholders. Stakeholder support is crucial for successful implementation so these concerns should be addressed prior to the introduction of the legislation. The empirical literature indicates high levels of support among service users and families, but lower levels of support among clinicians. A range of strategies are being employed to increase usage in mental health settings including education, support and embedding ADs under the recovery approach. ADs are reported to increase autonomy and empowerment and communication even if they are never invoked or honoured.663 The development of an AD may therefore be the most important aspect of the measure for both clinicians and service users.

12. Gaps in the Literature and Directions for Future Research
The gaps in the literature must be considered for future research. Despite the interest in mental health ADs, little empirical research was completed prior to 2004. The research has considered: demand for ADs;664 the barriers that prevent or limit completion;665 their role in reducing the occurrence of mental health crises;666

662 GA Res 61/106. UN Doc A/Res/61/106 (entered into force 3 May 2008), Article 12 provides for equal recognition before the law. Article 14 provides for right to liberty and Article 17 provides a right to physical and mental integrity.
reducing coercion and increasing adherence to treatment. Some commentators have expressed concerns that randomised control trials and readmission rates are an inappropriate method of assessment. The focus on quantitative measures such as readmission rates fails to consider the developmental benefits of making wishes known, even if the AD is never legally invoked.

The effect of ADs on empowerment, self-esteem, legal capacity, engagement and service satisfaction should also be considered in the research. Other possible benefits of ADs include promoting responsibility and the impact on stigma. There is also a need for more informal and contextualised information about the practical elements of ADs not reported in the formal scientific literature. Other researchers have suggested that future studies should focus on a variety of outcomes including involuntary and voluntary admissions; social inclusion; capacity building benefits; quality of life; satisfaction with mental health services and how accurately ADs reflect the wishes of the person.

13. How the Current Research will address some of the Gaps in the Literature
The CRPD provides a new human rights framework for the implementation of ADs. The use of ADs under the recovery approach and the supported decision-making model are part of the context in which they can develop. The research has yet to consider the implementation of appropriate forms of ADs under the new approach to legal capacity in the CRPD and their role under the supported decision-making

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model. It is therefore necessary to consider their implementation from a CRPD perspective. The thesis will consider the implementation of ADs under the CRPD in chapter 3.

The evidence base in relation to the complete implementation of ADs from the introduction of legislation to practice outcomes is incomplete. While ADs have received extensive legislative support, little is known about how they can be effectively implemented into practice. Further research is needed on the effective implementation of ADs in different legal and system contexts. The State of Virginia is attempting to successfully introduce and implement a legal framework for ADs into mental health settings with the support of stakeholders and international experts. The three-phase study focuses on knowledge, attitudes to facilitation, content and completion and will help inform the implementation of ADs in other jurisdictions. This thesis will consider the features of the Virginia legislation, compliance with the CRPD and the lessons from the implementation process in chapter 5.

The effective implementation of a legal framework for ADs is dependent on the support of key stakeholder groups involved in development and enforcement. While much has been written internationally concerning ADs, there is a dearth of Irish literature on the topic. Empirical research addressing stakeholder views of ADs is currently lacking in Ireland and has never been addressed in any detail. The empirical study in this thesis will examine the views and preferences of Irish service users and consultant psychiatrists in chapter 6. The features of the Irish legal, policy and system framework will also be explored in chapter 4 and set the context for the empirical study. The literature review, the international, comparative, national legal frameworks and contexts and the views of Irish service users and psychiatrists will inform the conclusions for the introduction and implementation of ADs in Ireland in the final chapter (chapter 7).


CHAPTER 3
International and European Legal Framework for Advance Directives in Mental Health Care

1. Introduction
In this chapter, the use of ADs under international and European human rights frameworks will be examined. The development of international human rights is constantly evolving and is increasingly used to develop national mental health policies and legislation. The foundations of mental health law are thus continuously shifting with human rights norms. The European Convention on Human Rights (ECHR) and the UN Convention on the Rights of Persons with Disabilities (CRPD) are key drivers of legislative reform in Ireland. The CRPD presents new challenges for mental health law and grounds for introducing ADs. The concept of mental health ADs has gathered momentum in the past decade and is increasingly recognised in national and international law.\(^1\) While ADs are not explicitly acknowledged in international instruments relating to mental health, they are widely recognised as vehicles for the principles of participation, non-discrimination, acceptability and accessibility.\(^2\) The inclusion of ADs in mental health settings is part of an international impetus towards the recognition of human rights for individuals with mental health conditions.\(^3\) The analysis of the international and European human rights frameworks in this chapter will set the stage for the consideration of ADs in the Irish context.

2. Development of Human Rights in Mental Health
The formal recognition of ADs coincided with the rise of the human rights movement and the articulation of the right to highest standard of health by the international human rights community.\(^4\) These foundational principles were

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4 Sofia Gruskin and others, Perspectives on Health and Human Rights (Routledge 2005).
originally expressed in the Universal Declaration of Human Rights (UDHR), which emphasises the inherent dignity and equal and inalienable rights of all persons.\(^5\) These rights have been reaffirmed and extended in the CRPD. The origins of human rights in mental health can be traced back to the establishment of the UDHR in 1948\(^6\) and the ECHR in 1950.\(^7\) The UN created seven core human rights Conventions between World War II and the end of the twentieth century.\(^8\) Equality before the law is a basic and general human rights principle, with roots in the International Covenant on Civil and Political Rights (ICCPR).\(^9\) The UDHR, the ICCPR and the CRPD specifically guarantee the right to equality before the law and stipulate that it is operative everywhere regardless of circumstances. The history of exclusion and discrimination in mental health reiterates the need for human rights protections in this area. Individuals with mental health conditions are routinely treated against their will and deprived of freedom and dignity.\(^10\) In the community, they often remain imprisoned by social exclusion and barriers to participation. Human rights law provides fundamental protections for this vulnerable group.\(^11\)

Rosenthal and Rubenstein conceptualised mental disability as an international human rights issue in a seminal article in 1993.\(^12\) In recent decades, there has been an explosion of interest in the area as non-governmental organisations and mental health advocacy organisations have brought human rights violations to the fore. The

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5 The UDHR include political and civil, and economic, social and cultural rights.
6 Universal Declaration for Human Rights, GA Res 217A (III), UN GAOR, 3\(^{rd}\) sess, 183\(^{rd}\) plenary meeting, UN Doc A/810 (10 December 1948).
8 International Covenant on Civil and Political Rights (16 December 1966); International Covenant on Economic, Social and Cultural Rights (16 December 1966); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (10 December 1984); Convention on the Elimination of All Forms of Discrimination against Women (18 December 1979); International Convention on the Elimination of All Forms of Racial Discrimination (7 March 1966); International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (18 December 1990); Convention on the Rights of the Child (20 November 1989).
rights of persons with mental disabilities have been somewhat absent from international human rights instruments and have lagged behind political, social and economic rights. The human rights community have generally been more ambivalent about the rights of persons with mental health conditions. Perlin argues that this is a result of the irrational prejudice or ‘sanism’, which permeates all aspects of mental disability law and has distorted jurisprudence in the area. These prejudices have hindered reintegration into society and had a negative impact on the lives of individuals with mental health conditions.

3. International Instruments

Ireland is a signatory to a number of international documents that are instrumental in enhancing the dignity and autonomy of individuals with mental health conditions. Some Conventions are legally binding and create rights that are enforceable in international or domestic courts and are referred to as ‘hard law’. The UN Charter and Covenants are often considered to be ‘hard law’. Other non-binding international instruments referred to as ‘soft law’ are useful in achieving compliance, setting standards and providing persuasive authority in domestic courts. These include recommendations and resolutions. International instruments can impose both positive and negative obligations on states. A number of international legal and policy instruments set standards for mental health treatment and care.

3.1. International Covenant on Civil and Political Rights (ICCPR) and International Covenant on Economic, Social and Cultural Rights (ICESCR)

Several international documents have dealt directly or indirectly with disability, but many are ambiguous and non-binding. The International Covenant on Civil and

13 Sanism is an irrational prejudice that cause prevailing social attitudes such racism, sexism, homophobia. Michael Perlin, *International Human Rights and Mental Disability Law: When the Silenced are Heard* (Oxford University Press 2012) 34.


Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), to which Ireland is a signatory, impose binding obligations on State Parties based on the UDHR principles. These Covenants do not refer explicitly to mental disability, but it is considered to be implicitly protected.\textsuperscript{19} The universality principle in human rights extends to all persons regardless of status.\textsuperscript{20} The protected rights include a right to self-determination, the highest standard of physical and mental health and a prohibition on discrimination.\textsuperscript{21} The UDHR and the ICCPR specifically guarantee the right to equality before the law. The CRPD reaffirms and extends this right to persons with disabilities. Participation in decisions is a crucial element of the right to health under Article 12 of the ICESCR. The right to health in the ICESCR includes the right to control one’s own health and body and the right to be free from torture and non-consensual treatment.\textsuperscript{22} Other regional instruments include the ECHR and the lesser used Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (IACPD). Quinn argues that the varying pace of development of human rights in mental health, intellectual disability and equal opportunity law has acted as a barrier to the realisation of disability rights.\textsuperscript{23} International instruments in the area of mental health traditionally adopted a paternalistic stance,\textsuperscript{24} or tried to establish international standards for compulsory intervention.\textsuperscript{25}

3.2. *UN Principles for the Protection of Persons with Mental Illness (MI Principles)*

The human rights of individuals with mental health conditions were first specifically addressed in an international document in the UN Principles for the Protection of

\textsuperscript{21} Article 2(1) ICCPR; Article 2(2) ICESCR.; ICCPR, Article 1(1); ICESCR Article 1(1); Article 12 ICESCR.
\textsuperscript{22} UN Committee on Economic, Social and Cultural Rights, ‘The Right to the Highest Attainable Standard of Health, CESCIR General Comment 14, 22\textsuperscript{nd} Session, Agenda Item 3, UN Doc E/C 12/2000/4 (2000). In order to interpret ICESCR rights, the Economic and Social Council (ECOSOC) periodically issues general comments.
\textsuperscript{24} UN Declaration on the Rights of Mentally Retarded Persons, GA Res 2856 (XXVI) 26 UN GAOR Supp (No 29) at 93, UN Doc A/8429 (1971).
\textsuperscript{25} UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, General Assembly Resolution 46/119 (17 December 1991).
Persons with Mental Illness in 1991 (MI Principles).\textsuperscript{26} The non-binding guidelines set out minimum standards for treatment, the preservation of autonomy and a duty to treat patients in the least restrictive environment.\textsuperscript{27} The principles are now criticised for promoting the medical model of disability\textsuperscript{28} and providing minimum protection for the right to informed consent.\textsuperscript{29} The MI principles were developed without significant participation by individuals with mental disabilities. This reduced their credibility in the area. The CRPD provisions now supersede the MI principles.

3.3 \textit{UN Convention on the Rights of Persons with Disabilities (CRPD)}

The UN Convention on the Rights of Disabilities (CRPD) is the first internationally binding document, which explicitly applies to disabilities and been ratified by the European Union (EU) in its own right.\textsuperscript{30} It is regarded as the most significant development in human rights and mental disability law and was the first UN Convention of the new millennium.\textsuperscript{31} The CRPD has been embraced widely by the disability movement and has taken precedence over previous instruments.\textsuperscript{32} Previous international instruments on mental disability started from the premise that coercion was justified in certain circumstances.\textsuperscript{33} The CRPD, in contrast, prohibits coercion on the basis of disability.\textsuperscript{34} It forces us to consider the prejudices perpetuated by the legal system towards persons with mental disabilities and provides much greater

\textsuperscript{26} Ibid.
\textsuperscript{27} Ibid 9(4).
\textsuperscript{30} The EU became the 97\textsuperscript{th} party to the treaty when it ratified it on the 23\textsuperscript{rd} of December 2010. Twenty four of the 28 EU Member States have ratified the CRPD.
\textsuperscript{31} Michael Perlin, ‘International Human Rights and Mental Disability Law: When the Silenced are Heard’ (Oxford University Press 2012) 143.
\textsuperscript{33} Peter Bartlett, ‘A Mental Disorder of a Kind or Degree Warranting Confinement: Examining Justifications for Psychiatric Detention’ (2012) 16 (6) The International Journal of Human Rights 831.
\textsuperscript{34} Article 14(1).
depth than other human rights treaties in prohibiting discrimination and achieving equality.\textsuperscript{35}

The purpose of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.”\textsuperscript{36} All the provisions further this purpose and are informed by this objective. It does not explicitly define disability, but states that it includes persons with long-term physical, mental, intellectual or physical impairments.\textsuperscript{37} The CRPD clearly recognises persons with disabilities as equal bearers of rights and aims to eliminate discrimination.\textsuperscript{38} It heralds a novel approach shifting towards a social model of disability requiring State Parties to remove barriers.\textsuperscript{39} The emphasis is on non-discrimination, supported autonomy and social inclusion.\textsuperscript{40} The general principles include respect for inherent dignity, autonomy including the freedom to make one’s own choices, non-discrimination and full and effective participation in society.\textsuperscript{41} The Office of the High Commissioner for Human Rights (OCHCR)\textsuperscript{42} and the Special Rapporteur on Torture\textsuperscript{43} have affirmed that non-discrimination on the ground of mental disability\textsuperscript{44} is included. The involvement of persons with disabilities in the drafting of the CRPD gives it more legitimacy in this area. Any country which ratifies the CRPD consents to be bound by its provisions and is obliged to promote and realise the rights set out in it. The CRPD requires the immediate implementation of civil and political rights. Article 33 also requires the persons with disabilities and their representation

\textsuperscript{35} Michael Perlin, ‘International Human Rights and Mental Disability Law: When the Silenced are Heard’ (Oxford University Press 2012) 36.


\textsuperscript{37} Ibid.


\textsuperscript{39} The social model of disability concentrates on altering environmental barriers, changing attitudes and programmes and advancing human rights in Michael Prince, ‘Canadian Disability Policy: Still a Hit and Miss Affair’ (2004) 29 Canadian Journal of Sociology 59.


\textsuperscript{41} Article 3.


\textsuperscript{43} Interim Report of the Special Rapporteur on Torture and other Cruel, Inhuman and Degrading Treatment or Punishment (SR Torture Interim Report), 28 July 2008, UN Doc A/63/175.

\textsuperscript{44} Negotiating states preferred the term ‘mental’ to ‘psychosocial’ disability. People with psychosocial disabilities are those who experience mental health issues, and/or who identify as ‘mental health consumers’ or ‘psychiatric survivors’.
organisations to be involved in monitoring implementation. Ireland signed the CRPD in 2007 but has not yet ratified its terms. In the Programme for Government, the Irish State has committed to introducing capacity legislation that complies with the CRPD. The publication of the Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill) is viewed a key step towards ratification.

3.3.1. CRPD and Mental Health Laws
The CRPD requires us to engage in new approaches to decision-making in mental health law and to develop a range of support strategies. The philosophical underpinnings of mental health laws and their justification must be reviewed in light of the provisions. Mental health law has traditionally authorised interventions, which would otherwise be unlawful including loss of liberty and non-consensual treatment. These actions are often justified on the premise that individuals should be required to accept treatment for the protection of themselves or others. Prior to the CRPD, there was little consideration of the lawfulness of mental health laws under international human rights frameworks outside of procedural protections.

Several articles of the CRPD have placed doubt over current mental health laws including provisions relating to the right to non-discrimination (Article 5), legal capacity (Article 12), liberty (Article 14), physical and mental integrity (Article 17) and torture or cruel, inhuman or degrading treatment (Article 15). The CRPD requires the abolition of policies and legislative provisions that allow or perpetuate forced treatment and substitute decision-making to ensure legal capacity is restored to persons with disabilities on an equal basis with others. The CRPD Committee recognises that persons with mental disabilities have been disproportionately affected by substitute decision-making and denials of legal capacity. The CRPD model requires the abolition of substitute decision-making regimes to one based on supported decision-making. The Committee recommends that State Parties should

48 Ibid para 9.
49 Ibid para 46.
ensure that decisions which involve physical or mental integrity should only be taken with the free and informed consent of the person.\textsuperscript{50}

The CRPD provides a new benchmark for the development of mental health and capacity law. It requires legislators and policymakers to understand the underlying philosophy and to give tangible effect to the provisions.\textsuperscript{51} The provisions challenge how current mental health laws are conceptualised.\textsuperscript{52} State Parties are required to holistically examine all areas of law to ensure that persons with disabilities are not denied their right to legal capacity.\textsuperscript{53} The CRPD requires repeal of legislation, which provides for substitute decision-making or authorises treatment without informed consent.\textsuperscript{54} This will create a need for support measures such as ADs, which enable individuals to exercise legal capacity and provide for consent when they may be unable to articulate decisions. The CRPD will also require equal access to ADs for individuals with mental health conditions and the elimination of discriminatory standards.

3.3.2. \textit{CRPD and the Convention against Torture and Other Cruel Inhuman or Degrading Treatment (CAT)}

Individuals with mental health conditions are particularly vulnerable to forced treatment. Under the CRPD, involuntary treatment by psychiatric and other health professionals is considered to be a violation of the right to equal recognition before the law, an infringement upon the rights to personal integrity, freedom from torture and violence and the right to legal capacity.\textsuperscript{55} The CRPD Committee have expressed

\begin{itemize}
\item \textsuperscript{50} Ibid para 38.
\item \textsuperscript{51} Gerard Quinn, Statement by Professor Gerard Quinn, Director, Centre for Disability Law & Policy to the Oireachtas Joint Committee on Justice, Defence and Equality, Re: Hearing on the Mental Capacity Bill, February 29, 2012.
\item \textsuperscript{53} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 7.
\item \textsuperscript{54} Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities (OHCHR) Legal Measures Study) UN Doc A/HRC/10/48, 26 January 2009, 49.
\item \textsuperscript{55} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 38.
\end{itemize}
concerns about the scope of legislation protecting against forced treatment and recommends the adoption of measures based on the consent of the person.

The UN Special Rapporteur on Torture points to how the CRPD can complement the Convention against Torture (CAT). The 2008 mandate on torture made significant progress in the development of standards for the abolition of forced psychiatric interventions. In a recent report, the Rapporteur called on states to impose a ban on all forced and non-consensual medical treatment against persons with disabilities, including the non-consensual administration of psychosurgery, ECT, neuroleptics and the use of restraint. The report reiterated the immediate obligation on State Parties to the CRPD to end forced psychiatric interventions. The Rapporteur stated that involuntary detention and treatment should be replaced by community services that respect autonomy, choice, dignity and privacy. This requires peer support, awareness-raising and training. The report recommended providing human rights education and training to health care personnel, judges and police to promote a culture of respect. The Special Rapporteur on the right to health also stated that the grounds upon which treatment can be administered without consent should not be based on disability. Treatment without consent should only proceed in life-threatening emergencies and accountability mechanisms should be put in place so violations are investigated. These statements imply that a validly executed AD should only be overridden in life-threatening emergencies and failure to comply with the person’s wishes should be monitored.

58 The United Nations Commission on Human Rights, in resolution 1985/33, decided to appoint an expert, a special rapporteur, to examine questions relevant to torture. The mandate was extended the Human Rights Council resolution 8/8 in June 2008. It covers all countries, irrespective of whether a State has ratified the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.
59 UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (New York 10 December 1984) A/RES/39/46.
60 A/63/175.
61 Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (United Nations February 2013), A/HRC/22/53 89.
62 Article 4( 2).
63 Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (United Nations February 2013), A/HRC/22/53 89.
64 Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/64/272, para 74.
65 Ibid para 12.
3.3.3. *Article 14 of the CRPD*

Article 14 of the CRPD clearly states that the “existence of a disability shall in no case justify a deprivation of liberty.” This provision challenges the grounds for involuntary detention in mental health law. The CRPD Committee has explicitly called for the prohibition of disability-based detention and recommended that State Parties review laws that provide for involuntary admission. The most recent observations of the Committee suggest that involuntary detention is prohibited under Article 14. According to the OHCHR, unlawful detention encompasses situations where the deprivation of liberty is based on mental disability and other elements such as dangerousness. The OHCHR stated that Article 14 requires repeal of legislation, which authorises treatment without informed consent, preventative detention and where grounds of care, treatment and public security are linked in the law to disability. ADs are at the forefront of contemporary measures to reduce the need for involuntary admission and treatment. The measure can play an important role in averting the need for involuntary admission by promoting self-directed recovery and providing advance consent to treatment acceptable to the person. The measure can also be used as less restrictive alternative to the imposition of community treatment orders and help increase voluntary engagement with treatment.

The prohibition on detention based on disability may be problematic for countries governed by the ECHR and the CRPD. Under Article 5 of the ECHR, the arbitrary prohibition on the deprivation of liberty is subject to certain exceptions for

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68 Committee on the Rights of Persons with Disabilities, Sixth Session 19-23 September 2011, Concluding Observations.
individuals with mental health conditions. These exceptions include that the condition is of a certain severity, but this is excluded under the CRPD. Fennell and Khaliq argue that while the “CRPD represents a radical approach to the rights of people with psychosocial disabilities, by comparison with the ECHR, it suffers a number of shortcomings.” While the European Court is reluctant to question medical judgement, they argue it would be unwise to dismiss the procedural safeguards afforded by the ECHR “without some credible alternative.” It is still not clear how the tensions between the instruments will be resolved. The EU and most Council of Europe member states are also signatories to the CRPD suggesting the need for integration.

3.3.4. Article 12 of the CRPD

Equal recognition before the law is a general principle of human rights and is pivotal for the exercise of other rights. Article 12 further expands on this right and echoes the statement in the preamble and the general principles of the CRPD, which affirm the importance of autonomy, independence and freedom of choice. It recognises the right of persons with disabilities to make decisions on an equal basis with others and have those decisions respected. Article 12 is at the core of the CRPD and affirms the presumption of legal capacity for all persons and the restoration of other rights such as participation and accessibility. The central requirement of Article 12 is the replacement of substitute decision-making regimes by supported decision-making.

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75 Ibid 674.
76 Ibid 662.
measures that respect the ‘will and preferences’ of the person.\footnote{Committee on the Rights of Persons with Disabilities Sixth Session, Consideration of Reports of State Parties under Article 35 of the Convention, CRPD/C/ESP/CO/1, 19 October 2011: Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess (September 2-13 2013) para 22.} Article 12(1) reaffirms that persons with disabilities have the right to equal recognition before the law and recognises that every human being has legal personhood.\footnote{University of Leeds, Department of Disability Studies, Legal Opinion on Article 12 of the CRPD, June 21 2008 <http://disability-studies.leeds.ac.uk/files/library/legal-opinion-LegalOpinion-Art12-FINAL.pdf> [accessed 13 March 2014].} Article 12(2) promotes an equality based approach to legal capacity by requiring State Parties to “recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”\footnote{Article 12(2).} This is complemented by Article 12(3), which places an obligation on States to provide access to appropriate support to exercise legal capacity.\footnote{Article 12(3).} Article 12(4) requires States to create appropriate and effective safeguards for the exercise of legal capacity and to ensure supports respect the rights and ‘will and preferences’ of the person.\footnote{Article 12(4).} This section must be read holistically with the rest of Article 12 and the other provisions of the CRPD.\footnote{Article 12(4).} Article 12 is a vehicle of non-discrimination which “protects people against the behaviour of third parties by giving a voice back to people to direct their own lives.”\footnote{Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 18.} It “... lies at the very heart of the revolution in disability-treating people as subjects and not objects.”\footnote{Gerard Quinn, European Foundation Centre, Consortium on Human Rights and Disability, Seminar on Legal Capacity, An Ideas Paper Brussels, 4 June 2009 <http://www.nuigalway.ie/cdlp/documents/events/EFCGQfinal.doc> [accessed 13 March 2014].}  

3.3.5. Legal Capacity under Article 12

absence of legal capacity, everyday decisions, including those relating to mental health treatment, have no legal force. Individuals with disabilities have been routinely stripped of their legal capacity to make decisions through judicial declarations or medical determinations of incapacity.\textsuperscript{91} Minkowitz states that without legal capacity all other fundamental rights can be violated in law and in fact.\textsuperscript{92} The recognition of legal capacity is linked to the enjoyment of other CRPD rights, including respect for mental and physical integrity and consent to medical treatment.\textsuperscript{93} Lauri Sivonen from the Council of Europe office described legal capacity as “the basic right to have rights.”\textsuperscript{94} Involuntary mental health treatment denies the legal capacity to choose treatment. State Parties must instead provide access to support measures such as ADs to allow individuals to make mental health treatment decisions.\textsuperscript{95}

The CRPD Committee distinguishes between mental and legal capacity.\textsuperscript{96} Legal capacity is the ability to hold rights and to exercise those rights. Mental capacity, in comparison, refers to the decision-making skills of the individual, which naturally vary.\textsuperscript{97} Article 12 does not permit deficits in mental capacity to be used as a justification for denying legal capacity.\textsuperscript{98} States must instead provide access to appropriate supports to exercise legal capacity. The CRPD requires reform of the functional approach to capacity, which is based on mental capacity and focuses on the individual’s ability to make decisions based on their ability to understand and retain information. Functional tests of mental capacity are considered to lead to denials of legal capacity and disproportionately affect persons with disabilities.\textsuperscript{99} The International Disability Alliance (IDA) challenges the functional approach to

\textsuperscript{91} Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (United Nations, February 2013), A/HRC/22/53, 15.
\textsuperscript{92} Tina Minkowitz, ‘Submission to the Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12’ 22 January 2014, 1.
\textsuperscript{93} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 27.
\textsuperscript{94} Lorcan Roche, ‘Basic Right to have Rights’ April (2012) Law Society Gazette 18.
\textsuperscript{95} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 38.
\textsuperscript{96} Ibid para 12.
\textsuperscript{97} Ibid.
\textsuperscript{98} Ibid.
\textsuperscript{99} Ibid para 21.
arguing that it reinforces discrimination. The World Network of Users and Survivors of Psychiatry (WNUSP) state that the functional assessment will always discriminate against persons with disabilities due to the association with mental disability. The right to legal capacity includes the right to make unwise decisions on an equal basis with others. Minkowitz distinguishes between systems of universal legal capacity espoused in the CRPD from regimes that graft supported decision-making onto mental or functional assessments. The 2013 Bill proposes a functional test for capacity in Irish legislation.

Presumptions of incapacity permeate law and policy making in the mental health context. Article 12 requires a move away from reliance on medical decision-making and the loss of capacity in mental health settings. Bach and Kerzner assert that decisions in relation to admittance for mental health treatment should be made either by the individual themselves independently, or with support representatives. They recommend removing the authority from clinicians to involuntarily admit a person to hospital. According to a recent EU survey, many individuals with mental health conditions are not only formally deprived of their legal capacity, but are subject to informal restrictions by family members and carers who try to control decisions. The CRPD obligates State Parties to take the appropriate steps to raise awareness of the capabilities of persons with disabilities and to counter unfounded prejudices.

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100 Capacity is defined as the ability to understand the nature and consequences of a decision to be made by the person in the context of available choices at the time the decision has to be made under the functional approach: Assisted Decision-Making (Capacity) Bill 2013, s 3(1) and s 3(2).
101 International Disability Alliance, ‘IDA on Functional Capacity’ Correspondence from the International Disability Alliance to Professor Ronald McCallum, UN Committee on the Rights of Persons with Disabilities (July 2010) <www.chrusp.org/home/resources> [accessed 2 February 2014].
102 World Network of Users and Survivors of Psychiatry (WNUSP), Center for the Human Rights for Users and Survivors of Psychiatry, ‘Response to Draft General Comment on Article 12.’
103 Tina Minkowitz, Submission to the Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12, 22 January 2014, 2.
104 Assisted Decision-Making (Capacity) Bill 2013, s 3(1).
106 Ibid.
also requires the autonomy of the person to be respected at all times, including in crisis situations.\textsuperscript{109}

Law reformers worldwide are beginning to consider the implications of the right to legal capacity under the CRPD. The approach in Article 12 is a major paradigm shift from traditional approaches, which provide for substitute decision-making. The recognition of individuals with disabilities as equal subjects before the law requires a revision of distinctions between capacity and incapacity, and determinations of incapacity based on mental disability.\textsuperscript{110} The CRPD requires respect for the legal capacity of all persons, including those detained under mental health legislation.\textsuperscript{111} The introduction of supported decision-making measures will be a core part of CRPD based law reform. Wardship, guardianship regimes and mental health laws that deprive individuals of legal capacity and provide for substitute decision-making should be abolished. International disability organisations are advocating for reform of national mental health and capacity laws to comply with the CRPD.\textsuperscript{112}

\section*{4. Supported Decision-Making Measures}

The CRPD requires State Parties to replace substitute decision-making laws with supported decision-making alternatives. It provides a new legal paradigm for maximising autonomy for individuals with mental disabilities. Article 12 opens up the legal space beyond the traditional parameters of capacity law to include a diversity of individuals who reason and communicate in a range of ways.\textsuperscript{113} The supported decision-making model is based on the premise that most people use the

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\textsuperscript{109} Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess (September 2-13 2013) para 16.
\textsuperscript{110} Penelope Weller, ‘Human Rights and Mental Health Law’ in McSherry and Weller (eds), \textit{Rethinking Rights-Based Mental Health Law} (Hart Publishing 2010) 72.
\textsuperscript{111} Article 12 provides for equal recognition before the law, Article 14 provides for the right to liberty, and Article 17 provides a right to physical and mental integrity. Amnesty International and others, ‘Essential Principles: Irish Legal Capacity Law’ (April 2012) 1(d).
\textsuperscript{112} The International Disability Alliance (IDA) states that its goal is to promote the effective and full implementation of the CRPD worldwide. See International Disability Alliance, ‘Position Paper on the Rights of Persons with Disabilities (CRPD) and Other Instruments’ April 25 2008. The World Network of Users and Survivors of Psychiatry (WNUSP) is an international organization of users and survivors of psychiatry which advocates for human rights of users and survivors internationally and promote the implementation of the CRPD. <http://www.wnusp.net/index.php/crpd.html> [accessed 1 February 2014].
\end{flushleft}
support of others when making decisions. The model highlights that interdependence is a normal method of decision-making for everyone. The provision of support is a major departure in environments where individuals have been traditionally deprived of capacity. The supported decision-making model has the potential to transform current decision-making practice in mental health care and reduce the need for coercive treatment.

The CRPD requires State Parties to formulate new ways of supporting persons with disabilities to exercise their legal capacity. The CRPD Committee defines ‘support’ as a broad term capable of encompassing both informal and formal support arrangements, of varying types and intensity, which give primacy to the ‘will and preferences’ of the person. Examples of support include one or more trusted support persons to assist with the exercise of legal capacity, peer support, advocacy or assistance in communication. Supports can also include the articulation of preferences through an AD or the appointment of a trusted proxy decision-maker. WNUSP state that while supported decision-making regimes can take many forms, they should all include key provisions to ensure compliance with Article 12. These include placing an obligation on the State to provide formal and informal supports for individuals who are isolated. The legal mechanisms for the recognition of supporters should be available and accessible and the State should provide oversight to safeguard against abuse in support arrangements. The person also has the right to refuse support or end the support relationship anytime they choose. Bach asserts that six main types of support emerge under the supported decision making model including life planning, independent advocacy, communicational and interpretative,

114 Mental Disability Advocacy Center, Supported Decision-Making: An Alternative to Guardianship, [accessed 1 February 2014].
116 Ibid para 15.
117 World Network of Users and Survivors of Psychiatry (WNUSP), Center for the Human Rights for Users and Survivors of Psychiatry, Response to Draft General Comment on Article 12, 6.
119 Ibid para 25 (d)(e)(h).
120 Ibid para 25(g).
Informal support mechanisms can also facilitate autonomy and inclusion. In a report by the EU Agency for Fundamental Rights, participants with mental health conditions identified discussion and informal advice from family and friends as key sources of support. The importance of representative and user-led organisations, which offer peer support and practical assistance in navigating supports was also emphasised. Concerns were raised by participants about the declining availability of support options. Minkowitz argues that community circles of support are not sufficient to address the many factors that impinge on legal capacity. Legal capacity is a social construct dependent on context such as the legal system, social class, gender, and cultural practices related to decision-making. The contextual nature of legal capacity requires an examination of how individuals experience barriers to legal capacity and decision-making at local level in order to address effective ways of removing them. Contextual factors such as poverty and discrimination also need to be addressed. The link between poverty, education, employment and legal capacity barriers should also be addressed in support measures. Education is considered key to the development of a person’s knowledge and experience to inform decision-making. Several jurisdictions have adopted models that promote supported decision-making. Examples of existing

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122 Ibid.
124 Ibid.
125 Ibid.
128 Ibid.
129 World Network of Users and Survivors of Psychiatry (WNUSP), Center for the Human Rights for Users and Survivors of Psychiatry, Response to Draft General Comment on Article 12, 11.
130 Ibid.
programmes and supported decision-making measures in mental health practice will now be discussed.

4.1. Advance Directives under the CRPD

The CRPD can be interpreted as promoting various forms of supported decision-making measures. ADs are considered to be appropriate vehicles for supporting the exercise capacity by allowing individuals to state treatment preferences and other life choices prior to a mental health crisis. Participation in every aspect of life is a critical objective of the CRPD,131 which allows persons with disabilities to make independent choices with or without support. ADs can facilitate participation, collaboration and respect and reduce discrimination.132 The measure can also address the contradiction between involuntary treatment and autonomy by facilitating choice and enabling clinicians to respect human rights, while providing optimal care.133 The CRPD requires a reconceptualisation of ADs as measures that support the exercise of legal capacity even if they are never legally invoked. The AD development process provides an opportunity for dialogue and participation and yields capacity building benefits.134 Individuals who have been institutionalised or suffer social exclusion may lack direction in their lives making it difficult to make decisions. Psychiatric institutions have traditionally fostered dependency, incompetency, learned helplessness that is inconsistent with community readjustment and recovery.135 In the absence of appropriate support, some individuals may be confused, uncertain in decision-making processes, and appear unable to make decisions.136 ADs provide the opportunity for individuals to reveal their value system to others and to build capacity. The provision of support for life

planning is a key element of the AD completion process i.e. a process of identifying values and purpose, making key decisions congruent with those interests, and making and executing the necessary agreements. ADs also provide for regular evaluation and communication whether a mental health crisis has taken place or not allowing the person to identify effective recovery strategies. ADs are more than legal documents that are completed at a single point in time, but involve engagement over a longer period. The expanded vision of ADs views them as vehicles for articulating values and choices, directing care, evaluating treatments and identifying recovery strategies, thereby averting the need for involuntary admission or hospitalisation.

A major theme in developing a model for ADs is whether they are made independently or with support. Previous studies show mental health service users’ preferred support for AD completion. While participants with severe mental conditions were able to complete ADs, many of them needed support. Some participants needed help articulating values or treatment preferences or had insufficient information on treatment options. Support may also be needed with the technical aspects of writing or typing the AD document. Clinicians may not be appropriate support persons due to the power imbalance in the relationship. The state should provide trained peer facilitators to assist individuals to complete ADs. Individuals should also be able to include family, friends or other trusted persons in the completion process. ‘A one size fits all’ approach is unlikely to work in this context as some individuals may prefer an AD which is agreed jointly, while others may want to develop one independently. The legislative framework should therefore provide for both independent and interdependent decision-making. The provision of support for ADs has resource implications for State Parties. However, ADs are associated with a reduced need for hospital readmission and involuntary detention.

140 Ibid.
conferring economic and other benefits.\textsuperscript{142} The use of ADs can realise the rights in the CRPD by supporting individuals to exercise legal capacity and allow them to be free from involuntary admission and forced treatment.

The CRPD implies that the principles and objectives underpinning ADs should be considered in the broader legislative context.\textsuperscript{143} The legislation for mental health ADs is often characterised by exceptions to enforceability. Many statutes permit AD wishes to be overridden where a person is subject to involuntary admission. The right to equal recognition before the law and to exercise legal capacity implies that ADs should be equally available to all persons and respected during involuntary detention. The CRPD prohibits discrimination on the basis of disability and guarantees the right to equality and non-discrimination.\textsuperscript{144} The failure to recognise ADs during involuntary detention contravenes Articles 5 and 12.\textsuperscript{145} The CRPD implies that mental health treatment decisions should be guided by the same criteria as physical health decisions and individuals should be allowed to choose whether they wish to consent to mental health treatment.\textsuperscript{146} The equality and legal capacity provisions require the elimination of differential standards and exceptions to enforceability for ADs in mental health care.

The CRPD also requires a re-evaluation of capacity determinations for the activation and deactivation of ADs. Capacity has traditionally been used as a threshold for executing, invoking and revoking ADs. The validity of the directive often depends on whether the person was considered capable at the time it was executed and becomes operational when the person is deemed incapable. The challenge is to separate ADs from legal frameworks that use capacity as a threshold for activation


\textsuperscript{144} Articles 2, Article 5.

\textsuperscript{145} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 28.

\textsuperscript{146} Annegret Kampf, ‘Involuntary Treatment Decisions’ in Bernadette McSherry and Penelope Weller (eds), \textit{Rethinking Rights-Based Mental Health Law} (Hart Publishing 2010) 143.
and deactivation. The emphasis should move from capacity determinations and deficits to the identification of appropriate supports to execute the AD.\(^{147}\) The CRPD requires the use of more widely defined directives that enable the person to set out the circumstances in which he/she wishes the AD to be activated or deactivated and when trusted proxy decision-makers should be consulted e.g. when the person goes into crisis or is hospitalised. This does not imply that the person lacks capacity. Individuals who experience mental health crisis may be limited in their ability to articulate choices, but retain their legal capacity.\(^{148}\) ADs can assist the communication of preferences during mental health crises.\(^{149}\) The requirement for an individual to be declared legally incapable for an AD to be invoked or capable for it to be revoked severely limits their use and fails to comply with the presumption of capacity in Article 12. The CRPD requires an informal and flexible approach to ADs.\(^{150}\) The presumption of legal capacity requires the development of ADs that are designed to communicate wishes during mental health crises while retaining legal capacity allowing the AD to be invoked or revoked when the person chooses. The person should be able to revoke the directive at any time unless they have clearly stated that they wish their AD choices to be irrevocable during crisis periods at execution. A flexible and non-judgmental approach to capacity and a relationship of trust is appropriate for ADs in the CRPD era.

4.2. Peer Support

Peer support is being used internationally to support individuals in crisis. Peer support refers to the process where a person of equal standing advocates on behalf of another person who shares the experience.\(^{151}\) Trained peers can be used to support the person to express preferences and to inform other parties. The key to intentional peer support is the concept of shared power and responsibility. Under Mead’s

\(^{147}\) Article 12(3).


\(^{149}\) The Representation Agreement in British Columbia, Canada does not compromise any legal capacity by entering into it. Representation Agreement Act, RSBC, ch 405, pt 3, 26 (1996), s 6 (36).


approach, the thoughts and feelings of both the individual concerned and the peer supporter are explored in a conversation without a predetermined outcome. Peer support can play a vital role in supporting the development of ADs. The CRPD Committee refers to peers as a support measure under Article 12. Peer support is a core component of the AD completion process in Virginia (in chapter 5) and is being used in other U.S. states. Peers can provide meaningful support and increase AD completion rates among service users. ADs facilitated by external support persons have significantly higher completion rates, are more responsive to user needs and contain more valuable information. A peer facilitator may also act as a mediator and advocate for the person ensuring their choices are respected if the AD is facilitated by a mental health professional, family and or other support person. Peer facilitation provides an appropriate support for AD completion in mental health care.

4.3. PO Skane-Sweden

The Swedish framework reinforces rather than disregards the capacity for self-determination. Under the social model of disability, the problem is considered to be with society rather than the individual. Society must therefore relate to individuals in a manner that minimises any deficits in decision-making ability. The person should be supported to communicate wishes through relationships of trust, which

engage with the person and find the means to enable the articulation of preferences.  

PO-Skane is an innovative example of supported decision-making for individuals with mental health conditions. The scheme is a user controlled service that developed out of Swedish psychiatric reform in 1995. A PO or personal ombudsman is a professional person who works with the consent of the individual and provides support on a range of matters. He/she is normally employed by a non-governmental organisation and has no connection with psychiatry, social services, the client’s family or any other authority. The PO does not act in the person’s ‘best interests’ and only carries out the client’s instructions. All decisions are made by the client and the PO helps express and implement them. The PO develops a long term engagement with the client, usually over several years. The scheme places the person with mental disability at the top of the hierarchy which means services must be adapted to their individual needs. In other models, the client often has to adjust to the system but under this model, the PO has to find unconventional and creative ways to work with clients. The model genuinely supports persons with mental disabilities to exercise their decision-making capacity.

4.4. Open Dialogues Model—Finland

The term ‘Open Dialogue’ was first used to describe the entire family and social network-centred treatment. The main forum for dialogue is the treatment meeting where the participants join with the person to discuss relevant issues. All decisions and plans are made with the participation of all members. The function of the treatment meeting is to gather information about the problem; to build a treatment plan and to generate a psychotherapeutic dialogue.

160 Ibid.


4.5. Circles of Care

WNUSP recommend ‘circles of care’ as one of the types of support that can be established within local communities between ‘advocacy’ and ‘communication assistance’. A circle of support is a group of people who meet together on a regular basis to help somebody accomplish their personal goals. The concept developed in Canada and spread to the U.S. and U.K. in the 1980s. The circle acts as a community around a person who may be unable to achieve their life goals on their own. Members of the circle may include family, friends and other community members. The focus person decides who they want to be part of the circle. Circles of care are primarily about supporting individuals to take more control over their own lives.

4.6. Soteria Project

The Soteria treatment model was introduced by the American psychiatrist Loren Mosher in the early 1970s. The model was named after the Greek Goddess of safety and deliverance from harm. Mosher developed two research projects at the National Institute of Mental Health with the aim of investigating a support model for individuals with schizophrenia. In the project, psychiatric drug treatments remained under the control of each resident. After a two-week period of self-observation and staff reports, a joint decision was taken as to whether to continue with medication. The project provided a homelike environment and intensive milieu (being with) therapy for six to seven individuals. Seven staff were selected for their personal qualities rather than professional qualifications. Longer working shifts of up to two days gave staff the opportunity of ‘being with’ residents for extended periods of time. The study found that 43 per cent of participants were free from psychiatric drugs and had better outcomes than the group treated with neuroleptics showing the value of engagement and support. The Soteria approach has become influential in the debate on reform of mental health treatment and constitutes a major attempt to

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164 World Network of Users and Survivors of Psychiatry (WNUSP), Center for the Human Rights for Users and Survivors of Psychiatry, ‘Response to Draft General Comment on Article 12’, 3.
166 Volkmar Aderhold, Peter Stastny and Peter Lehmann, ‘Soteria: A Treatment Model and a Reform Movement in Psychiatry’ in Peter Stastny and Peter Lehmann (eds), Alternatives Beyond Psychiatry (Peter Lehmann 2007).
167 Neuroleptics are major tranquillisers used to depress nerve functions.
create a system of humane and non-medical support. A number of similar support projects have been set up around the world since the original project.

4.7. Facilitated Decision-Making Model

Bach and Kerzner propose a facilitated decision-making model for situations where the person’s ‘will and preferences’, remain unknown after significant efforts have been made to identify them.168 This option should only be used as a last resort after other supports have been exhausted. Facilitated decision-making involves an appointed person making decisions based on a detailed understanding of the person’s life plan, wishes and intentions, with the potential to enhance the capabilities of the person. Facilitators are bound to make decisions that are reflective of the person’s values or wishes. The fact that a person is in a facilitated status does not categorise them as being ‘legally incapable’ or represent a judgment about their cognitive status or abilities. Arstein-Kerslake and Flynn have built on the work of Bach and Kerzner and suggested that supports should be offered not imposed under Article 12.169 WNUSP also state that individuals should not be constrained to use support due to discrimination by institutions and other actors.170 Safeguards should ensure the decision reflect the rights, ‘will and preferences’ of the person receiving support.171

5. International Framework Summary

The CRPD challenges assumptions about the ability of persons with mental disabilities to make decisions for themselves and the principle of ‘best interests’.172 Many of these assumptions underpin traditional mental health laws. It raises profound questions for legal and social policy makers. While the CRPD presents many challenges, it is an important step in the move towards equal treatment for persons with mental disabilities. It seeks to reverse attitudes and behaviour that have

170 World Network of Users and Survivors of Psychiatry (WNUSP), Center for the Human Rights for Users and Survivors of Psychiatry, Response to Draft General Comment on Article 12, 3.
led to stigma and discrimination for centuries.\textsuperscript{173} The engagement of both service users and practitioners and support measures will be required to implement the new paradigm.\textsuperscript{174}

The CRPD seeks to build legal capacity and put in place a system of supports to ensure participation. The obligation to replace substitute decision-making regimes with supported decision-making alternatives requires the provision of a broad range of formal and informal measures to support the exercise of legal capacity and to eliminate the need for coercion and involuntary treatment.\textsuperscript{175} The introduction of ADs can help respect the rights, will and preferences of the person in mental health decision-making. The use of ADs is critical in environments where presumptions of incapacity, coercion and stigma are entrenched. ADs represent a broader attitudinal shift in the law in relation to individuals with mental health conditions, as subjects of rights rather than objects of treatment and protection. The implementation of ADs can act as a key driver of CRPD reform and help embed a culture of autonomy and participation in mental health decision-making. The reform process involves the foundation of a mental health system that includes recovery-oriented services, reduces stigmatisation, empowers users and gives meaningful participation.\textsuperscript{176} The implementation of the new paradigm will require system reform, the provision of support and education for mental health services staff, service users and those involved in the administration of justice. State Parties need to adopt an integrated human rights based approach to mental health law to reflect the CRPD. The introduction of an appropriate legal framework for ADs can facilitate implementation of the supported decision-making model and increase the use of directives in mental health care.

\textsuperscript{173} Michael Perlin, ‘International Human Rights and Mental Disability Law: When the Silenced are Heard’ (Oxford University Press 2012) 158.
\textsuperscript{175} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 24.
\textsuperscript{176} Richard Bonnie and others, ‘Tragedy and Mental Health System Transformation in Virginia’ (2009) 28 Health Affairs 793.
6. European Framework for ADs

6.1. Overview of ADs in European Jurisdictions

The debate on ADs is relatively recent in Europe. The legal status of ADs is disparate and validity remains unclear in many jurisdictions. Some countries have legal provisions for ADs and health care proxies, while others have no provisions. Only half of the 28 EU countries currently have legislative provisions. In jurisdictions where legislation does exist, it is not always fully implemented. The culture of patient autonomy is stronger in the U.S. where ADs are widely accepted. The Council of Europe recently stated that only a tiny minority of its 800 million citizens have ADs or continuing powers of attorney making it difficult to take their previously expressed wishes into account. The Parliamentary Assembly of the Council of Europe considers it essential that rapid progress is made on ADs and other measures to ensure the human rights and dignity of individuals across the whole continent.

The diverse legal and socio-cultural traditions in Europe have resulted in varying legal approaches. Opinions vary widely as to the general authority of ADs, their scope and the conditions of compliance. Some countries attach higher value to patient autonomy, while other countries have more paternalistic approaches. ADs are aligned to the common law, which recognises the principles of autonomy and self-determination in relation to medical treatment. Legal mechanisms such as continuing powers of attorney and ADs are therefore more prevalent in common law

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179 Laws addressing ADs have not yet been approved in Bulgaria, the Czech Republic, Greece, Ireland, Italy, Latvia, Lithuania, Poland, Portugal, Slovakia and Sweden.
180 Linh Nguyen and others, ‘End-of-life Care in the ICU: Commonalities between North America and Europe in Jean Louis Vincent (ed), Yearbook of Intensive Care and Emergency Medicine (Springer 2010) 562-564 e.g. Italy, Greece, Portugal.
181 The Council of Europe is the primary human rights institution in Europe and the 47 member states are all signatories to the European Convention on Human Rights (ECHR).
182 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012) para 6. 183 Ibid.
jurisdictions. Despite the diversity, all of the 19 countries represented in a European workshop agreed that ADs could potentially play a positive role in health care practice. A coordinated European approach to ADs from a moral and legal stance has been debated. In 2002, only three European countries (Austria, Germany and the Netherlands) had discussed the option of adopting ADs for mental health decisions into legislation. Mental health ADs have since been specifically recognised in a number of European jurisdictions including Germany, Norway, Finland, Estonia, Scotland, England and Wales and Switzerland. Other jurisdictions such as Spain, the Netherlands, Denmark, Hungary, Belgium and Austria have provisions for legally binding ADs, which are presumed to extend to mental health decisions.

AD provisions are usually found in capacity legislation, or in continuing powers of attorney or health legislation. Some provisions are legally binding while others are accorded due respect and consideration. Many of the laws provide for legally binding ADs, but opinions vary as to their legal status and the situations for which they can be developed. This is illustrated in Austrian legislation, which distinguishes between ADs, which are legally binding and those which can be taken into consideration. In many European countries, ADs still only have advisory value or can be overridden by physicians. Some countries provide an emergency clause, which authorises physicians to treat patients, if the AD is not available or

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186 European Science Foundation, ‘Advance Directives: Towards a Coordinated European Perspective?’ ESF Exploratory Workshop, Institute of Biomedical Ethics, University of Zurich 19–21 June 2008. The aim of the workshop was to bring together experts from different disciplines related to ADs to present the role and legal efficacy of the measure in their respective countries and to identify the most pressing concerns, and to explore the opportunity and the possibility of reaching a greater consensus on the issue across Europe. Participants from 19 European countries were represented.

187 Ibid.


190 Ibid.


192 Verbindliche Patientenverfügung and Beachtliche Patientenverfügung in Peter Lack, Nikola Biller-Andorno and Suzanne Brauer, Advance Directives (Springer 2014) v.

Three EU countries have national registries for ADs i.e. Denmark, Spain and Luxembourg. The Czech Republic recently introduced CRPD based capacity law reform, which includes written ADs. The ‘Respecting Choices’ best practice programme for advance care planning is being used in Germany, along with legally binding ADs and joint crisis plans. AD attitudes differ not only between countries, but also within cultures and states.

The influence of domestic capacity and mental health legislation on the ability to make an AD needs to be considered. ADs are only written into mental health legislation in a few jurisdictions, but the provisions usually supersede the directive. The circumstances in which ADs can be overridden by mental health law must be considered. Few jurisdictions allow a person to refuse mental health treatment without the option for clinicians to override refusals in certain circumstances. No jurisdiction allows a person to refuse involuntary admission, even if they can refuse treatment. Many of the practical issues regarding the use of ADs arise across jurisdictions. These include accessibility; activation; the circumstances in which a directive can be executed or revoked; content and concerns regarding legal liability. The legislative provisions for ADs may be strong or weak depending on whether they are legally binding, provide for consent and refusal of treatment and whether they are developed independently or on a co-operative basis with mental health professionals. The directive may only allow mental health

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194 Austria, Germany.
196 beizeiten begleiten®; Jurgen In der Schmitten and others, ‘A Complex Regional Intervention to Implement Advance Care Planning in one Town’s Nursing Homes: Protocol of a Controlled Inter-Regional Study’ (2011) 11 BMC Health Services Research 14.
199 Ibid 91.
200 Ibid 99.
treatment decisions or allow for treatment of other medical conditions and other life management choices.

6.2. European Legal Framework

Europe has become increasingly engaged in human rights and mental disability policy in the past decade. The CRPD has been ratified by 25 of the 28 EU member states and the EU formally acceded in 2010. The profile of human rights has grown significantly in the EU with the proclamation of the Charter of Fundamental Rights of the European Union and the establishment of the Fundamental Rights Agency in 2007. The European Commission developed a public framework for mental health in the EU in 2001. The Council of Europe is the primary human rights institution in Europe and the 47 member states are signatories to the ECHR. All 28 member states of the EU are Council of Europe members. The ECHR provides for the protection of human rights and fundamental freedoms in Europe. The European Court of Human Rights (European Court) established under the Convention guides policy and jurisprudence in this area. The ratification of the CRPD by the EU will further impact on the development rights in this area. More than half of the 47 member states of the Council of Europe have ratified the CRPD and approximately a dozen others are in the process of reforming legislation. A number of jurisdictions have already made significant changes to their capacity laws reflecting the social model of disability in the CRPD. Ireland is one of three EU member states yet to ratify the CRPD. The various European Conventions, Charters, Recommendations, Declarations, Action Plans, Viewpoints and Agencies of relevance to the rights of persons with mental disabilities and the use of ADs will

204 European Union Agency for Fundamental Rights, ‘Has your Country Ratified the CRPD?’ [accessed 10 March 2014]
205 OJ C364, 18/12/2000; and OJ C303, 14/12/2007.
207 European Commission, Public Framework for Mental Health in the EU (European Commission 2001).
209 Reforms are being discussed in France, Hungary, Ireland, Latvia, Portugal, Slovakia and Slovenia. Norway and Sweden are reviewing their legislation on compulsory psychiatric treatment and care.
210 e.g. Scotland, Germany, Spain, Sweden, the Czech Republic, Denmark and Greece.
211 Finland and the Netherlands are the two other member states.
be discussed. Further direction on ADs is provided in the Council of Europe Recommendations and the new Resolution.212

6.3. Council of Europe
The Council of Europe plays an active role in promoting and protecting the human rights of persons with disabilities. The Council promotes its aims by adopting legally binding Conventions and agreements. The Committee of Ministers adopts recommendations which provide policy guidance to governments and member states. Some of these recommendations have been particularly influential in the disability field.213 The first recommendations on health policy date back to 1978. The Committee of Ministers have created European standards on many areas of health policy. The Recommendation CM/Rec (2009) 11 concerning ADs and continuing powers of attorney was adopted in 2009 and the Council recently adopted a resolution relating to the previously expressed wishes of patients.214 This resolution stresses the importance of adopting ADs and continuing powers of attorney across member states to protect the human rights and dignity of Council of Europe citizens. Recommendations and resolutions are not legally binding on member states, but significantly influence national legislation and the case law of the European Court.

6.3.1. European Convention on Human Rights and Biomedicine (Oviedo Convention)
The Council of Europe Convention on Human Rights and Biomedicine (Oviedo Convention)215 was the first European legal instrument to include minimum legal standards for ADs.216 The Oviedo Convention demonstrated the importance of human rights in health care.217 It has been ratified by 29 member states of the Council of Europe and is binding on states that have ratified it. Ireland has neither

212 Council of Europe, European Committee on Legal Co-operation, Recommendation CM/Rec (2009) 11, 1073, adopted on 9 December, 2009; Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012).
216 Ibid Article 9.
217 Ibid.
signed nor ratified the Convention due to embryonic protection concerns. The Council of Europe incorporated the principle on consent to medical treatment from Article 8 of the ECHR into the Convention. The Oviedo Convention provides that a medical intervention may only be generally carried out after the person has given free and informed consent and treatment for individuals unable to consent must be for their direct benefit.

Article 9 of the Oviedo Convention states that the ‘previously expressed wishes ‘of the person should be taken into account if he/she is unable to express them at the time of treatment. This marked the first significant attempt to establish a legally binding framework for ADs in Europe. However, the provision is qualified by the statement that ADs should not ‘necessarily be followed’ and is vague in relation to the legal effect. A report to the Council of Europe Steering Committee on Bioethics (CDBI) suggests that ADs should be binding and not just ‘taken into account’. Although the Oviedo Convention has significant shortcomings, it places some obligation on physicians to justify treatment not in compliance with the person’s wishes. The Convention also specifies that special legal protections should be made available to reflect the ‘vulnerability and powerlessness’ of individuals with mental health conditions. Article 6 provides protection for persons unable to consent to treatment and specifies that the person must be given the opportunity to participate in the decision-making process as far as possible. Both the Council of Europe recommendations and the Oviedo Convention explicitly support the use of ADs and encourage member states to adopt legislation in this area.

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220 Ibid Article 5.
221 Ibid Article 6.
222 Ibid Article 9.
225 Ibid Article 6(3).
6.3.2. Council of Europe Recommendation on the Protection of Human Rights & Dignity of Persons with Mental Disorder

The 2004 Council of Europe Recommendation recognised the need to promote the human rights and dignity of individuals with mental health conditions particularly those subject to involuntary admission and treatment.\textsuperscript{226} The measure emphasised access to less restrictive alternatives to involuntary treatment and required the previously expressed wishes of the individual to be taken into account.\textsuperscript{227} The recommendation requires evidence of dangerousness and a therapeutic purpose for detention.\textsuperscript{228} The dangerousness requirement is included in the domestic mental health laws of many countries reinforcing the stereotype that individuals with mental health conditions are violent.\textsuperscript{229} In May 2009, the Committee adopted a recommendation on the human rights and dignity of persons with mental health conditions.\textsuperscript{230} The recommendation includes a checklist to determine the level of state compliance with the 2004 Recommendation.\textsuperscript{231} The checklist includes a broad range of issues including non-discrimination, the use of the least restrictive alternative and the quality of the legal framework for mental health treatment.\textsuperscript{232} ADs are a less restrictive alternative to involuntary admission and treatment.

6.3.3. Council of Europe Principles Concerning the Legal Protection of Incapable Adults

The Council of Europe Recommendation Rec 99(4) provides for the legal protection of incapable adults\textsuperscript{233} and has been expanded to include self-determination mechanisms such as ADs and powers of attorney. The functional approach to capacity was adopted in the principles.\textsuperscript{234} The principles recognise that individuals

\textsuperscript{226} Council of Europe Committee of Ministers, Recommendation Rec (2004) 10 of the Committee of Ministers to Member States Concerning the Protection of the Human Rights and Dignity of Persons with Mental Disorder, Preamble.
\textsuperscript{227} Ibid Article 17.
\textsuperscript{228} Peter Bartlett, ‘A Mental Disorder of a Kind or Degree warranting Confinement: Examining Justifications for Psychiatric Detention’ (2012) 16 (6) The International Journal of Human Rights 831.
\textsuperscript{229} Ibid.
\textsuperscript{231} Ibid.
\textsuperscript{233} Council of Europe Recommendation No R (99)4 of the Committee of Ministers to Member States Concerning the Legal Protection of Incapable Adults, February 23, 1999.
\textsuperscript{234} Ibid Principle 3.1.
with mental health conditions are particularly vulnerable and should only be treated without their consent if the condition is of a serious nature and being left untreated would result in harm to health.\textsuperscript{235} They also recognise the right of incapable persons to participate in the decision-making process and to be given the opportunity to express their views.\textsuperscript{236} The European Court referred to Recommendation 99(4) as a ‘common European standard’ in this area in \textit{Shtukaturov v Russia},\textsuperscript{237} which held that capacity should be assessed on an individual basis.

6.3.4. \textit{Council of Europe Principles Concerning Continuing Powers of Attorney and Advance Directives}

The Council of Europe Recommendation concerning Continuing Powers of Attorney and ADs, CM/Rec (2009) 11, was adopted in December 2009.\textsuperscript{238} It places obligations on states to provide a range of measures, making it possible to take different degrees of capacity and varying situations into account.\textsuperscript{239} ADs and continuing power of attorney are recognised as the principal means of self-determination for persons anticipating future periods of reduced decision-making capacity. The recommendation\textsuperscript{240} calls on member state governments to promote self-determination measures by introducing legislation in this area. Guidelines are also set out for decision-making by an attorney or proxy decision-maker. The attorney is obliged to take the person’s past and present wishes and feelings into consideration.\textsuperscript{241} States are obliged to provide oversight mechanisms to regulate any conflict of interests in the AD or power of attorney.\textsuperscript{242} The recommendations specify the need for an effective public supervisory authority to resolve any conflicts between proxy decision-makers and the person.\textsuperscript{243} While the recommendation is not legally binding, it signifies the European direction in this area and provides an important benchmark for ADs. The functional approach to capacity and the distinction between capacity and incapacity do not comply with CRPD standards but

\textsuperscript{235} Council of Europe Recommendation No R (99)4 of the Committee of Ministers to Member States Concerning the Legal Protection of Incapable Adults, February 23, 1999. Principle 25.
\textsuperscript{236} Ibid Principle 9.3.
\textsuperscript{237} \textit{Shtukaturov v Russia} Application No 44009/05, Judgment 27 March 2008.
\textsuperscript{238} Council of Europe, European Committee on Legal Co-operation, Recommendation CM/Rec (2009) 11, 1073.
\textsuperscript{239} Ibid Principle 2.1.
\textsuperscript{240} Ibid.
\textsuperscript{241} Ibid Principle 10.2.
\textsuperscript{242} Ibid Principle 12.2; Principle 11.
\textsuperscript{243} Ibid Explanatory Memorandum Recommendation no 54.
these may evolve over time. Despite the Council of Europe recommendations, many European countries have yet to introduce legislative provisions for ADs. Some commentators suggest that the Council of Europe recommendations should be invoked before the European Court and the Social Charter Committee to give substance to equality guarantees.244

6.3.5. Council of Europe Resolution for Protecting Human Rights and Dignity by Taking into Account Previously Expressed Wishes of Patients

A recent Parliamentary Assembly Resolution by the Council of Europe applied the term ‘previously expressed wishes’ to ADs, living wills or continuing powers of attorney.245 Resolution 1859246 and Recommendation 1993 concerning end-of-life rights247 were adopted by the Council of Europe in 2012. Resolution 1859 states that it is essential for member states to enact and fully implement legislation on ADs.248 The purpose of the resolution is to define the principles that govern the use of ADs in Europe. The resolution states that self-determination measures such as ADs should be given priority over other protection measures.249 The Parliamentary Assembly recommends that national legislatures respect the principles enshrined in the Oviedo Convention and Recommendation CM/Rec (2009) 11 when legislating in this area. The principles state that ADs and continuing powers of attorney should be in writing and be fully taken into account when registered.250 The document should be ideally placed in a state registry and the option to appoint separate attorneys for property and health decisions should be included.251 The possibility of a public appointment should be provided in cases where an individual does not have a trusted person he/she can appoint.252 The principles also state that ADs and continuing powers of attorney should be accessible to all, thus complex forms and expensive

245 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012).
246 Ibid.
247 Council of Europe, Recommendation 1993, Protecting Human Rights and Dignity by taking into account Previously Expressed Wishes of Patients (Council of Europe 2012).
248 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012) paras 3, 4, 6.
249 Ibid Principle 7.1.
250 Ibid Principle 7.2.
251 Ibid Principle 7.3.
252 Ibid Principle 7.3.
formalities should be avoided.\textsuperscript{253} The Parliamentary Assembly recommends encouraging the person to review the AD at regular intervals (e.g. once a year) and allowing them to be revoked or changed at any time.\textsuperscript{254} Member states are required to establish supervisory mechanisms to safeguard against abuse and empower a competent authority to investigate if an attorney is not acting in accordance with the instructions or the interests of the donor.\textsuperscript{255} Surrogate decisions which rely on general value judgements in society are not admissible, but where there is doubt, the resolution states that the decision should always be in favour of the prolongation of life.\textsuperscript{256}

The resolution recommends that member states ratify and fully implement the Oviedo Convention, apply the Committee of Ministers Recommendation CM/Rec (2009) 11 principles concerning ADs and continuing powers of attorney and review existing legislation. In countries with no specific legislation, the resolution recommends putting a ‘road map’ in place for introducing legislative provisions for ADs and/or continuing powers of attorney. This should involve consultation with stakeholders prior to the adoption of the legislation and information and awareness-raising campaigns for the general public and medical and legal professionals after the legislation is introduced.\textsuperscript{257} Countries with legislation should also ensure that the general public and medical and legal professions are aware of the provisions and implement them into practice. The report by the Rapporteur of the Committee on Social Affairs, noted that health professionals tend to focus on treatment withdrawal rather than positive requests.\textsuperscript{258} The Rapporteur argues that this feeds into prejudice in relation to age and disability.\textsuperscript{259} Positive treatment requests are common in the mental health context. The Council of Europe guidelines provide useful guidance for the introduction of ADs and the role of family members and other trusted persons.

The resolution reinforces the need for a legislative framework for ADs in member states such as Ireland.

\textsuperscript{252} Ibid Principle 7.5.
\textsuperscript{253} Ibid Principle 7.6.
\textsuperscript{254} Ibid Principle 7.7.
\textsuperscript{255} Ibid Principle 7.8.
\textsuperscript{256} Ibid Principle 6.3.1.
\textsuperscript{257} Jordi Xucla i Costa, Rapporteur, Committee on Social Affairs, Health and Sustainable Development, ‘Protecting Human Rights and Dignity by taking into Account previously Expressed Wishes of Patients’ Development Doc 12804, 25 January 2012.
\textsuperscript{258} Ibid para 6.25.
6.3.6. Commissioner for Human Rights of the Council of Europe-Viewpoint on Legal Capacity

The Commissioner for Human Rights of the Council of Europe promotes awareness and respect for human rights in Council of Europe member states. The Commissioner noted that the implementation of the CRPD and the Council of Europe Disability Plan remained far from satisfactory in a 2011 report.\(^{260}\) The Commissioner also wrote a viewpoint on the right to legal capacity for persons with mental disabilities,\(^{261}\) which notes that capacity is often restricted or completely denied to this group.\(^{262}\) The viewpoint distinguishes between the denial of legal capacity and providing access to support. The Commissioner refers to Article 12 of the CRPD highlighting the language of the Council of Europe Action Plan and the judgment of the European Court in *Shtukaturov v Russia.*\(^{263}\) The Commissioner recommends more case law on legal capacity in the European Court in order to integrate the CRPD model into European jurisprudence.\(^{264}\) A paper on the right to legal capacity for persons with intellectual and psychosocial disabilities was issued in 2012.\(^{265}\) In it, the Commissioner urges Council of Europe member states to ensure the legal capacity of persons with disabilities is recognised. According to the Commissioner, approximately one million Europeans are currently deprived of their legal capacity. Those who are denied legal capacity are not given the opportunity to make choices, contributing to stereotyping, exclusion, objectification, abuse and neglect.\(^{266}\) The Commissioner outlines the problems with the current European approach to capacity under the status, outcome and functional approaches and advocates the social model of disability. The statement by the Commissioner at the European Movement Conference in 2011, reflected the CRPD approach to decision-making:

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262 Ibid.
263 Application No 44009/05, 27 March 2008.
266 Ibid para 1.2.
“It is essential that people with disabilities can participate in all decisions affecting their lives. Persons with mental health problems and intellectual disabilities can still face problems when they want to take decisions for themselves. Even in important matters, their legal capacity is restricted or ignored. Instead, we have to focus on individual capacity and the availability of support for assisted decision-making, respecting their autonomy and viewing them as subjects entitled to the full range of human rights.”

The Commissioner recommends developing supported decision-making alternatives for those who need assistance in making or communicating decisions. These measures should respect the ‘will and preferences’ of the person. On a visit to Ireland in 2011, the Commissioner expressed concern on Ireland’s progress in the area of mental health. He also called on the Irish authorities to ratify the CRPD and to implement it, using the Council of Europe Disability Action Plan 2006-2015 as guidance. In another speech, the Commissioner stated that while the rights of persons with disabilities are protected, the transition from theory to practice is slow and “the fundamental principle is that people with disabilities must be able to participate in all decisions affecting their lives.” ADs can assist persons with mental disabilities to participate in the decision-making process.

6.3.7. European Convention on Human Rights (ECHR)
The European Convention on Human Rights (ECHR) is the most prominent Council of Europe treaty. The aim of the Convention was to give expression to the UDHR values including civil and political rights. The ECHR promotes and protects other core human rights and is binding on domestic courts in states with a system of direct incorporation. The ECHR is a living instrument that can be interpreted in the

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270 Ireland and the UK have a dualist approach i.e. does not become part of domestic law until it is incorporated by constitutional or legislative act. Article 15 and 29 of Constitution. The majority of member states have a monist approach.
context of present day conditions and prevailing standards in member states.\textsuperscript{271} The European Court is the central supervisory organ for the ECHR and its jurisdiction extends to cases involving the interpretation and application of the ECHR. The ECHR does not explicitly refer to the rights of persons with disabilities, but cases have been brought before the European Court on several grounds. The case law is a vital source for determining the legal status of ADs in mental health settings.\textsuperscript{272} The ECHR has been pivotal to the modernisation of mental health law in Europe and the development of Irish mental health legislation. In \textit{Pretty v United Kingdom}\textsuperscript{273} it was stated that ‘the very essence of the Convention is respect for human dignity and freedom’.

The European Convention on Human Rights Act 2003 incorporated the ECHR into Irish law at sub-constitutional level. The Irish courts are obliged to interpret legislation as far as possible with the provisions. The 2003 Act requires that the Irish courts interpret domestic law in a manner compatible with the State’s obligations under the ECHR in so far as possible.\textsuperscript{274} It also states that the domestic courts will take Convention provisions and any judgment of the European Court into account.\textsuperscript{275} The primacy of the Constitution, the lack of an effective enforcement mechanism in the Act, combined with the attitude of the courts has meant the ECHR has had a minimal impact in the Irish courts.\textsuperscript{276} However, a recent High Court judgment suggests an increased willingness to consider the ECHR and the CRPD.\textsuperscript{277} The decision in \textit{MX v HSE} referred to the issue of constitutionality and compliance with

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  \item\textsuperscript{271} \textit{Bayatyan v Armenia}, Application No 23459/03, Judgment 7 July 2011.
  \item\textsuperscript{273} \textit{Pretty v United Kingdom}, Application No 2346/02, Judgment 29 April 2002, para 90.
  \item\textsuperscript{274} Section 2 of the ECHR Act 2003 states: “In interpreting and applying any statutory provision or rule of law, a court shall, in so far as is possible, subject to the rules of law relating to such interpretation and application, do so in a manner compatible with the State’s obligations under the Convention provisions.”
  \item\textsuperscript{275} Section 4 of the ECHR Act 2003 provides that: “Judicial notice shall be taken of the Convention provisions and of- (a) any declaration, decision, advisory opinion or judgment of the European Court of Human Rights established under the Convention on any question in respect of which that Court has jurisdiction, (b) any decision or opinion of the European Commission of Human Rights so established on any question in respect of which it had jurisdiction, (c) any decision of the Committee of Ministers established under the Statute of the Council of Europe on any question in respect of which it has jurisdiction, and a court shall, when interpreting and applying the Convention provisions, take due account of the principles laid down by those declarations, decisions, advisory opinions, opinions and judgments.”
  \item\textsuperscript{276} This approach was adopted by McGuinness J. in \textit{Gooden v Waterford Regional Hospital} [2005] 3 IR 617. The case was decided under the Mental Treatment Act 1945.
  \item\textsuperscript{277} \textit{MX v HSE} [2012] IEHC 491.
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the ECHR in relation to mental health treatment without consent. 278 Although the High Court did not find the rights of the plaintiff were breached under the Constitution or the ECHR, important observations were made in regard to Constitutional rights, the applicability of the CRPD in domestic law and the right of the patient to be heard in mental health treatment decisions.

The ECHR approach to mental health law is based on a traditional liberal approach to rights focusing on liberty and autonomy. The rights are not absolute and can be restricted in certain circumstances. The traditional liberal model in the ECHR differs from the CRPD approach where the focus is on positive rights 279 and the social model of disability. The European Human Rights authorities have been criticised for being overly deferential to medical opinion and upholding wide boundaries for the infringement of the rights of persons with mental disabilities. 280 An analysis of the case law suggests that the European Court has interpreted the ECHR ‘very restrictively in psychiatric cases’. 281 Perlin suggests that this may be indicative of prejudice in the European Court. 282 While all the provisions of the ECHR are relevant to disability, Articles 3, 5 and 8 are of particular importance in the mental health context. The right to self-determination is primarily protected by Article 8, which concerns the right to respect for private and family life. The right to personal autonomy and the principle of consent are derived from this provision. Article 14 also prohibits discrimination against disabled persons. 283 The ECHR has the potential to accommodate a wider range of claims. 284 The rights to dignity and autonomy set out in the ECHR are central to the use of ADs in mental health care.

278 Ibid.
279 Positive rights usually oblige action.
282 Pretextuality defines the way in which the courts either implicitly or explicitly accepts testimonial dishonesty and decision-making towards individuals with mental health conditions. Michael Perlin, ‘International Human Rights and Mental Disability Law: When the Silenced are Heard’ (Oxford University Press 2012) 34.
283 Glor v Switzerland, Application No 13444/04, Judgment 30 April 2009.
Article 3 of the ECHR prohibits torture, inhuman and degrading treatment and is of fundamental importance to the dignity of individuals with mental health conditions.\textsuperscript{285} The Council of Europe Convention for the Prevention of Torture and Inhuman and Degrading Treatment or Punishment strengthens Article 3 by creating a robust system of prevention through the establishment of a European Committee for the Prevention of Torture (CPT), which conducts visits to places of detention.\textsuperscript{286} The European Court has described inhuman or degrading treatment where ‘it humiliates or debases an individual showing a lack of respect for, or diminishing, his or her human dignity or arouses feelings of fear, anguish or inferiority capable of breaking a person’s moral and physical resistance’.\textsuperscript{287} The treatment must reach a minimum level of severity in order to gain protection.\textsuperscript{288} In \textit{Herczegfalvy v Austria}\textsuperscript{289} the European Court confirmed Article 3 could apply to mental health treatment and to those lacking capacity. However, treatment which is shown to be medically necessary does not infringe the right.\textsuperscript{290} The scope of the provision may widen as the CPT interprets Article 3 more extensively.\textsuperscript{291} ADs can protect against inhuman and degrading treatment by enabling the person to specify treatments they refuse or accept in advance, thereby reducing the need for coercion. The identification of effective recovery strategies through ADs can also avert the need for readmission for treatment.

The right to liberty and security is protected by Article 5 of the ECHR. The core aim of Article 5 is to protect against arbitrary detention.\textsuperscript{292} Article 5(1) (e) is of pivotal importance to mental health as it refers to the detention of ‘persons of unsound mind’. It has been applied in a number of cases involving the deprivation of liberty

\textsuperscript{285} \textit{Keenan v United Kingdom} (2001) 33 EHRR 913.
\textsuperscript{287} \textit{Pretty v United Kingdom} Application No 2346/02, 29 April 2002, para 52.
\textsuperscript{288} Peter Bartlett and others, \textit{Mental Disability and the European Convention on Human Rights} (Brill 2007).
\textsuperscript{289} (1992) EHRR 437.
\textsuperscript{290} Ibid.
\textsuperscript{291} Council of Europe, European Committee for the Prevention of Torture and Inhuman and Degrading Treatment or Punishment, 7\textsuperscript{th} General Report (Brussels 1997).
\textsuperscript{292} \textit{HL v United Kingdom} (2005) 40 EHRR 761; \textit{Storck v Germany} (2006) 43 EHRR 96. Detention which is properly motivated but disproportionate can also be in violation of Article 5.
for individuals with mental health conditions. Certain criteria can justify the deprivation of liberty under Article 5 including the risk of danger to oneself or others. In Winterwerp v Netherlands, the Court found that there must be a finding of mental disorder that requires detention and the person must have an opportunity for a hearing. The purpose of the detention should also be related to the treatment of the condition. Article 5 is also relevant to Article 3 when addressing the conditions of detention. In Shtukaturov v Russia, the applicant alleged that he was deprived of his legal capacity without his knowledge. He also alleged that he was unlawfully confined to a psychiatric institution, was unable to obtain a review of his status and was treated against his will. The European Court found that Article 5 (1)(e) was violated as it had not been shown that the applicant’s mental condition was one which required lawful detention.

Article 8 of the ECHR provides for a right to respect for private and family life and the physical and psychological integrity of the individual. The European Court has interpreted ‘private life’ under Article 8 to include the ability to develop personhood and relationships. The principles of autonomy and consent flow from this right. The general consensus on Article 8 is that interventions should not be administered without the consent of the person. The principles hold that a capable adult has a right to refuse medical treatment and no-one can be compelled to undergo treatment against his or her will. The Commissioner for Human Rights of the Council of Europe, states that Article 8 prohibits unlawful deprivations of legal capacity. The need for tailor-made measures for persons in need of assistance with capacity has

293 Article 5(1) provides that: ‘No one shall be deprived of his liberty save in the following cases and in accordance with a procedure-prescribed by law.’ Para(e) provides for the lawful detention of persons of ‘unsound mind’.
294 Winterwerp v the Netherlands, Application No 6301/73, Judgment of 24 October 1979.
297 X and Y v Netherlands (1986) 8 EHRR 235.
299 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012) para 1.
300 Ibid.

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also been highlighted.\textsuperscript{303} The positive obligations in Article 8 have been hailed as instrumental in providing a duty to facilitate social inclusion into the substantive provisions of the ECHR, but some commentators argue that it has been responsible for relatively few developments to date.\textsuperscript{304}

Article 8 is particularly significant in the context of mental health and capacity law. The European Court stated its position in relation to the capacity of persons with mental disabilities in \textit{Shtukaturov v Russia},\textsuperscript{305} when it found that the existence of a mental disorder alone, could not justify a finding of incapacity. The Court found that the decision was a serious violation of the right to private life under Article 8 and was disproportionate to the aim of protecting others. The Russian legislation made a distinction between full capacity and incapacity and made no allowances for varying degrees of decision-making ability.\textsuperscript{306} The Court referred to the Council of Europe Recommendation Rec (99)4 concerning the legal protection of incapable adults, in which it recommended, that the legislation provide more ‘tailor-made’ responses to individual cases. The decision reflects the CRPD approach to legal capacity. It also implies that the deprivation of legal capacity where less restrictive remedies are appropriate may be in breach of Article 8.\textsuperscript{307} The decision is significant for the use of ADs as they provide a less restrictive response to the deprivation of legal capacity for individuals with mental health disabilities. The European Court also recognised that the deprivation of legal capacity in relation to mental disability was a violation of Article 8 in \textit{Salontaji-Drobnjak v Serbia}\textsuperscript{308} and set out constraints on the ability of states to limit it.

Article 8 also includes the protection of personal autonomy, which underpins the moral and legal validity of ADs. In \textit{Pretty v United Kingdom}, it was found that “the notion of personal autonomy is an important principle underlying the interpretation

\textsuperscript{305} ECHR Application Number 44009/05, 27 March 2008.
\textsuperscript{306} David Por Bjorgvinsson, ‘The Protection of the Rights of Persons with Disabilities in the Case Law’ in Oddny Mjoll Arnardottir and Gerard Quinn, \textit{The European Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives} (Martinus Nijhoff 2009) 153.\
\textsuperscript{307} Ibid.
\textsuperscript{308} Application No 36500/05, Judgment 13 October 2009.
of [Article 8] guarantees.”  

The right to informed consent was also recognised as an important safeguard to personal integrity. The Court found that treatment of a competent person without their consent constitutes an interference with Article 8 even where the refusal may lead to death. Article 8 includes the right to be free from compulsory medical interventions and to exercise control over treatment and care. The wide interpretation of the right to respect for private life in *Pretty* supports the conclusion that the individual’s interpretation of bodily, psychological and moral integrity will be given weight in deciding whether Article 8(1) has been breached. However, the right is not absolute and may be limited by one of the grounds under Article 8(2), which include health, prevention of crime and protecting the rights and freedoms of others. The judgment in *Glass v United Kingdom* supports the conclusion that a person or a proxy decision-maker is entitled to challenge the denial of health care. In *Herzegefalvey v Austria*, it was held that interference with the right to autonomy must be proportionate. The European Court also referred to the need for increased vigilance due to the powerlessness of individuals detained in psychiatric institutions. In *Storck v Germany*, the Court held that Article 8 had been breached by the administration of medication against the will of a patient who was involuntarily detained. A minor interference with the physical integrity of the person was regarded as an interference with the right to private life if it is against the patients will. The Court has also asserted that treatment must be justified and cannot be imposed against a person’s will just because they are deemed to lack capacity.

It is clear that respect for patient autonomy is central to Article 8 and it is suggested that the failure to respect an AD may constitute a breach of the right. The European Court first explicitly referred to ADs in the case of *Jehovah’s Witnesses of Moscow v Russia* concerning ‘no blood cards’. The basis for autonomy and self-

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309 Application No 2346/02, 29 April 2002, para 61.
310 Ibid.
311 Ibid.
316 Application No 302/02, 10 June 2010.
317 These cards are often carried by Jehovah Witnessed and are considered a form of AD.
determination were broadened in the case. The Court stated that ADs should be legally binding as far as possible and that a proxy decision-maker should be obliged to make healthcare decisions in line with the instructions of the individual not in their ‘best interests’. The European Court may apply these principles to ADs for mental health decisions in the future.

The European Court has issued a number of recent judgments, which indicate support for less restrictive measures for legal capacity. These judgments include both positive and negative developments for the rights of persons with disabilities. The European Court has increasingly emphasised the importance of procedural safeguards where the legal capacity of the person is at risk. In Stanev v Bulgaria, the Grand Chamber held that the detention of a man with schizophrenia under guardianship and detained in a psychiatric institution were a deprivation of his liberty under Article 5 and the conditions were a violation of Article 3. It also found a violation of his right to a fair trial under Article 6 because Bulgarian law provided no mechanism for Mr. Stanev to restore his legal capacity. The Court declined to investigate complaints about the deprivation of legal capacity under Article 8. The plaintiff argued that his right to respect for private life under Article 8 was violated as a result of the deprivation of legal capacity and his preferences being ignored. The failure to address legal capacity is in contrast with other case law. In a dissenting judgment, one of the judges argued that Bulgarian law failed to respect the plaintiff’s wishes and preferences by contemporary standards.

While the Stanev judgment is a significant advance in international human rights law, the Court failed to interpret the ECHR in the context of the CRPD. It also

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318 The proxy decision stems from knowledge of the person’s will and preferences when they are unable to communicate them. The hybrid directive combines the appointment of a proxy with the person’s instructions.
319 Shtukatorov v Russia, Application No 44009/05, Judgment 27 March 2008.
322 Stanev v Bulgaria, Application No 36760/06, Judgment 17 January 2012.
324 Ibid.
failed to consider the CRPD in a number of previous judgments on legal capacity.\(^{325}\)

The European Court first referred to the CRPD in 2009 in *Glor v Switzerland*, when it stated that it represented a European and universal consensus on the treatment of persons with disabilities.\(^{326}\) In referring to the ECHR case law on the rights of persons with mental disabilities, the President of the European Court who adjudicated on *Stanev* observed that since the *Winterwerp v the Netherlands* decision,\(^{327}\) there has been “almost complete dearth of judicial decisions in this vitally important area.”\(^{328}\) The President believes that the gap may be explained by the significant practical and legal difficulties experienced by individuals with mental disabilities in asserting their rights and bringing claims before the domestic and European Courts.\(^{329}\) The European Court has paid little attention as to how disablement occurs due to difficulties accessing justice.\(^{330}\) Bartlett asserts that the detention of individuals in mental health institutions moves beyond the deprivation of liberty to non-consensual treatments and environments that hinder social and personal development through stigma and disempowerment.\(^{331}\) The violation of bodily integrity by intrusive treatments, the restriction of development and impact of systematic disempowerment raise issues under Article 3.\(^{332}\) In the past five years, the case law of the European Court has shown developments in legal capacity jurisprudence. This is due in part to the efforts of European NGOs,\(^{333}\) but it still falls short of the substantive rights in Article 12 of the CRPD.\(^{334}\) According to Lewis, the *Stanev* case clears the ‘path towards freedom’ and a time when persons with

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\(^{325}\) Shtukatturov v Russia, Application No 44009/05, Judgment 27 March 2008; Salontaji-Drobnjak v Serbia Application No 36500/05, Judgment 13 October 2009; Krušković v Croatia, Application No 46185/08, Judgment 21 June 2011.

\(^{326}\) Glor v Switzerland, Application No 13444/04, Judgment 30 April 2009.

\(^{327}\) Winterwerp v the Netherlands, Application No 6301/73, Judgment 24 October 1979.

\(^{328}\) Foreword by Sir Nicholas Bratza in Peter Bartlett, Oliver Lewis, and Oliver Thorold, *Mental Disability and the European Convention on Human Rights* (Brill 2007).

\(^{329}\) Ibid.


\(^{332}\) Ibid.

\(^{333}\) Mental Disability Advocacy Centre (MDAC), the International Centre for Legal Protection of Human Rights (Interights) and Regional Helsinki Committees.

disabilities are “treated as full and equal subjects of human rights and fundamental freedoms.”\textsuperscript{335}

In \textit{DD v Lithuania},\textsuperscript{336} the plaintiff who had paranoid schizophrenia complained to the Court that she was admitted to a care home without her consent or the possibility of judicial review under Article 5(1) and (4) of the ECHR. She also claimed unfair proceedings under Article 6(1) and inhuman and degrading treatment under Article 3. The Court found that preventing the applicant from pursuing a legal remedy to challenge her continued involuntary hospitalisation was a violation of Article 5(4).\textsuperscript{337} The fact that the applicant did not participate in any of the court proceedings in relation to the finding of incapacity and was not notified of the hearing, where her personal autonomy in almost all areas of life were decided was considered to be a violation of Article 6(1) of the ECHR.\textsuperscript{338} The finding in relation to access to the courts has been welcomed, but the decision in relation to the grounds for detention under Article 5 (1)(e) has been criticised. Article 5 (1)(e) allows for the ‘lawful detention of … persons of unsound mind.’

In \textit{Lashin v Russia},\textsuperscript{339} the European Court recognised the right of persons with psychosocial disabilities under guardianship to marry. The Court stated that a blanket ban on the right to marry for persons deprived of their legal capacity under guardianship was incompatible with the ECHR. The right to private and family life under Article 8 was also violated because of the incapacity status of the plaintiff and the inability to have it reviewed. The Court also found a violation of Article 5(1) due to the detention of the plaintiff in a psychiatric hospital and a breach of Article 5 (4) because of the inability to have the detention reviewed. The judgment referred to the Council of Europe principles concerning the legal protection of incapable adults,\textsuperscript{340} in relation to the provision of measures, which are proportionate and flexible and maximise the capacity of the person, suggesting support for the use of ADs.\textsuperscript{341}

\textsuperscript{336} \textit{DD v Lithuania}, Application No 13469/06, Judgment of 14 February 2012.
\textsuperscript{337} Article 5(4) provides that anyone deprived of liberty shall be entitled to take proceedings by which the lawfulness of his detention shall be decided.
\textsuperscript{338} \textit{DD v Lithuania}, Application No 13469/06, Judgment of 14 February 2012 para 120, 126.
\textsuperscript{339} \textit{Lashin v Russia}, Application No 33117/02, Judgment of 22 January 2013.
\textsuperscript{340} Recommendation No R(99)4
\textsuperscript{341} \textit{Lashin v Russia}, Application No 33117/02, 22 January 2013, para 65.
However, the functional approach to capacity used in the decision contravenes the CRPD.\textsuperscript{342} The Court referred to Article 12(3) and (4) of the CRPD in relation to the right to legal capacity for all persons and the provision of appropriate and proportionate safeguards to prevent abuse but did not include it in the final decision.\textsuperscript{343}

The case law of the European Court suggests that coercive treatment is unlawful if less restrictive alternatives exist and has repeatedly referred to the Council of Europe recommendations for more tailored responses.\textsuperscript{344} The Council of Europe also recognises this as a fundamental principle in protecting individuals with mental disabilities. While the European Court is mainly involved in the application and interpretation of the ECHR, it has repeatedly referred to other international instruments in relation to Article 3 and 5.\textsuperscript{345} Given that the EU and many of the contracting parties of the ECHR have also ratified the CRPD, it seems likely that the principles will find their way into the case law of the European Court. The Court has already explicitly invoked the CRPD in interpreting the ECHR.\textsuperscript{346} The rights of individuals with mental health conditions may therefore be expanded under the ECHR, including increased autonomy and the right to exercise legal capacity on an equal basis with others in mental health treatment decisions.

The recognition of ADs and continuing powers of attorney as the principal means of self-determination in the Council of Europe recommendation and resolution in conjunction with the requirement to provide support measures to exercise legal capacity in the CRPD may influence future decisions of the European Court. The Court may require states to provide equal access to support measures such as ADs to enable individuals with mental health conditions to exercise legal capacity and to provide a less restrictive alternative to involuntary treatment. ADs can protect the


\textsuperscript{343} Lashin v Russia, Application No 33117/02, 22 January 2013, para 66.

\textsuperscript{344} This is known as the ‘Principle of Last Restriction’ which states that there must be ‘pressing social needs’ and the restrictions must be ‘proportionate to the aim pursued.’


right to autonomy and to be free from inhuman and degrading treatment by allowing
the person to articulate their preferences in advance. They can also potentially avert
the need for loss of liberty by avoiding the need for involuntary admission. The
availability of ADs for individuals with mental health conditions may be the subject
of a future European Court decision.

6.3.8. European Social Charter
The European Social Charter\(^{347}\) is a Council of Europe treaty which guarantees
economic and social rights. The Charter complements the civil and political rights of
the ECHR and is binding on all member states. The Charter was adopted in 1961 and
revised in 1996. The Revised Charter strengthens the protections afforded to
disability.\(^ {348}\) Article E includes a prohibition on discrimination which has been
interpreted as including discrimination on the grounds of disability.\(^ {349}\) Article 15 of
the Revised Charter is designed to ensure the right to independence, social
integration and participation in community life for persons with disabilities.\(^ {350}\)
Ireland ratified the revised Charter in 2000, accepting 92 of the 98 paragraphs.\(^ {351}\)

6.3.9. European Convention for the Prevention of Torture and Inhuman or
Degrading Treatment or Punishment (CPT)
Article 3 of the ECHR led to the adoption of the European Convention for the
Prevention of Torture and Inhuman or Degrading Treatment or Punishment.\(^ {352}\) The
European Committee set up under the Convention (CPT) provides a non-judicial
preventative mechanism to protect persons deprived of their liberty against torture
and other forms of ill treatment through visits to place of detention, complementing
the work of the European Court. The CPT provides protection to detainees based on
a system of visits to institutions where individuals are detained. The purpose of the
visit is to ascertain how individuals deprived of their liberty are treated and make

\(^{347}\) Council of Europe, European Social Charter
\(^{348}\) Lisa Waddington and Gerard Quinn, ‘The Council of Europe’ in European Yearbook of Disability
\(^{349}\) Ibid 273.
\(^{350}\) Ibid.
\(^{351}\) Council of Europe European Social Charter, Ireland and the European Social Charter
\(<http://www.coe.int/t/dghl/monitoring/socialcharter/CountryFactsheets/Ireland_en.pdf>\) [accessed 10
March 2014].
\(^{352}\) Council of Europe, European Committee for the Prevention of Torture and Inhumane or Degrading
Treatment or Punishment CPT/Inf/C (2002) 1.
recommendations to State Parties. The CPT Committee has developed standards in relation to involuntary detention in psychiatric institutions.\textsuperscript{353} All of the 47 member states of the Council of Europe have ratified the Convention.

6.4. Charter of Fundamental Rights of the European Union
The Charter of Fundamental Rights of the European Union is a soft law instrument that draws on the ECHR and the European Social Charter (ESC). It aims to set out civil, political, economic and social rights for EU citizens and residents.\textsuperscript{354} The Charter was proclaimed in 2000 and became binding in December 2009 when the Lisbon Treaty came into force. Article 21 of the Charter lists disability as one of the grounds for prohibiting discrimination. Article 3 promotes physical and mental integrity and includes the doctrine of informed consent as a fundamental principle. Under Article 3(2), the free and informed consent of the person concerned must be respected, according to the procedures laid down by law.

6.5. World Health Organisation (WHO)
The EU/WHO Ministerial conference in 2003 recognised that combating stigma and discrimination in mental health required a multiplicity of strategies including effective legislation and the promotion of social inclusion.\textsuperscript{355} This position was subsequently supported by the Council of the European Union. At the WHO European Ministerial Conference on Mental Health in 2005, the Ministers for Health committed to a Mental Health Declaration and a Mental Health Action Plan for Europe.\textsuperscript{356} The empowerment of individuals with mental health conditions was identified as a key priority.\textsuperscript{357} The Declaration requires member states to “implement the necessary legislation in order to empower people at risk or suffering from mental health problems and disabilities to participate fully and equally in society”, moving

\textsuperscript{355} Athanassios Constantopoulos, ‘Mental Illness and Stigma in Europe: Facing up to the Challenges of Social Inclusion and Equity’ (European Commission 2003).
\textsuperscript{356} World Health Organisation Europe, Mental Health: Facing the Challenges, Building Solutions: Report from the WHO European Ministerial Conference, EUR/04/5047810/6 (WHO 2005); World Health Organisation Europe, Mental Health Action Plan for Europe: Facing the Challenges, Building Solutions, EUR/04/5047810/7 (WHO 2005).
\textsuperscript{357} World Health Organisation Europe, Mental Health: Facing the Challenges, Building Solutions: Report from the WHO European Ministerial Conference, EUR/04/5047810/6 (WHO 2005).
from a more paternalistic approach. The WHO published a report in 2008 detailing progress in the areas described in the Declaration and Action Plan. Since 2005, 57 per cent of countries have adopted new mental health policies and 48 per cent have adopted new legislation. In 2009, a partnership project was launched to support member states in developing policies designed to empower persons with mental disabilities and carers. It includes a number of components including the creation of an environment conducive to participation and the mainstreaming of good practice in user empowerment and mental health.

In 2010, the European office of the WHO published a statement on user empowerment in mental health. The statement refers to the importance of legal capacity and participation in decision-making. It refers to the CRPD and the obligation on States to provide support to individuals who require assistance to make decisions. According to the statement, individuals cannot become independent without the opportunity to make decisions about their lives. Without decision-making supports, users are kept in long-term dependency relationships. The WHO described the New Zealand model of ADs in their handbook on mental health, human rights and legislation. A recent WHO report recognises that individuals with mental health conditions experience stigma and discrimination, restrictions on their civil and political rights and ability to participate in society. This is often due to the perception that individuals with mental health conditions lack the capacity to make decisions about their lives. According to the report, capacity needs to be

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358 Ibid.
362 Ibid.
367 Ibid 12.
built through policies and laws that address mental health, human rights and the capacity to participate. Governments can help achieve this goal by ensuring individuals with mental health conditions have access to legal procedures that promote and protect their rights. National governments and legislatures have an important role in enacting comprehensive disability legislation with the aim of protecting the human rights. An open and positive dialogue in the political arena can also reduce stigma and discrimination.

6.7. EU and the CRPD

The EU ratified the CRPD in December 2010. This is the first occasion on which the EU became party to an international human rights treaty at the same time as member states. The CRPD will take on a new legal status in EU law and have to be respected in its totality. EU ratification will oblige all EU institutions including the European Court of Justice, Commission, Council and Parliament to uphold the rights set out in the CRPD. Member states will also share best practice in regard to the implementation. The Commission aims at ensuring effective implementation across the EU, with the European Disability Strategy 2010-2020. The CRPD helped inform the objectives of the strategy. While the EU will be under an obligation to comply with the CRPD provisions in relation to disability but the exact

368 Ibid 58.
369 Ibid 58.
374 The objectives were also informed by the Council of Europe, EU Institution Policy Documents, EU Disability Action Plan 2003-2010 and consultations with Member States, stakeholders and the general public.
The scope of the duties is still uncertain. The EU may take an expansive or minimalist view to compliance.

7. Conclusions

ADs are recognised as the principal means of self-determination in the Council of Europe Recommendations and in the Oviedo Convention and have been referred to in the case law of the European Court. The recent Parliamentary Assembly resolution by the Council of Europe provides more specific guidance on the implementation of ADs, along with the CRPD obligations in relation to legal capacity and the development of support measures. The analysis suggests the need for a more substantial agreement on ADs beyond the minimal consensus in the Oviedo Convention and the more detailed principles set out in Council of Europe the recommendations and resolution. It is clear that wide cultural, national and professional differences in legislation and the understanding of ADs exists across Europe.

The participants in a European wide workshop suggested the Oviedo Convention may be an appropriate starting point for a cross-cultural European agreement on ADs. More detailed standards have been provided by the Council of Europe recommendations and resolutions, but they are not legally binding and need to be amended to comply with new CRPD standards on capacity. Some participants in the workshop considered a more substantial European agreement was desirable and consensus could be reached. The workshop recommendations included the


The CRPD is a mixed agreement, which partly falls within the scope of the EU or part within the responsibilities of the Member States in Delia Ferri, Centro di Documentazione Europea-Università de Catania, Working Paper 2010, Serie Speciale/4 (2010) <http://www.cde.unict.it/sites/default/files/4_2010.pdf> [accessed 21 November 2013].


Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Article 9 (Oviedo 1997).

Jehovah’s Witnesses of Moscow v Russia, Application No 302/02, 10 June 2010.

Workshop participants were divided into three Working Groups to examine the ethical, medical, and legal aspects of ADs. ‘Exploratory Workshop on Advance Directives’ Institute of Biomedical Ethics, University of Zurich, 18-22 June 2008.

adoption of a broader terminology, which extends beyond ‘wishes’ to the persons ‘goals and values’; common standards in relation to the appointment of healthcare proxies and the circumstances in which the person’s preferences can be legitimately overridden by medical professionals. The participants also recommended the development of common AD models, which can be translated into different languages and used to facilitate European wide implementation. A European network of registries on ADs was suggested for individuals travelling between jurisdictions. All the participating countries agreed that ADs could play a positive role in health care practice and reduce the need for futile or disproportionate treatment. However, participants also pointed to the current lack of empirical data in relation to ADs across European countries, suggesting a need for further research in this area. Other European commentators point to the importance of a broader understanding of ADs in the context of advance care planning, rather than a narrow, legalistic approach. They also call for specific legal safeguards and for common standards to determine when an AD is activated.

It is clear from the analysis that there is an increasing trend toward the equal right to legal capacity and the recognition of ADs at both European and international level. The EU, UN and Council of Europe are beginning to move in a common direction in this area. The evolving human rights framework implies that persons with mental health disabilities have equal dignity and freedom to make their own decisions. ADs are a means by which some of these rights can be realised and are key drivers of new approaches to decision-making in mental health care. The jurisprudence of the European Court and the Council of Europe recommendations and resolutions will have to be harmonised with the CRPD and implemented into national mental health and capacity laws to ensure the widespread use of ADs across Europe. The ratification of the CRPD will impose new obligations on the EU and State Parties. This will further the development of a more comprehensive and cohesive approach

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382 Ibid.
384 Ibid.
The stage is set for the legal recognition of ADs at international and European level making it an appropriate time for the introduction of a legislative framework in Ireland.

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CHAPTER 4
Advance Directives under the Irish Legal, Policy and Mental Health System Framework

1. Introduction
The introduction of a legal framework for ADs requires consideration of the legal, policy, cultural and other system contexts in which they will operate. The aim of this chapter is to consider the introduction of ADs under the Irish legal framework and the factors associated with implementation into practice. This will be achieved by examining the history of mental health treatment in Ireland, the legislative and policy framework and the relevant system and cultural context. The successful implementation of ADs will largely depend on the stakeholders involved in implementation and the prevailing culture in the mental health system. The features of the Irish mental health services and the views of stakeholders will therefore be reviewed through the literature and the empirical research. The international research suggests that the introduction of ADs may have limited impact if these issues are not addressed.

This chapter will also examine the philosophical underpinnings of Irish mental health policy and services. The recovery approach has been explicitly adopted as the guiding principle of mental health policy and service planning in Ireland.\(^1\) The CRPD\(^2\) and the ECHR are also key drivers of law and policy reform in this area.\(^3\) The Programme for Government includes a commitment to reviewing the Mental Health Act, 2001 in accordance with human rights standards and to introducing capacity legislation in line with the CRPD.\(^4\) This analysis will help inform the implementation of an appropriate legislative framework for ADs in Ireland and set the context for the empirical study with Irish service users and consultant psychiatrists in chapter 6.

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\(^3\) The CRPD has been one of the main driving forces in the development of the new Assisted Decision-Making (Capacity) Bill 2013, which will provide a modern statutory framework for those who need assistance in making decisions in Ireland.
1.1. Mental Health in Ireland

Mental distress is a major social and economic issue in Ireland. The National Psychological and Wellbeing Survey carried out between 2005 and 2007 suggested that as many as 389,258 Irish adults are experiencing psychological distress at any given time.\(^5\) It is estimated that 44 per cent of Irish people have experienced a mental health difficulty either personally or through a family member or friend.\(^6\) Depression is estimated to affect 450,000 people in Ireland.\(^7\) The economic downturn may have further exacerbated these figures. Higher levels of mental ill-health have been found among lower income groups, medical card holders, those with lower levels of education and the unemployed.\(^8\) An EU study identified a number of groups that may be at increased risk of mental ill-health including those living in financial insecurity or experiencing loss or change.\(^9\) Recent research from the Royal College of Surgeons in Ireland (RCSI) showed that one in five young people between the ages of 19 and 24 were experiencing mental distress.\(^10\) These figures are higher than rates in the U.S. and Europe. In addition, Ireland has the fourth highest rate of death by suicide among young people in the EU.\(^11\) The male suicide rate is also higher than international comparisons.\(^12\) An Irish study found males and older people were less willing to communicate distress to others.\(^13\) According to the Health Research Board, “there is a need for acknowledgement and recognition of the extent of distress


\(^6\) Mental Health in Ireland, Mental Health Reform Promoting Improved Mental Health Services, <http://www.mentalhealthreform.ie/home/mental-health-in-ireland/> [accessed 13 March 2014].

\(^7\) Aware, ‘Information on Depression’ <http://www.aware.ie/help/information/information-on-depression/> [accessed 27 February 2014].


\(^9\) European Commission, ‘Mental Health in the EU-Key Facts, Figures and Activities: A Background Paper provided by the Support Project’ (Luxembourg 2008) 15.


\(^11\) National Office for Suicide Prevention, *Annual Report 2012* (National Office for Suicide Prevention, HSE, 2013). Ireland ranks fourth highest in the EU for deaths by suicide among young people up to 24 years old, at 13.9 per 100,000 population.

\(^12\) Ibid. There were 495 deaths by suicide in Ireland in 2010, representing a rate of 10.9 per 100,000 population. 405 (82%) of these were among men.

\(^13\) Mark Ward and others, *It’s good to talk: Distress Disclosure and Psychological Wellbeing* HRB Research Series 1 (Health Research Board 2007).
in the Irish population so that appropriate inter-sectoral responses can be developed.”

The increased incidence of mental distress in Ireland reinforces the need for alternative responses. Significant progress has been made in the Irish mental health services in the past decade, but cultural and structural challenges still remain. Individuals with mental health conditions experience substantial stigma, prejudice and discrimination. The introduction of mental health ADs can change the conceptualisation of mental distress and how it is treated in Ireland. ADs represent a broader attitudinal shift in the law in relation to individuals with mental health conditions and are important symbolically in reducing discrimination. The introduction of ADs can promote trust and respect in the mental health system and wider Irish society.

2. History of Mental Health Treatment in Ireland

The focus has shifted from institutionalisation to community mental health care in Ireland in recent decades. Until relatively recently, a range of institutions were used to confine individuals with mental health conditions. The nineteenth and early twentieth century governments embarked on a policy of institutionalising individuals in purpose built asylums. A national asylum system was established in Ireland during the nineteenth century through acts passed in 1817 and 1821. Prior to the eighteenth century, organised responses to mental illness were limited.

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15 Recent figures show that the rate of suicide and self-harm has increased. Carl O’Brien, ‘After the Asylum’ Irish Times 13 July 2013. Unemployment remains high at 14%.
17 Dermot Walsh and Antoinette Daly, Mental illness in Ireland, 1750–2002: Reflections on the Rise and Fall of Institutional Care (Health Research Board 2004) 11.
19 Dermot Walsh and Antoinette Daly, Mental illness in Ireland, 1750–2002: Reflections on the Rise and Fall of Institutional Care (Health Research Board 2004) 14.
attitudes towards mental ill-health changed dramatically in the first half of the
nineteenth century with increases in populations and a focus on social order. The
rise in the number of individuals confined to psychiatric institutions in Ireland during
this period resulted in the introduction of a number of pieces of legislation, including
the Lunacy (Ireland) Act 1821, Lunacy (Ireland) Act 1826, the Criminal Lunatics
(Ireland) Act 1838 and the Private Lunatic Asylums (Amendment) Act 1842. The
therapeutic paradigm switched from isolation and classification in the early 1800s to
the moral management approach. The moral approach emphasised the importance
of the doctor-patient relationship and used the principles of reward and punishment,
reason and emotion to reduce symptoms.

The political and economic developments during the early part of the twentieth century also had a substantial influence on the
development of Irish health services. The institutions established in the nineteenth
century were now managed by the Irish State and hospitals were established
throughout Ireland.

The enactment of the Mental Treatment Act 1945 (1945 Act) was a major milestone in
Irish mental health law and policy. The absence of a legislative framework, prior
to the introduction of the 1945 Act, perpetuated the link between imprisonment and
psychiatric admission. By the time the 1945 Act commenced, 17,708 individuals
were resident in psychiatric hospitals in the Republic of Ireland. The 1945 Act
replaced the term lunatic with ‘person of unsound mind’ and aimed to reduce
stigma. One of the goals of the Act was to reduce the number of inpatients, but the

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20 The Irish population was estimated to have increased to eight million by 1800.
21 Brendan Kelly, ‘Mental Illness in Nineteenth Century Ireland: A Qualitative Study of Workhouse
Economic and Social Review 280.
23 Normal Dain and Eric Carlson, ‘The Psychotherapy that was Moral Treatment’ in Brendan Kelly,
‘Mental Health Law in Ireland 1821-1902: Building the Asylums’ [http://www.medico-
25 Ibid.
26 Ruth Barrington, Health, Medicine and Politics in Ireland 1900–1970 (Institute
of Public Administration 1987).
27 Dermot Walsh and Antoinette Daly, Mental Illness in Ireland, 1750–2002: Reflections on the Rise
and Fall of Institutional Care (Health Research Board 2004).
28 Stigma is a socially constructed mark of disapproval, shame or disgrace that causes significant
disadvantage through the curtailment of opportunities.
rate increased to more than one per cent of the population by 1951. The increase in patient numbers was attributed to the power conferred on medical personnel in the detention process. In 1944, an anonymous psychiatrist wrote an article, commenting on the history of mental health treatment in Ireland:

“The history of insanity in this country does not differ from that in others. Its incidence was about the same; its causes were similar; the attitude of the public towards it was equally callous and the absence of any attempt at scientific treatment equally noticeable. In the early decades of the 19th century some differences became apparent. Neighbouring countries began to do something about it and their governments took active steps in providing ‘asylums’ for the mentally afflicted, but the Irish government lagged behind and, even though many years have passed, that lag is still apparent.”

O’Donnell and O’Sullivan state that the 1950s was an era of low formal crime in Ireland and high perceived deviance in Ireland. The violation of social norms was frequently met with institutional responses. The dominance of religion and the church meant the need to atone and conform was strong and deviance was deliberately stigmatised. These factors together with family rejection were sufficient to confine people to institutions even though the legal basis for detention was often weak or non-existent. Confinement played a vital role in the maintenance of social order in an economic climate where there were limited alternatives for those who did not emigrate. The boundaries of acceptable conduct were vigorously patrolled by family members, who were active agents in the institutionalisation process.

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31 Deviance is defined as diverging from usual or accepted standards, especially in social or sexual behaviour Oxford English Dictionary, <http://www.oxforddictionaries.com/definition/english/deviance> [accessed 5 January 2014].
33 Ibid.
34 Ibid.
McCullagh suggests psychiatric commitment provided a solution to the preservation of the inheritance system in rural Ireland.  

According to the ‘Commission of Inquiry on Mental Illness Report 1966’, there were 21,075 patients resident in psychiatric hospitals at the end of 1961. This was one of the highest rates of psychiatric hospitalisation in the world. One in every 70 Irish people over the age of 24 was in a psychiatric hospital or 7.3 psychiatric beds per 1,000 of population. This compared to rates of 4.6 in England and Wales and 4.3 per 1,000 in the U.S. The ‘Commission of Inquiry on Mental Illness’ commented on the high number of patients involuntarily detained in such hospitals stating that:

“Statistics in respect of different countries may not be directly comparable, but, even if allowance is made for this, the number of in-patients in Ireland seems to be extremely high—it appears to be the highest in the world. It is hard to explain this.”

The Commission noted that, while some of the hospitals were new, most were erected at a time when the emphasis was on custodial care. In a series of articles published in the Irish Times in 1968, the investigative journalist, Michael Viney, stated that Irish mental health policy was one of hospitalisation and supervisory care. The articles highlighted the problems in the system and the large numbers detained in Irish mental health facilities. A similar set of articles highlighting problems with approaches to care and resources in the Irish mental health system were published in the Irish Times in July 2013.
Over the past 50 years, the number of patients resident in Irish psychiatric units and hospitals decreased by 88 per cent from 19,801 in 1963 to 2,407 in 2013.\(^4\) The decline in hospitalisation is in line with the policy of deinstitutionalisation. On census night in 2013, over a third of patients were resident in psychiatric hospitals, 30 per cent were resident in general hospital psychiatric units and 24 per cent in private hospitals.\(^4\) The proportion of patients resident in psychiatric hospitals decreased from 90 per cent in 1981 to 35 per cent in 2013, while the proportion of patients resident in general hospital psychiatric units increased from 3 per cent in 1981 to 30 per cent in the same period.\(^4\) Although the inpatient population had been falling continuously, the psychiatric hospital population was still higher than the Irish prison population in 2002.\(^4\) The Inspector of Mental Hospitals reported that more than half the patients in psychiatric hospitals were long-stay residents, with more than one in three hospitalised for over five years at this time.\(^4\) The CPT highlighted the case of an 85 year old man who was found unfit to plead at trial in 1937, and was still in the Central Mental Hospital when the Committee visited 61 years later.\(^4\) The number of patients resident in Irish psychiatric units and hospitals totalled 2,407 in March 2013, representing a hospitalisation rate of 52.5 per 100,000 of population.\(^4\) Over a third of the patients were long stay i.e. had been in hospital for one year or more.\(^4\) Patients with schizophrenia had the highest rate of hospitalisation, while males had higher rates than females.

Prior to the publication of ‘A Vision for Change’ in 2006, Irish mental health policy was governed by a document, published in 1984, entitled ‘The Psychiatric Services-Planning for the Future’.\(^5\) The policy recommended a community-oriented

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\(^4\) Ibid
\(^4\) Ibid.
\(^4\) Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), *Report to the Irish Government on the Visit carried out by the CPT from 31 August to 9 September 1998* (Council of Europe 2000) para 116.
\(^4\) Ibid.
approach, with multidisciplinary, co-ordinated and continuous care. Despite the recommendations of the 1984 policy, the Inspector of Mental Health Services commented on the continued lack of innovation and willingness to use new delivery approaches in 2000.52 Although the recommendations of the 1984 policy were not fully implemented, it succeeded in achieving significant improvements in deinstitutionalisation.53 In 2002, Speed stated that the lack of an organised service user led movement in the Irish mental health system resulted in the dominance of psychiatry and services driven by government policies rather than users.54 A strong service user movement has since developed in Ireland with the emergence of NGO service user organisations such as the Irish Advocacy Network and more radical voices such as Mind Freedom Ireland and the Critical Voices Network.55

3. Legislative and Policy Developments in Ireland
The decades following the introduction of the 1945 Act were characterised by considerable legislative and social change and the development of rights at international level. In a consultation paper on capacity law reform in 2005, the Law Reform Commission (LRC) noted a fundamental shift in societal attitudes and a move away from benign paternalism56 towards a social and human rights understanding of disability with an emphasis on autonomy.57 The Oxford English Dictionary defines paternalism as “the policy or practice on the part of people in authority of restricting the freedom and responsibilities of those subordinate to or otherwise dependent on them in their supposed interest.”58 Several attempts were made to challenge the constitutionality of the 1945 Act, which conferred control on

53 The number of individuals in public psychiatric hospitals had fallen to 3,384 in 2002 from a peak of 21,075 in 1961. Dermot Walsh and Antoinette Daly, Mental Illness in Ireland, 1750–2002: Reflections on the Rise and Fall of Institutional Care (Health Research Board 2004).
55 The Irish Advocacy Network emerged as a user run organisation providing peer advocacy services at approved centres. Other radical voices have also emerged such as the Critical Voices Network, Mind Freedom Ireland and Mad Pride. A National Service Users Executive (NSUE) has also been established.
56 Benign paternalism can be described as forcing individuals to act in certain ways for their own good. Non-benign paternalism can be portrayed as forcing individuals to act in certain ways for the good of others.
the medical profession and lacked independent oversight. In *Re Philip Clarke*, the Supreme Court stated that the 1945 Act was of a paternal character. However, no challenges were taken until the mid-1990s when two cases were taken against Ireland in the European Court. In *Croke v Ireland*, the 1945 Act was challenged under Article 5 of the ECHR. The applicant argued that the absence of an independent and automatic review of his detention was in breach of his human rights, but the Irish government agreed to enact legislation before the European Court issued a judgment.

The 1945 Act had a decisive influence on mental health services in Ireland in the latter half of the twentieth century and remained in force until the Mental Health Act 2001 (2001 Act) became fully operational in 2006. The post-2006 case law has generally imported the paternalism reflected in *Re Philip Clarke*. Kelly contends that the substantive influence of the 1945 Act may echo through the Irish mental health services for many decades to come. The reliance on medical opinion and the institutional mind-set of the legislation is still evident. The paternalism of the 1945 Act prevails in judicial decision-making, the culture of the mental health services and Irish society. According to the CEO of St. Patrick’s Hospital, Paul Gilligan, “we have deeply ingrained negatives views in Ireland, some of which date back to how we used to deal with mental health in the past, and I think we really need to tackle them on a number of levels.”

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59 *RT v Director of Central Mental Hospital* [1995] 2 IR 65. s 207 of the 1945 Act was declared unconstitutional. The case stated lapsed because the patient had been transferred back to an ordinary hospital by time it reached the Supreme Court.
62 *Croke v Ireland*, Application no 33267/96 (struck out 21 December 2000). This case was resolved by way of ‘friendly settlement’ between the parties. It was on foot of this settlement that the Mental Health Bill 1999 was introduced.
The historic analysis suggests that the Irish mental health system has been characterised by a culture of institutional control and has been traditionally ‘hospital prone’. Institutionalisation has steadily decreased in recent decades, but community-based services are not sufficiently developed and a culture of control is still prevalent. The mental health services have failed to achieve many of the changes envisaged by successive policy documents. Approximately 3,000 residents of the former psychiatric institutions are now living in state-funded group homes, but the system continues to readmit individuals who could be treated in the community. The climate and culture of many of these residences are reflective of a ‘mini institution’. In 2008, the Inspector of Mental Health Services stated the failure to provide adequate recovery services meant that many individuals “are left to live out cold, empty, colourless lives in old institutions, forgotten and neglected”, while others are ‘warehoused’ in smaller community-based institutions often with little in the way of a meaningful existence, highlighting the disconnect between the national mental health services and where people actually live their lives.

In 2012, the Inspector of Mental Health Services found service development had stagnated and may even have deteriorated due to reduced staff numbers and poor governance. Treatment was largely based on the medical model rather than the holistic recovery approach envisaged in Irish mental health policy. The result is an understaffed service that often leaves service users disempowered and isolated. A holistic approach requires measures, which allow individuals to develop the skills to manage their recovery and the opportunity to make choices. These issues should be prioritised by government. The World Health Organisation (WHO) states that

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67 Health Research Board, Selected Findings and Policy Implications from 10 Years of HRB Mental Health Research (Health Research Board 2013).
68 Ibid.
69 Donna Tedstone Doherty, Dermot Walsh and Rosalyn Moran, Happy Living Here...A Survey and Evaluation of Community Residential Mental Health Services in Ireland (Health Research Board, Mental Health Commission 2007) 8.
70 The first aim of inspection of approved centres and other mental health services is to confirm that the human rights of patients are respected with no occurrence of abuse or neglect. Inspectorate of Mental Health Services, ‘National Review of the Mental Health Services 2008’ in Mental Health Commission Annual Report 2008 including the Report of the Inspector of Mental Health Services, (Mental Health Commission 2008) 64.
governments are equally responsible for the mental and physical health of their citizens.\textsuperscript{74} In order to comply with the CRPD and provide respect for choice, deinstitutionalisation must be achieved at every level.\textsuperscript{75}

3.1. National Mental Health Policy- ‘A Vision for Change’

The rapid changes in Irish society between 1984 and 2006 resulted in the development of a new mental health policy framework. ‘A Vision for Change’ provided a blueprint for the modernisation of Irish mental health services for a seven to ten year period.\textsuperscript{76} The policy proposed significant changes and improvements for Irish mental health services including recommendations for empowerment, advocacy, and recovery.\textsuperscript{77} It sets out principles in relation to citizenship, respect, partnership and recovery.\textsuperscript{78} An Independent Monitoring Group (IMG) was established to oversee and report on implementation, but this has been disbanded since 2012 and no subsequent group has been appointed.\textsuperscript{79} A central theme of ‘A Vision for Change’ is the adoption of ‘a person centred treatment approach’. The aim was to migrate from a traditional institutional based model to a community-based approach. Advance planning is a core part of good person-centred care. The policy recommends the agreement of treatment through an integrated care plan, agreed between service users and carers.\textsuperscript{80} ‘A Vision for Change’ explicitly supports the use of ADs and states that:

“A person-centred approach to the delivery of care will both highlight and moderate these conflicting rights, offering measures such as advance directives that can be put into effect at times when the user may not be well enough to make informed decisions.”\textsuperscript{81}

\textsuperscript{75} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12: Advance Unedited Version’ 10th Sess (September 2-13 2013) para 42.
\textsuperscript{80} Ibid 8.
\textsuperscript{81} Ibid 30.
The policy refers to participation as a principle of service delivery and to the use of ADs and enduring powers of attorney in mental health services for older people.\textsuperscript{82} The involvement of service users and their families at every level of service provision is seen as the next step in development. This includes enabling service users to participate in future treatment decisions. The policy will be reviewed in 2015 leading to an updated policy beyond 2016. However, many aspects of the current document remain unfulfilled and some stakeholders are concerned that a new policy could lead to regression. The Mental Health Commission noted that much of the optimism surrounding the publication of ‘A Vision for Change’ had been replaced by disappointment.\textsuperscript{83} Successive reports of the IMG expressed concern at the pace of implementation and found resources, changes in the delivery of services “… and most importantly a cultural shift of attitude and practice by service providers and mental health professionals” were needed.\textsuperscript{84} The 2012 report recommended a cultural shift towards recovery,\textsuperscript{85} supporting the recommendation for a national programme for change.\textsuperscript{86} The clear authority and accountability to deliver a national plan has been structurally lacking within the health services, while culturally, changes in attitudes behaviour and power structures by professionals and service users are required.\textsuperscript{87}

Amnesty International Ireland (AI) states that as long as Ireland fails to implement ‘A Vision for Change’, it will fail to meet international human rights standards and individuals will be detained in situations, which may not have arisen if supports were available.\textsuperscript{88} Some of the recommendations may be placed on a statutory basis in the review of the 2001 Act. According to the WHO the implementation of mental health

\textsuperscript{82} Ibid 119.
\textsuperscript{87} Orla Barry, ‘Mental Health Services need Long-Overdue Cultural and Structural Revamp’ Opinion: Progress in Implementing 2006 Reform Plan has been Painfully Slow, \textit{Irish Times} (Dublin 17\textsuperscript{th} May 2013).
policy often requires legislation.\textsuperscript{89} The challenge is to transplant the philosophical underpinnings of the policy and legislation into meaningful action in the mental health services. In order to achieve these goals, detailed targets, time-lines, resources and designated responsibility for implementation are needed. Although concern has been expressed at the rate of implementation, modernisation is occurring slowly and examples of good practice have been found in some parts of the mental health services.\textsuperscript{90} According to a recent article on the mental health services in Ireland published in the Irish Times:

“The old granite and red brick buildings are closing. But shutting the door on a culture which often ignored the voice of patients isn’t necessarily as easy.”\textsuperscript{91}

ADs are a key driver in the transition to person-centred services. The implementation of ADs can assist the ‘paradigm shift’ towards participation and respect by providing a forum for the voice of the person in Irish mental health care.

3.2. Advance Directives in Irish Case Law

Ireland currently lacks legislative provisions for ADs, but it is planned to incorporate them into the Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill) at the Committee stage of the legislative process.\textsuperscript{92} The draft legislative scheme for advance healthcare directives was published by the Department of Health in February 2014 and was opened for public consultation at the time of writing.\textsuperscript{93} The scheme proposes a single legislative framework, which encompasses ADs for general and mental health care. Ireland lags behind other comparable jurisdictions in providing for ADs in general or mental health care.\textsuperscript{94} While there is no law prohibiting a person from expressing their treatment wishes, the absence of a statutory framework makes their legal status uncertain. The first significant Irish

\textsuperscript{90} Mental Health Reform, Guiding a Vision for Change-Manifesto (Mental Health Reform 2012).
\textsuperscript{91} Carl O’Brien, ‘After the Asylum’ Irish Times (Dublin July 15 2013).
\textsuperscript{92} The Committee stage is the third of the five stages in the legislative process and includes a detailed examination and consideration of the 2013 Bill section by section either in a committee of the whole house, a select committee or a special committee.
\textsuperscript{93} Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.
\textsuperscript{94} Scotland, United States, Canada, New Zealand.
discussion on ADs arose in a lecture by the late Justice Declan Costello in 1986, where the enforceability of end-of-life directives in Irish law was strongly supported. The authority as to whether an AD will be respected is under the ‘parens patriae’ jurisdiction of the court, which obliges it to act in the ‘best interests’ of the individual. The issue was first considered by the Irish courts in Re a Ward of Court (No.2). The case involved a woman, who was in a minimally conscious state for over 23 years, having suffered irreversible brain damage as a result of cardiac arrest. The family of the ward asked the gastronomy tube to be removed. The court held that it was in the ‘best interests’ of the ward that the artificial nutrition and hydration (ANH) should be withdrawn. The constitutional right to refuse medical treatment was recognised for incompetent patients by the Supreme Court when O’Flaherty J. stated that:

“… consent to medical treatment is required in the case of a competent person ... and, as a corollary, there is an absolute right in a competent person to refuse medical treatment even if it leads to death.”

Denham J added that an adult may refuse treatment for reasons that may not be medical or appear to be rational. The court stated that loss of capacity did not result in any diminution of the constitutional rights of the ward, including the right to life, bodily integrity, privacy (including self-determination), or the right to refuse medical treatment. The court recognised the right of an incapable patient to bodily integrity when the treatment was regarded as intrusive. Although the case did not deal directly with ADs, the Supreme Court made indirect reference to the issue suggesting they would be respected by the Irish courts. O’Flaherty J. stated obiter that while he found it:

96 [1996] 2 IR 79.
97 Ibid 129.
98 Ibid 156.
99 Ibid 124, 125.
“... impossible to adapt the idea of the ‘substituted judgment’ to the circumstances of this case and, it may be, that it is only appropriate where the person has had the foresight to provide for future eventualities.”

The reference to substituted decision-making in the case referred to the wishes of the ward rather than another person. O’Flaherty J’s comments suggest that if an individual had the foresight to express his wishes in an AD, it would be upheld by an Irish court. Mills argues that the only logical corollary to the right to personal autonomy recognised in the decision is that a validly executed AD would be acceptable in Irish law. A number of subsequent cases have reinforced the decision in Re a Ward of Court, including JM v The Board of Management of St Vincent’s Hospital and Fitzpatrick v FK (No. 2). While the case law suggests that a valid AD would be upheld in Irish law, a legal framework is needed to provide certainty, particularly in relation to mental health decisions.

The right to autonomy was reaffirmed in Fitzpatrick v FK (No. 2), when Laffoy J. noted it was protected by Art.40.3.1 and Art.40.3.2 of the Constitution. However, the court held that Ms. K did not have the capacity to refuse medical treatment stating that there was a rebuttable presumption of capacity. The decision introduced the ‘functional’ test of capacity into Irish law using the three-stage approach established in the English case of Re C. This test requires an individual to be able to use, weigh and retain the relevant information, to understand and appreciate the nature and consequences of the decision and to believe the information provided. The 2001 Act has a limited definition of capacity, which refers to consent to treatment as “capable of understanding, the nature, purpose and likely effects of the proposed treatment.” The definition of capacity in the 2001 Act is narrower than

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101 Re a Ward of Court [1996] 2 IR 79, 133.
102 Substitute decision-making is now being used to describe situations, where another person is imposing the decision on the person.
107 Ibid.
110 Mental Health Act, 2001, s 56.
the three-stage test adopted in *Fitzpatrick v FK*.111 Donnelly argues that the narrower standard is unjustified and may be discriminatory.112 It also contrasts with the wider functional test adopted in the 2013 Bill, which defines capacity as the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is made.113 The 2001 Act includes a presumption of capacity, but it is not sufficiently stated. The Nursing Home Support Scheme Act (Fair Deals) 2009 also provides a definition of capacity based on the functional approach.114 Under the functional approach, capacity is determined by an external non-disabled standard, which denies capacity to persons who do not meet it.115 Models and definitions of capacity are considered over inclusive and reinforce the association between disability and incapacity.116 The denial of legal capacity based on mental capacity under the functional approach is considered to be a violation of Article 12 of the CRPD.117

The LRC concluded that an AD by a capable person would be upheld in the Irish courts based on the decisions in *Re a Ward of Court*118 and *Fitzpatrick v F.K.*,119 but acknowledged that a clear statutory framework was necessary to deal with the issue.120 The paternalism in the Irish courts and the mental health system reinforces the need for a clear legislative framework that explicitly includes ADs for mental health decisions. However, a recent High Court decision suggests the Irish courts may be willing to respect advance decisions for mental health treatment.121

111 [2008] IEHC 104.
113 Assisted Decision-Making (Capacity) Bill 2013 s 3(1).
114 Nursing Home Support Scheme Act (Fair Deals) 2009, s 21.
116 Ibid.
118 *Re a Ward of Court* [1996] 2 IR 79.
121 *MX v HSE* [2012] IEHC 491.
The *MX v HSE* decision suggests ADs for mental health treatment decisions may be recognised by the Irish courts.\(^{122}\) The plaintiff, who was detained at the Central Mental Hospital, sought to challenge a number of aspects of her treatment and care, including the taking of blood tests without her consent. She claimed that medical decisions made in the context of her incapacity, failed to recognise her right to equal recognition before the law. She further claimed that the decision on her capacity to consent to treatment should be subject to independent review and she was entitled to support to make treatment decisions. The plaintiff submitted that s.57 of the 2001 Act, under which she was being treated, was repugnant to the Constitution, incompatible with the ECHR and failed to have regard to the CRPD. Although the High Court did not find the rights of plaintiff were violated under the Constitution or the ECHR, McMenamin J made important observations regarding the right of detained persons to be heard in treatment decisions.\(^{123}\) The argument that the CRPD was applicable to Ireland through EU ratification was rejected, but the court acknowledged the guidance it provides in regard to ‘prevailing ideas and concepts’ on legal capacity.\(^{124}\) The court concluded that the plaintiff was entitled to an independent review and to decision-making support to vindicate her rights, but that blood samples could be taken without her consent, where the safe administration of mental health treatment required it and confirmed that the ‘best interests’ test applied where the patient lacks capacity. The need for on-going review of the decision, by means of an independent tribunal or court hearing was dismissed on the basis that it would constitute an unnecessary degree of legal involvement in the field of psychiatry. In recognising the right of the patient to be heard in treatment decisions, McMenamin J stated:

“Why then should the voice of the patient not be heard, and if not by the patient, then through a representative?” and “... the patient should, where necessary be assisted in expressing their view as part of the decision-making process?”\(^{125}\)

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\(^{122}\) *Ibid* 73, 20.

\(^{123}\) The court found that treatment regime was that under s 60 of the Mental Health Act 2001, rather than s 57.

\(^{124}\) *MX v HSE* [2012] IEHC 491.

\(^{125}\) *Ibid* 73.
These comments suggest the wishes of the patient expressed through an AD or a proxy decision-making representative would be recognised by the Irish courts. The court also referred to the need for assistance for individuals who lack capacity to express their view in order to vindicate their constitutional rights:

“If a patient lacks capacity, does it not follow that, in order to vindicate these rights, the patient should, where necessary, be assisted in expressing their view as part of the decision-making process? It cannot be said that such a process is impractical. I think the constitutional duty involved here is a positive one.”

The court concluded that the patient’s decision or choice, should be recorded and due regard should be given to it whether assisted or not. McMenamin J also referred to the need to review Form 17, which is used to administer medicine for longer than three months, so that it includes a space to record the service user’s views. The Mental Health Commission introduced new forms in August 2013, which include sections for discussion on medication, ECT and psychosurgery treatments, the views expressed by the patient and details of any assistance given in decision-making. However, the court, went onto state that “the patient’s choice, however conveyed, will not always be determinative, but must always be part of the balance” and referred to the pivotal role of the psychiatrist. This suggests a continued deference to medical opinion. While the judgment ultimately affirmed the paternalistic approach adopted by the Supreme Court in EH, in relation to the deprivation of liberty, the decision signifies an attitudinal shift in relation to participation in mental health treatment and a willingness to recognise supported decision-making measures such as ADs. The High Court subsequently affirmed and extended the MX decision relating to blood tests without consent to children in Re XY: Health Service Executive v JM stating that XY’s ‘best interests’ were served by permitting the sample. Flynn argues that if support for legal capacity, as required by Article

126 Ibid 73.
127 Mental Health Act 2001, s 60.
129 MX v HSE [2012] IEHC 491, 82.
130 EH v Clinical Director of St Vincent’s Hospital [2009] 3 IR 774.
12(3) of the CRPD, were provided to the plaintiff in the *MX* case, a different outcome may have been reached.\textsuperscript{132} The provision of supports such as advocacy, information in an appropriate format and the development of an AD could have enabled the plaintiff to make decisions about future treatment or to communicate preferences through a proxy decision-maker.

In the absence of a statutory framework, the recognition of ADs for mental health treatment decisions is uncertain given the paternalistic approach taken by the Irish courts in other decisions. A subsequent decision reported in the Irish newspapers\textsuperscript{133} suggests a return to the paternalistic approach and failed to respect the wishes of the person or the family. In this case, the High Court granted permission for the administration of ECT against the will of an elderly woman suffering from psychotic depression and Parkinson’s disease, despite a clearly expressed wish not to be treated with ECT prior to the deterioration in her mental health and the resistance of her family. The President of the High Court, Kearns J, granted an application by the HSE against the woman and her family to ensure that treatment could be administered without her consent. The plaintiff was admitted involuntarily to an approved centre in 2012 for treatment, but her condition deteriorated, and she refused medication on occasion. The treating doctors believed she no longer had the capacity to make decisions and ECT would assist in the treatment of her depressive state. The family communicated that their mother was adamant in her wish not to be treated with ECT. Newspaper reports highlighted the discrepancy in Irish law in relation to the provision of ADs, which would have enabled the woman to specify future treatment preferences or authorise a family member to make decisions on her behalf.\textsuperscript{134} The Irish College of Psychiatrists refers to the need to take an AD and the views of relatives into account, in situations where a person lacks capacity to consent to ECT.\textsuperscript{135}


\textsuperscript{134} Ibid.

\textsuperscript{135} College of Psychiatrists in Ireland, Electroconvulsive Therapy (ECT) Position Statement EAP01/2011 (College of Psychiatrists in Ireland 2011); College of Psychiatrists of Ireland, ‘On the Road to Recovery’ A Paper written by Refocus CPsychI (College of Psychiatrists of Ireland 2013) 7.
The failure to respect the refusal of treatment by a voluntary patient was highlighted in a recent Irish case. In *KC v Clinical Director of St Loman’s Hospital*, a voluntary patient who was refusing treatment, but did not indicate a wish to leave the hospital, had her status changed to involuntary so treatment could be administered against her will. Under the 2001 Act, the patient must have indicated a wish to leave the approved centre to have their status changed to involuntary. The provision caters for involuntary patients who need ongoing treatment, but indicate a wish to leave the hospital. The *KC* decision suggests that the threat of involuntary treatment also exists for voluntary patients. The decision reinforces the need for legally binding ADs for both voluntary and involuntary patients to protect against unwanted mental health treatment.

3.3. **Development of Proposals for a Legislative Framework for ADs in Irish Law**

The move to reform Irish capacity law and to introduce legislative provisions for ADs originated in the work of the Law Reform Commission (LRC) and the Irish Council of Bioethics. The LRC’s second programme of law reform recognised the need for changes in the law in relation to vulnerable adults. In June 2003, the LRC published a ‘Consultation Paper on Law and the Elderly’, which set out a new decision-making structure to replace the ward of court system, which currently governs individuals deemed to lack decision-making capacity in Ireland. The 2006 report on ‘Vulnerable Adults and the Law’ set out proposals for a new guardianship system, a presumption of capacity for all adults and a functional approach to capacity determinations. The report informed the publication of the Scheme of the Mental Capacity Bill 2008. ADs were briefly discussed in the

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137 Mental Health Act 2001, s 23(1).
138 The Law Reform Commission is an independent statutory body whose main purpose is to review the law and to make practical proposals for reform.
141 Lunacy Regulation (Ireland) Act 1871; Orders 65 and 67 of the Rules of the Superior Courts 1986 provide for an order making a person a ward of court.
143 A functional approach focuses on cognitive understanding of the decision to be made, rather than the outcome.
report, but detailed analysis was postponed pending the publication of research by
the Irish Council of Bioethics.

The Irish Council of Bioethics undertook a public consultation survey in 2005,
which supported the introduction of a legal framework for ADs in general
healthcare.\textsuperscript{145} The findings highlighted the need for legislation in this area.\textsuperscript{146} The
survey indicated that 39 per cent of Irish adults had a strong preference for legally
binding ADs.\textsuperscript{147} A survey by the Irish Hospice Foundation in 2007 found 71 per cent
of participants had never heard of the term ‘advance directive’, whereas over half
were familiar with the ‘living will’.\textsuperscript{148} The surveys conducted between 2004 and
2007 suggested the AD or ‘living will’ completion rate ranged between 5 per cent
and 14 per cent in Ireland.\textsuperscript{149}

The LRC proposed a statutory framework for general ‘advance care directives’ in a
Consultation Paper in 2008.\textsuperscript{150} These recommendations were published in a report on
ADs in 2009.\textsuperscript{151} The report set out the LRC’s final recommendations on ADs,
together with a draft Mental Capacity (Advance Care Directives) Bill.\textsuperscript{152} The
publication of the Council of Europe Recommendations on ADs in 2009\textsuperscript{153} and the
new CRPD generated a growing momentum for legislative provisions in this area.\textsuperscript{154}
The LRC report proposed a legal framework for ADs under the Scheme of the
Mental Capacity Bill 2008, but specifically excluded ‘psychiatric advance directives’

\textsuperscript{145} The Irish Council for Bioethics, \textit{Public Attitudes Towards Bioethics} (Irish Council of Bioethics 2005).
\textsuperscript{146} Irish Council for Bioethics, Opinion, \textit{Is It Time for Advance Healthcare Directives?} (Irish Council
for Bioethics 2007).
\textsuperscript{147} Ibid.
\textsuperscript{148} John Weafer, Joan McCarthy and Mark Loughrey, \textit{Exploring Death and Dying: The Views of the
Irish Public} (Irish Hospice Foundation 2009).
\textsuperscript{149} Weafer Research Associates, \textit{A Nationwide Survey of Public Attitudes and Experiences regarding
Death and Dying} (Irish Hospice Foundation and National Partnership Forum 2004);
John Weafer, Joan McCarthy and Mark Loughrey, \textit{Exploring Death and Dying: The Views of the Irish
Public} (Irish Hospice Foundation 2009).
\textsuperscript{150} Law Reform Commission, \textit{Bioethics: Advance Care Directives, Consultation Paper LRC CP 51-2008} (Law Reform
\textsuperscript{151} Law Reform Commission, \textit{Bioethics: Advance Care Directives, LRC 94-2009} (Law Reform
Commission 2009).
\textsuperscript{152} Ibid.
\textsuperscript{153} Council of Europe, European Committee on Legal Co-operation, CM (2009) 1073, December 9,
2009.
\textsuperscript{154} Law Reform Commission, \textit{Bioethics: Advance Care Directives, LRC 94-2009} (Law Reform
Commission 2009) 35.
from its scope due to the inherent complexities.\textsuperscript{155} The report recommended a separate review to assess the 2001 Act and the work of the Mental Health Commission. The LRC acknowledged the potential benefits of ADs in the context of recurring mental health difficulties; treatment planning; quality of life and a reduced need for hospitalisation.\textsuperscript{156} The Heads of the 2008 Bill included proposals to extend enduring power of attorney (EPA) to healthcare decisions,\textsuperscript{157} but did not include a statutory framework for ADs.

The LRC recommendations included providing for legally binding ADs for the refusal of treatment only.\textsuperscript{158} The provision of non-legally binding directives for positive treatment requests reflects the decision in the English Court of Appeal in \textit{R (Burke) v General Medical Council}.\textsuperscript{159} In a recent Dáil debate on the 2013 Bill, one of the deputies pointed to the fact that it is often easier to legislate for what people do not want in future situations.\textsuperscript{160} Other recommendations included unwritten directives for non-life sustaining treatment\textsuperscript{161} and a rebuttable presumption of capacity.\textsuperscript{162} The appointment of a healthcare proxy\textsuperscript{163} and informal revocation (including oral revocation) of the AD were also included.\textsuperscript{164} The recommendations included providing for regular review in a code of practice without specific time limits;\textsuperscript{165} the establishment of a registry;\textsuperscript{166} and consultation with a health professional.\textsuperscript{167} The LRC recommendations for the presumption of capacity, the appointment of a proxy decision-maker, informal revocation and review and the establishment of a registry are positive. However, the exclusion of mental health

\textsuperscript{155} Ibid.
\textsuperscript{157} Department of Justice, Scheme of Mental Capacity Bill 2008, Head 48.
\textsuperscript{158} Law Reform Commission, \textit{Bioethics: Advance Care Directives} (Law Reform Commission LRC 94-2009) para 1.82.
\textsuperscript{159} [2005] EWCA Civ 1003; [2005] 2 FLR 1223.
\textsuperscript{161} Ibid para 3.41.
\textsuperscript{163} Ibid para 3.105.
\textsuperscript{164} Ibid para 3.89.
\textsuperscript{165} Ibid para 5.32.
\textsuperscript{166} Ibid para 3.96.
\textsuperscript{167} Ibid para 3.104.
decisions failed to comply with the right to equal recognition before the law and to exercise legal capacity in the CRPD.\footnote{168 GA Res 61/106. UN Doc A/Res/61/106 (entered into force 3 May 2008) Article 12, Article 5.} State Parties are required to refrain from any action, which deprives persons with disabilities of their right to equal recognition before the law.\footnote{169 Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12: Advance Unedited Version’ 10th Sess (September 2-13 2013) para 20.} An Advance Healthcare Decisions Bill was presented to the Dáil and referred to a select sub-committee on health in 2012, but this was subsequently withdrawn.\footnote{170 Advance Healthcare Decisions Bill 2012.} The provisions of the 2012 Bill did not apply to lawful treatment under the Mental Health Act, 2001.\footnote{171 Advance Healthcare Decisions Bill 2012, s 6 (8)(b).}

Despite the recommendations and proposals, Ireland still lacks a legislative framework for ADs.\footnote{172 Irish Council for Bioethics, \textit{Is it time for Advance Healthcare Directives? Opinion} (Irish Council for Bioethics 2007).} The 2013 Bill proposes to incorporate legislative provisions for ADs. A draft scheme for advance healthcare decisions was published in February 2014.\footnote{173 Department of Health, 'Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.'} The scheme includes ADs for general and mental health care in a single legislative framework, but excludes the use of legally binding ADs during periods of involuntary detention.\footnote{174 Ibid Head 5.}

In the absence of legislation, many Irish hospitals and professional bodies have developed guidelines and protocols based on ‘best practice’ models from other jurisdictions.\footnote{175 Information provided to the Law Reform Commission during the consultation process on advance directives. Law Reform Commission, \textit{Bioethics: Advance Care Directives, Consultation Paper} (Law Reform Commission LRC CP 51-2008) 27.} The Irish Medical Council has developed guidelines to assist medical staff to provide care for the person in line with his/her ethical values and principles.\footnote{176 Irish Medical Council, \textit{Guide to Ethical Conduct and Behaviour} (Irish Medical Council 2009) \url{http://www.medicalcouncil.ie/News-and-Publications/Publications/Discussion-Documents/Advanced-Directives.html} [accessed 13 March 2013].} In a 2003 study, 27 per cent of general healthcare physicians in Ireland had experience of ADs being presented to them.\footnote{177 Marcus Butler, ‘Dissatisfaction with Do Not Attempt Resuscitation Orders: A Nationwide Study of Irish Consultant Physician Practices’ (2006) 99 (7) Irish Medical Journal 208.} This figure may have increased with increasing participation and awareness over the past decade. The guidelines state that doctors should take an AD into account and that an advance refusal has the
same ethical status as a contemporaneous refusal\textsuperscript{178} provided it was made at a time the person was competent; is applicable to the situation and the person has not changed his/her mind.\textsuperscript{179} The Council does, however, highlight potential concerns in relation to ADs, including their applicability to the situation; the difficulty in predicting future medical treatment; changes in prognosis or treatment and the possibility that the person has changed his/her mind and is unable to communicate it.

3.4. Mental Health Legislation

The Mental Health Act 2001 (2001 Act) marked a major reform in mental health law and practice in Ireland. The 2001 Act moved towards a rights-based approach to mental health law and was a significant departure from the 1945 Act. A green paper published by the Department of Health in 1992 initiated the process of legislative reform.\textsuperscript{180} The government published a white paper on mental health law reform in 1995, which noted that the 1945 Act was not in compliance with the ECHR.\textsuperscript{181} The new legislation was designed to ensure ECHR compliance. The CRPD now provides an additional new benchmark for domestic law.\textsuperscript{182} The 2001 Act provides important procedural safeguards for involuntary patients and puts in place mechanisms whereby the standards of care and treatment can be monitored and regulated by the Mental Health Commission and the Inspectorate of Mental Health Services.\textsuperscript{183} Mental disorder is defined under the Act as “a mental illness, severe dementia or a significant intellectual disability” that results in a serious likelihood of immediate and serious harm to themselves or others or where the condition is so serious that failure to admit for treatment would lead to a serious deterioration and detention or treatment would benefit or alleviate the condition.\textsuperscript{184} In making a decision regarding the care or treatment of a person under the Act, it states that:

\textsuperscript{178} Same as a current or synchronous refusal of treatment given at same time.
\textsuperscript{180} Department of Health, Green Paper on Mental Health (Stationery Office 1992).
\textsuperscript{181} Department of Health, White Paper, A New Mental Health Act (Stationery Office 1995).
\textsuperscript{182} Ireland signed the CRPD in 2007 but has not yet ratified the Convention. The EU ratified the CRPD in 2010. The Irish Government has committed to ratifying the CRPD and to enacting new capacity legislation in the programme for Government.
\textsuperscript{183} Under the Mental Health Act, 2001, the Inspectorate carries out a review of mental health services in the state and provides a report on the quality of care and treatment given to service users.
\textsuperscript{184} Mental Health Act 2001, s 4(1).
“… the best interests of the person shall be the principal consideration with due regard being given to the interests of other persons who may be at risk of serious harm if the decision is not made.”

The failure to define ‘best interests’ in the 2001 Act, has led to paternalistic interpretations by the courts. The CRPD Committee requires the abolition of substitute decision-making regimes, which are defined as systems where legal capacity is removed from the person, even for a single decision. A substitute decision-maker is defined by the Committee as a person appointed by someone other than the individual and makes decisions based on his/her objective ‘best interests’ rather than the person’s ‘will and preferences’. The ‘best interests’ provisions in the 2001 Act will therefore have to be amended to comply with the CRPD and the ‘will and preferences’ provisions in the 2013 Bill. A representative from the office of the Council of Europe Commissioner for Human Rights suggested the ‘best interests’ model is outdated stating that “… we are still making decision for persons, although the philosophy and the obligations of the CRPD are clear that the starting point is that the person has capacity.” Some of the issues arising in relation to the application of the ‘best interests’ test were highlighted in a recent U.K. case, where the Court of Protection authorised the delivery of a baby by caesarean section ‘against the will’ of a woman with bipolar disorder, while she was detained under the Mental Health Act 1983. The authorities feared that the woman would suffer a rupture unless the baby was delivered by caesarean section. The judge remarked that “I would have thought it was in her best interests, that is, her mental health ‘best interests’, that her child should be born alive and healthy …” The court was given evidence that she suffered ‘psychotic episodes’ and ‘delusional beliefs’ and lacked

185 Ibid, s 4(3).
187 Ibid.
188 Assisted Decision-Making (Capacity) Bill 2013, s 8(7)(b). The term ‘best interests’ has been omitted from the 2013 Bill and the guiding principles state that interventions must give effect, as far as possible, to the past and present ‘will and preferences’ of the person.
189 In the matter of Re P (A Child) [2013] EW Misc 20 (CC).
191 Claire Duffin, ‘Forced Caesarean was ‘manifestly’ in Alessandra Pacchieri’s Interest, says Judge’ The Telegraph (London 4 December 2013).
the capacity to decide for herself. In *Re MB (An Adult: Medical Treatment)*, best interests’ were found not to be limited to best medical interests.

3.4.1. Participation and Autonomy in the Mental Health Act 2001
Participation and inclusion are fundamental to respecting the ‘will and preferences’ of the person under the CRPD. The principle of participation is emphasised in section 4(2) of the 2001 Act when the person must be notified ‘as far as is reasonably practicable’ of the proposed admission order or treatment and due consideration must be given to any representations. However, this section of the Act has not been vigorously enforced. Participation is also referred to in the guiding principles of the 2013 Bill where the intervener must facilitate and encourage the person to participate in interventions as far as practicable. Section 4(3) of the 2001 Act refers to autonomy in making a decision concerning the care or treatment of a person when it states that “due regard shall be given to respect the right of the person to dignity, bodily integrity, privacy and autonomy.” A number of difficulties arise when trying to balance the ‘best interests’ principle in s. 4(1) with the right to autonomy in s. 4(3) of the 2001 Act. Donnelly asserts that the protections afforded to autonomy and participation are insufficient. This is evident in the case law where the rights of service users have been given little recognition. The failure to define ‘best interests’, has led to the continued use of paternalism and inadequate protection of autonomy in the Irish courts. According to Brennan:

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194 Article 3; Article 12(4).
195 Mental Health Act 2001, s 4(2). The patient does not appear to have an entitlement to make representations in relation to a proposed Renewal Order.
196 Assisted Decision-Making (Capacity) Bill, s 8 (7)(a).
197 Mental Health Act 2001, s 4(3).
“… an incessantly objective approach has been applied by the courts in Ireland which utilises the ‘best interest’ principle to defend the failure of doctors to adhere to procedural due process as prescribed.”

The common law has traditionally given control to medical professionals. The Supreme Court adopted a strongly paternalistic interpretation of the 2001 Act in *EH v St. Vincent’s Hospital*, reflecting the approach taken in preceding High Court decisions. The decision in *PL v Clinical Director of St Patrick’s Hospital*, reaffirmed the approach taken in *EH*. Peart J relied on “the established paternalistic nature” of the 2001 Act to justify the decision that the plaintiff was not unlawfully detained. Murray argues that the Irish courts have failed to engage with the ECHR in the area of mental health, which has contributed to an inadequate protection of rights. The failure to vindicate the rights of persons with mental health conditions under the 2001 Act reinforces the need for enforceable legally binding ADs for mental health treatment decisions. The introduction of legislative provisions for ADs can promote autonomy under the 2001 Act by allowing the person’s choices to be respected during detention and reduce the need for involuntary admission and non-consensual treatment. The inclusion of mental health ADs in the legal framework can help change the culture from coercion to one of respect for treatment decisions.

### 3.4.2. Human Rights in the Mental Health Act 2001

The 2001 Act fails to comply with the national mental health policy framework or international human rights norms, due to lack of respect for legal capacity and autonomy. In a review on human rights in mental health legislation, the 2001 Act was found to comply with under half the 175 standards in the WHO Resource Book.

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204 *MR v Byrne* [2007] 3 IR 211; *JH v Lawlor* [2008] 1 IR 476.
The literature highlights on-going issues with Irish mental health legislation including the protection of voluntary patients, consent to treatment and the administration of ECT to unable and unwilling involuntary patients. The 2001 Act only provides procedural safeguards and review for the 11 per cent of patients who are subject to involuntary admission in Ireland. National statistics show that almost half of those admitted involuntarily do not have a tribunal hearing and only 8 per cent of the reviewed orders are revoked. Appeals can be made to the Circuit Court against tribunal decisions, but of the 116 appeals made in 2012, only 17 cases went to hearing and none were successful. The practice of revoking involuntary admission orders in order to avoid tribunal hearings was acknowledged in a survey with psychiatrists. A total of 1,530 orders were revoked by the responsible consultant psychiatrist (RCP) before the hearing in 2012. In a previous study, none of the participants who had their status changed from involuntary to voluntary requested the tribunal hearing to proceed. The figures highlight the difficulty individuals with mental health conditions have in vindicating their rights. The low uptake of the habeas corpus remedy whereby individuals can challenge the legality of their detention showed similar access barriers. The legislation needs to include accessible and enforceable human rights for vulnerable groups. The legislative provisions for ADs should therefore be easily executable and enforceable.

210 Ibid.
211 Ibid.
advocate commented on the difficulties exercising rights in the mental health context “you have your human rights until you try to exercise them.”

Legal compliance and respect for human rights is also needed in mental health practice. The Inspector of Mental Health Services was dismayed at non-compliance with aspects of the 2001 Act in respect to involuntary admission and the administration of medication without consent in a recent report. According to the Inspector, “it was in this area that the most glaring effects of inadequate governance were exposed.” In another report nearly six out of ten inpatients were not given any written information about their rights despite obligations to do so. A recent qualitative study with patients who had been detained highlighted the lack of information, particularly in the early part of the admission process. The report of the Inspector of Mental Health Services states that the delivery of mental health services from a human rights perspective will require a philosophical adjustment and understanding of the importance of rights to improve treatment and care. ADs are important both symbolically and practically in promoting human rights in mental health care.

3.4.3. Consent to Treatment
The general principle of the law requires consent to medical treatment, unless a person is deemed unable to consent. The invasive and harmful effect of mental health treatment increases the importance of consent in this area. The requirement for consent to treatment is recognised in common law, Irish case law, the

220 Ibid.
221 Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011), s 16 of the Mental Health Act 2001 requires that the psychiatrist who makes an admission or renewal order, must give a statement in writing within 24 hours. The statement should include seven pieces of information on entitlements.
224 Darius Whelan, Mental Health Law and Practice (Roundhall 2009) 322.
Constitution and international human rights law. In the absence of an AD, treatment may be administered to those deemed to lack capacity to consent in their ‘best interests’ under Irish law. Mental health legislation can also override the requirement for consent in certain circumstances. The administration of treatment without consent is normally justified on the basis of risk of harm to self or others. While important principles have been laid down in the case law on the refusal of treatment, the threat of coercion in mental health makes individuals vulnerable to complying with professional wishes. This was highlighted in the KC case where the refusal of treatment by a voluntary patient resulted in her status being changed to involuntary so treatment could be administered without her consent.226

The 2001 Act contains specific provisions in relation to the treatment of involuntary patients.227 While the 2001 Act requires consent to treatment, the exceptions are wide and lack adequate independent review. Consent is defined in the 2001 Act as consent “obtained freely without threats or inducements”, where the person is “… capable of understanding the nature, purpose and likely effects of the proposed treatment” and where they have been provided with “adequate information, in a form and language that the patient can understand.”228 Consent to treatment is required for involuntary patients, except where the consultant psychiatrist considers the treatment is necessary to safeguard the life of the patient, to restore health, to alleviate the condition, to relieve suffering or where the person is incapable of giving consent due to mental disorder.229 The capacity to consent to treatment is determined by the RCP without independent review. The power vested in the treating psychiatrist to determine decision-making capacity is deemed to be a major weakness in the legislation and creates a risk that a person who refuses the treatment proposed will be deemed incapable.230 Moreover, the definition of mental disorder for involuntary patients includes a reference to impaired judgment, which is not defined and may be

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226 KC v Clinical Director of St. Loman’s Hospital [2013] IEHC 310.
228 Ibid, s 56.
229 Ibid, s 57(1).
230 Amnesty International Ireland (AI) convened a citizen’s jury to facilitate the involvement of individuals with mental health conditions in the introduction of new capacity law in early summer 2012. Amnesty International Ireland, A Citizens’ Jury on Legal Capacity Law (Amnesty International Ireland 2012).
associated with lack of capacity. Donnelly states that the right to refuse treatment is 'illusory' under the 2001 Act, due to a lack of a remedy for enforcement.

The 2001 Act sets out protections in relation to consent to ECT, psychosurgery and the administration of medication beyond three months. These treatments can only be given to a person who is ‘unable or unwilling’ to consent, with the approval of the responsible treating psychiatrist and a second consultant psychiatrist, who is not required to be independent. The CPT identified the need for an independent second opinion in the 2001 Act. The Inspector of Mental Health Services was particularly concerned with non-compliance with the requirements for administering medication without consent in a recent report. The failure to comply with the consent to treatment requirements suggests an even greater need for legally binding ADs in Irish mental health care. Roche refers to a lack of awareness of the harmful impact of coercive interventions amongst psychiatrists, which is compounded by the fact that the treatment is believed to be in the ‘best interests’ of the person. Ballard argues that ‘best interests’ does not justify the widespread use of harmful psychiatric treatments. In referring to the catastrophic impact of antipsychotic treatment in the context of dementia, he states “it is difficult to see how neuroleptic treatment can be in the ‘best interests’ of anyone other than the harassed doctor making the prescription.”

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231 Mental Health Act, 2001, s 3 (1)(b)(i).
233 Mental Health Act, 2001, s. 58 (1); s 59 (1)(b); s 60.
234 Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Report to the Government of Ireland on the Visit to Ireland carried out by the European Committee on the Prevention of Torture, Inhuman and Degrading Treatment and Punishment (CPT) from 25 January to 5 February 2010 (Council of Europe 2010) para 126
235 Mental Health Commission, Annual Report 2012 including Report of the Inspector of Mental Health Services (Mental Health Commission 2013) 54. Section 60 of the 2001 Act requires the consent of the person in writing or the authorisation of the treating consultant psychiatrist and another consultant psychiatrist where the person is unable or unwilling to consent to the continued administration of medication beyond three months. The requirement for consent must be satisfied in the first three months unless the treatment is necessary to safeguard the life of the patient, restore his/her health or alleviate the condition or relieve suffering where the person is incapable of consenting.
238 Clive Ballard and Julia Cream, ‘Drugs used to Relieve Behavioural Symptoms in People with Dementia or an Unacceptable Chemical Cosh’ (2005) 17 (1) International Psychogeriatrics 4.
considered to be a violation of the right to legal capacity, an infringement on right to personal integrity and freedom from torture, violence and abuse under the CRPD. The CRPD requires State Parties to provide access to support for decisions about mental health treatment and abolish policies and legislative provisions that allow or perpetuate forced treatment.

3.4.4. Consent to ECT Treatment in Irish Legislation

Irish law provides minimal protection against non-consensual ECT treatment. The 2001 Act allows detained persons to be treated with ECT if they are ‘unable or unwilling’ to consent with the authorisation of the treating psychiatrist and another consultant psychiatrist. The legislation does not require the second consultant psychiatrist to be independent from the approved centre or provide for appeal of the decision. Voluntary patients can be treated with ECT if they are deemed ‘unable’ to consent to treatment and the treating psychiatrist believes it is in their ‘best interests’. The Code of Practice on the use of ECT for voluntary patients states that written consent should be obtained.

Overall, 332 people received ECT treatment in Ireland in 2011; 25 (7.5%) of these programmes were given to patients who were ‘unable’ or ‘unwilling’ to consent to treatment, representing a decrease from 12 per cent in 2008. In 72 per cent of cases (18/25), where ECT was administered without consent, both consultant psychiatrists determined that the person did not have the capacity to consent to treatment and the person was categorised as ‘unwilling’ to consent in 12 per cent (3/25) of cases. The figures highlight the lack

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240 Ibid.
241 Mental Health Act 2001, s 59 (1)(b). Section 59(1)(b)(ii) and s 60 (1)(b)(ii)of the Mental Health Act 2001 both provide that the matter will be referred to the second-opinion psychiatrist by ‘the first-mentioned psychiatrist’ who is the treating psychiatrist.
244 In the other four cases, a combination of unwilling and unable was found by both consultant psychiatrists. Mental Health Commission, The Administration of Electroconvulsive Therapy in Approved Centres: Activity Report 2011 (Mental Health Commission 2013) 35. The rules specify that Form 16 must be completed by both consultant psychiatrists and placed in the patient’s clinical file. A copy must also be sent to the Mental Health Commission. Twenty five forms were received by the
of consistency and guidance in using capacity as a threshold for administering treatment without consent. Although the number of people receiving ECT treatment has decreased significantly in Ireland, the provision of ADs can protect the bodily integrity of individuals who do not wish to receive such treatment. The empirical study (in chapter 6) shows a strong preference for the option to provide advance refusal of ECT among Irish service users. The empirical study also indicates that individuals are increasingly expressing mental health treatment preferences to their doctors and developing ADs informally. The Seanad passed a Bill in 2012, which proposed to delete the term ‘unwilling’ from the 2001 Act, but this has not passed in the Dáil and may form part of the current review of the legislation.\footnote{245} Even if the unwilling ground is removed, a person can still be deemed unable to consent to ECT treatment. The provisions reinforce the need for legally binding ADs to protect against non-consensual ECT treatment for both voluntary and involuntary patients.

The 2001 Act raises serious concerns in relation to capacity and consent issues, which need to be addressed if there is to be meaningful participation for individuals with mental health conditions. The UN Special Rapporteur on Torture emphasised the importance of providing appropriate supports to enable persons with disabilities to exercise their legal capacity, in accordance with Article 12 of the CRPD.\footnote{246} A refusal of treatment should be respected through a contemporaneous refusal or through an AD. Critics argue that recourse to a second opinion or independent review cannot fully protect the rights of the person due to the use of non-disabled standards in capacity determinations.\footnote{247} The mental health legislation should, therefore, include supports such as ADs to enable individuals to state their treatment preferences. The introduction of support measures such as ADs can facilitate meaningful participation and respect for autonomy in mental health treatment.

\footnotesize{Commission in 2011. The administration of ECT without consent did not proceed in two of these cases.\footnote{245} Section 59 of the Mental Health Act 2001 is amended in subsection (1) (b) by the deletion of ‘or unwilling’. Mental Health (Amendment) Bill 2008 (changed from) Mental Health (Involuntary Procedures) (Amendment) Bill 2008 as passed by Seanad Eireann, Seanad Eireann Debate, Volume 207, Number 12.\footnote{246} Interim report of the UN Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, UN Doc. A/63/175 (July 2008) 18.\footnote{247} Amita Dhanda, ‘Universal Legal Capacity as a Universal Human Right’ in Michael Dudley, Derrick Silove and Fran Gale (eds), \textit{Mental and Human Rights: Vision, Praxis and Courage} (Oxford University Press 2012) 181.}
Several advocacy groups and other organisations have recommended that the 2001 Act be amended to give effect to ADs. AI commented that in its current form, the 2001 Act:

“… encourages a culture of exclusion and non-participation in treatment decisions, which is firmly at odds with the recovery ethos advocated by ‘A Vision for Change’, as well as provisions of international law, including in particular the CRPD.”

3.4.5. National Consent Policy
The Health Service Executive (HSE) published a ‘National Consent Policy’ in 2013, for use across all Irish public health services. The policy was developed in the context of the national mental health policy ‘A Vision for Change’ and developments in human rights standards. The requirement for consent extends to all interventions conducted by or on behalf of the HSE. The knowledge and importance of obtaining consent is expected of all staff. Consent is defined in the policy as the giving of permission or agreement for an intervention, following a process of communication. The policy requires health professionals to adopt a ‘presumption of capacity’ for all persons and states that capacity is not to be equated with the rationality of the decision. The 2013 Bill includes a presumption of capacity and provides that an unwise decision is not indicative of decision-making ability. The consent policy states mental health legislation does not remove the ethical obligation to maximise the capacity of the person or to involve those with reduced capacity in the decision-making process. The policy states that the AD should be respected provided the decision was an informed choice, is applicable to the situation and the person has not changed his or her mind. However, it also states that treatment decisions should be made in the ‘best interests’ of the person with reference to his or her known ‘values and preferences’, where there is doubt in relation to the existence

249 The Health Service Executive (HSE) runs all of the public health services in Ireland and employs more than a 100,000 people.
251 Ibid 20.
252 Ibid 20.
253 Ibid 30.
254 Assisted Decision-Making (Capacity) Bill 2013 s 8(4) and s 3(3).
255 HSE Quality and Patient Safety Directorate, National Consent Policy (HSE 2013) 43.
256 Ibid 44.
of an AD, its applicability or the capacity of the person at execution. The ‘best interests’ provision conflicts with the emphasis on ‘will and preferences’ in the CRPD and the 2013 Bill.

3.4.6. Review of the Mental Health Act, 2001
The Department of Health is currently undertaking a review of the 2001 Act, following the publication of an interim report in 2012. The review coincides with the introduction of new capacity legislation (2013 Bill). The Programme for Government committed to reviewing the 2001 Act in consultation with service users and other stakeholders in line with human rights standards. A five-year statutory review is also provided for in the legislation. The review will examine the operation of the Act; the extent to which the recommendations in ‘A Vision for Change’ should be underpinned by the legislation; the provisions of the CRPD; and the economic climate. The interim report suggested 25 provisions needed to be examined from a human rights perspective. The interim recommendations included incorporating human rights as a guiding principle and including key provisions on the right to autonomy and self-determination. The report also suggests that the 2001 Act should list a hierarchy of rights to guide judicial decision-making and to ensure negative paternalism is not carried forward into the amended legislation. The interim report recognised the need for a legislative framework for ADs to ‘provide a method for ascertaining a person’s wishes’. The establishment of a legislative basis for ADs was viewed as underscoring the recovery ethos in ‘A Vision for Change’ and enhancing autonomy and empowerment.

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257 Ibid 32.
258 Assisted Decision-Making (Capacity) Bill 2013, s 8.
261 Mental Health Act, 2001, s 75.
264 Ibid 11.
265 Ibid 11.
266 Ibid 51.
267 Ibid 51.
recommended the integration of ADs for mental health decisions in the overarching capacity legislation rather than in specific provisions.\textsuperscript{268}

Commentators have expressed hope that the review of the 2001 Act will not only lead to legislative change, but to an attitudinal shift in how we respond to individuals with mental health conditions. The review provides the opportunity to change outdated attitudes and to fully respect the rights of individuals with mental health conditions, benefiting the whole of society.\textsuperscript{269} However, the legislation will have a limited impact without the support of stakeholders charged with applying the law. Murray asserts that an effective rights-based model of mental health law includes: legislation; judicial interpretation and implementation by mental health services staff.\textsuperscript{270} She also highlights the need to monitor the legislation to ensure it is protecting rights and to educate those with responsibility for implementation.\textsuperscript{271} The interpretation of the law can be assisted by judicial and provider education on the legislation and human rights standards. Practitioners often lack the knowledge and training needed to support new legislation.

3.5. \textit{Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill)}

The introduction of a legal framework for ADs should also be viewed in the context of capacity law reform, due to the association with consent to treatment and recognition of the ‘will and preferences’ of the person. The 2013 Bill proposes to provide a modern statutory framework for those who may require assistance in making decisions and allows them to appoint appropriate support persons. The guiding principles of the 2013 Bill include a ‘presumption of capacity’ with due regard to the rights to dignity, bodily integrity, privacy and autonomy in respect to interventions for relevant persons.\textsuperscript{272} It proposes to provide greater autonomy and a continuum of supported decision-making agreements tailored to the person’s needs and circumstances and is viewed as a key step towards Irish ratification of the

\textsuperscript{271} Ibid.
\textsuperscript{272} Assisted Decision-Making (Capacity) Bill 2013, s 8(2) and (6)(b).
CRPD. The 2013 Bill emphasises the ‘will and preferences’ of the individual, rather than his or her ‘best interests’. The commitment to introduce CRPD compliant capacity legislation was included in the Programme for Government. The CRPD places an obligation on State Parties to replace substitute decision-making regimes with modern capacity legislation and supported decision-making alternatives. The development of supported decision-making systems, while retaining substitute decision-making is not sufficient for compliance. The 2013 Bill will reform the existing Ward of Court system and replace the Lunacy Regulation (Ireland) Act 1871, which currently governs the law on capacity in Ireland. The effects of wardship are ‘monumental’ and include total loss of decision-making authority without provision for review. The wardship system fails to take account of variations or changes in decision-making ability or the need for support to exercise capacity. The High Court heard 2,344 wardship cases in 2012 and 92 of these were due to mental health difficulties. A number of disability rights organisations and international bodies have pointed to the failure of the system to comply with human rights standards.

The 2013 Bill replaces the Scheme for the Mental Capacity Bill 2008, which provided for modified guardianship and was not considered compliant with Article 12 of the CRPD. The Minister for State attributed a great deal of the changes in the 2013 Bill to engagement with civil society groups. A number of seminars and conferences were undertaken by AI and the Centre for Disability Law and Policy at NUI Galway in relation to the legislation and consultations were undertaken with the experts by experience advisory group. The Oireachtas Justice Committee held a series of hearings in February 2012 to hear the views of relevant organisations and an advisor from the Office of the Council of Europe Commissioner for Human Rights.

274 Ibid.
275 Lunacy Regulation (Ireland) Act 1871, and Orders 65 and 67 of the Rules of the Superior Courts 1986 provide for an order making a person a ward of court.
276 Mental Disability Advocacy Center (MDAC), Legal Capacity in Europe: A Call to Action to Governments and the EU (MDAC 2013) 21.
277 Department of Justice, Equality and Law Reform, Scheme of Mental Capacity Bill 2008.
Rights. The advisor commented on the enormous will in the Irish parliament to enact capacity legislation in accordance with international best practice.\textsuperscript{279} The Commissioner has recommended that all member states ratify the CRPD and examine current legislation to ensure it is compliant and ensure persons with disabilities enjoy the right to accept or reject medical interventions.\textsuperscript{280} According to the Commissioner, the majority of European legal capacity systems are outdated and in urgent need of reform.\textsuperscript{281}

The draft legislative provisions for ADs incorporate mental health treatment decisions.\textsuperscript{282} However, differential standards are proposed for treatment decisions under the 2001 Act. The draft legislation proposes to provide non-legally binding ADs, which will be taken into consideration during involuntary detention.\textsuperscript{283} While non-legally binding ADs with accountability mechanisms are ethically valuable, the use of differential standards for mental health and general healthcare directives reinforces the notion that the rights of individuals with mental health conditions are not respected on an equal basis with others. The integration of ADs for mental health decisions in the legislative framework on an equal basis with other treatment decisions is important symbolically in reducing stigma and discrimination. The CRPD requires equal recognition before the law and respect for the legal capacity of all persons implying that ADs should be equally available to everyone, including those detained under mental health legislation. State Parties should ensure that decisions that involve a person’s physical or mental integrity can only be taken with the free and informed consent of the person.\textsuperscript{284} Legislative provisions that allow or perpetuate forced treatment must, therefore, be abolished.\textsuperscript{285} ADs can facilitate free and informed consent during periods when the person is able to articulate their choices minimising the need for involuntary treatment. The 2001 Act will have to be amended to ensure ADs are enforceable for treatment under Part 4 of the Act. Some

\textsuperscript{279} Lorcan Roche, ‘Basic Right to have Rights’ April (2012) Law Society Gazette 18.
\textsuperscript{281} Ibid.
\textsuperscript{282} Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.’
\textsuperscript{283} Ibid Head 5(7).
\textsuperscript{285} Ibid.
groups have expressed concerns that the 2013 Bill is not CRPD compliant for individuals with mental health conditions.\textsuperscript{286} The interface between the provisions of the 2013 Bill and the 2001 Act are still unclear and will need to be clarified to ensure the capacity of individuals with mental health conditions are equally respected.

Human rights organisations and other civil society groups published a submission on issues arising in the 2013 Bill based on the principles for legal capacity law.\textsuperscript{287} The submission recommends reform of the functional test to comply with CRPD standards.\textsuperscript{288} The 2013 Bill includes a definition of ‘capacity’ and ‘lack of capacity’, based on the functional approach, which suggests mental capacity is a precondition for making legally binding agreements.\textsuperscript{289} The functional test of mental capacity can lead to denials of legal capacity and violate Article 12 if it disproportionately affects the rights of persons with disabilities to equality before the law.\textsuperscript{290} Flynn suggests the legislation could be improved significantly from a human rights perspective if it were open to all, and did not require mental capacity as a precondition for legal capacity.\textsuperscript{291}

While the 2013 Bill introduces supported decision-making, it still retains certain forms of substitute decision-making. The decisions of court appointed decision-making representatives and co-decision-makers may constitute substitute decision-making, where decision-makers are not chosen by the person or decisions are not made in accordance with the person’s ‘will and preferences’. Co-decision makers are


\textsuperscript{288} Mental capacity, or decision-making ability, assesses people’s ability to make decisions based on their ability to understand and retain information, and to use it in reaching a decision.

\textsuperscript{289} Capacity is defined as the ability to understand the nature and consequences of a decision to be made by the person in the context of available choices at the time the decision has to be made. Assisted Decision-Making (Capacity) Bill 2013 s 3(1) and s 3(2).


only required to support the person’s decision where a reasonable person would have made the decision and no harm is likely to the person or other persons.292 This is of particular concern in mental health where the perceived rationality of the decision is often used to deny legal capacity.293 Flynn asserts that, “we all have different levels of decision-making ability, based on a multiplicity of factors, but for most of us, our decision-making is never legally questioned, even where it is irrational or unwise.”294 Other areas of concern include the legal status of daily decisions made by informal decision-makers without safeguards.295 The challenge is to break the link between mental and legal capacity in the legislation, and the presumption that a person has less decision-making capacity because they have a disability.296

Supported decision-making requires the provision of various support options, which give primacy to the person’s ‘will and preferences’. While the general principles of the 2013 Bill require that decision-makers give effect to the ‘will and preferences’ of the person, as far as possible, the provisions must be accompanied by appropriate support measures such as ADs to enable the person to exercise legal capacity. The draft scheme for ADs proposes that the terms of the directive and any appointed decision-making representative will take precedence over other decision-makers and any treatment under the jurisdiction of the High Court.297

3.5.1. Enduring Power of Attorney Legislation
An enduring power of attorney (EPA) enables a capable person to delegate decision-making power to an appointed person in the event of incapacity in the future and is sometimes used as a form of AD. Some individuals may prefer to use the EPA due to the formalities and safeguards associated with the preparation, registration and activation than nominate a proxy decision-maker through an AD. These formalities

292 Ibid.
297 Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 6(2). The High Court has jurisdiction over matters relating to non-therapeutic sterilisation, the withdrawal of life sustaining treatment and organ donation under s 4(2) of the 2013 Bill.
may also act as barriers to executing an EPA. The Power of Attorney Act 1996 is currently the only mechanism in Irish law, which allows a person to plan for periods when capacity may be impaired. The 1996 Act reflects a global approach to capacity, by enabling a competent person to delegate decision-making power to another person in relation to property, financial and limited personal care decisions in anticipation of future incapacity, but excludes healthcare decisions.298 The uptake for power of attorney has been extremely low in Ireland due to lack of public awareness and the exclusion of healthcare decisions.299

The 2013 Bill proposes to allow individuals to create an EPA for healthcare decisions, where they lack or will shortly lack capacity to make decisions.300 The principles of the 2013 Bill requires that all decisions give effect to the past and present ‘will and preferences’ and take account of the person’s ‘beliefs and values’.301 The attorney can consent to or refuse treatment on behalf of the person.302

The draft legislation for ADs further expands on the EPA provisions stating that the attorney can make personal welfare decisions regarding all forms of treatment including life-sustaining treatment.303 The proposed legislation will allow a donor to apply restrictions on the decision-making powers of the attorney304 and the appointment of one or more attorneys for different decisions.305 The draft scheme also clarifies the mechanism by which disagreements between an individual’s EPA and AD can be resolved, stating that the more recent of the two instruments should take precedence.306 Disagreements between the decision-making representative and the donor, which cannot be resolved between the parties, will be made by the High Court.307 An attorney cannot restrain a donor unless he or she reasonably believes it

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298 Two types of power of attorney are allowed under Irish law. Power of attorney which gives either a specific or a general power and ceases as soon as the donor becomes incapable. Enduring power of attorney which takes effect on the incapacity of the donor.
299 489 enduring powers of attorney were registered in the High Court in 2012, compared to 168 in 2006. The Courts Service, Courts Service Annual Report 2012, Court Statistics (Courts Service, 2012) 47.
300 Assisted Decision-Making (Capacity) Bill 2013 s 40.
301 Ibid s 8(7)(b) and s 8 (7)(c)(i).
304 Assisted Decision-Making (Capacity) Bill 2013, s 41(3).
305 Assisted Decision-Making (Capacity) Bill 2013. s 40(5).
306 Head 8 (2)(a).
307 Head 8 (2)(b).
is necessary to prevent harm to the donor or another person and it is proportionate. The donor can only revoke the enduring power of attorney if he or she has the capacity to do so and this may require a statement from a legal or medical practitioner. The 2013 Bill may also require a medical practitioner to certify capacity at registration. While the attorney must give effect to the ‘presumption of capacity’ and other principles, the requirement for a capacity assessment at execution, the formality of the process and the total loss of decision-making power create significant barriers and are not in compliance with the CRPD provisions. The person should be able to specify when the EPA should take effect and a lower threshold is needed to revoke it. The CRPD also requires that financial resources are not a barrier to accessing support to exercise legal capacity.


The Irish mental health system has been characterised by a culture of control and lack of respect for individual preference. Significant progress has been achieved in recent decades, but further legislative and cultural changes are still needed. Many people still have difficulty getting their voice heard in the mental health system and are not given choice in their treatment. Others feel marginalised and have little meaningful say in their care. The failure to comply with consent to treatment requirements is particularly problematic and illustrates the need for legally binding ADs to protect against unwanted mental health treatment. Furthermore, the case law highlights continued paternalism in the Irish courts in relation to individuals with mental health conditions and their right to make decisions. The introduction of a strong legal framework for ADs can enhance the autonomy and dignity of the individual in mental health treatment. The Irish legal and policy framework supports

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308 Assisted Decision-Making (Capacity) Bill 2013 s 41(4)(b) and (c). The provisions also refer to the interface with s 69 of the Mental Health Act 2001, stating that the section shall not constrain the operation of rules made under it. Assisted Decision-Making (Capacity) Bill 2013 s 41(7).
309 Assisted Decision-Making (Capacity) Bill 2013, s 50(1) and s.50 (2)(d)(ii)(iii).
310 Assisted Decision-Making (Capacity) Bill 2013, s 45(4).
311 Article 12.
312 Assisted Decision-Making (Capacity) Bill 2013, s 49(4).
314 Orla Barry, Director of Mental Health Law Reform, ‘Mental Health Services need Long-Overdue Cultural and Structural Revamp’ Opinion: Progress in Implementing 2006 Reform Plan has been Painfully Slow, Irish Times (Dublin 17 May 2013).
the introduction of ADs and recent case law suggests that advance decisions for mental health treatment may be respected by the Irish courts, but a clear statutory framework is needed to provide certainty.

The 2013 Bill provides an appropriate location for ADs, but consideration must be given to the interface with mental health legislation. The exceptions proposed for treatment under the 2001 Act in the draft legislation for ADs perpetuates stigma and limits their use in mental health settings. The provisions for legally binding ADs should apply equally to all mental health treatment decisions. The integration of mental health ADs with general legislation means they should operate in the same way as other directives, subject to defined life-threatening emergencies and involuntary admission to hospital.316 AD treatment decisions should be enforceable during any periods of involuntary detention. The 2001 Act should be amended to reflect the principles of the 2013 Bill and to ensure respect for AD treatment preferences during involuntary detention. The CRPD requires respect for legal capacity and the ‘will and preferences’ of all persons, implying that ADs should be available to everyone, including those detained under mental health legislation.317

5. The Implementation of ADs in the Irish Mental Health System
In addition to an examination of the legal and policy framework, the introduction of ADs requires consideration of the system and cultural context in which they will operate. The law has to be effectively implemented into practice for rights to be protected.318 Once ADs are enshrined into legislation, considerable attention must be given to implementation. The transition from law into practice poses a myriad of challenges. The level of service user participation in the mental health system, the views of stakeholders and the implementation of the recovery approach will be examined to assess the structural and cultural context in which ADs will operate. This will help inform the introduction of an appropriate legislative framework and implementation strategy.

5.1. Participation in Healthcare

ADs arose in the context of service user participation in treatment decisions. Participation has become a key element of the healthcare strategies of many countries since the Alma-Ata Declaration by the WHO in 1978, which states that “people have a right and duty to participate individually and collectively in the planning and implementation of their healthcare.”[^319] The literature identifies a range of benefits from participation including: improved health and treatment outcomes; more appropriate and relevant services; enhanced sense of dignity and self-worth; increased satisfaction; improvement in staff and service user morale and cultural change in the health system.[^320] The empirical studies suggest service user centred approaches require time; information and training; improved interpersonal communication; mutual understanding and trust.[^321] Participation involves clinicians and service users becoming aware of each other’s perspectives and developing enhanced communication and respect.[^322] The perceived opportunity to participate can be the most important feature for service users.[^323]

5.1.1. Service User Involvement in the Irish Health Services

Service user participation in healthcare has been traditionally low in Ireland. A 2006 report concluded that the consultation processes in health and social services were relatively ad-hoc and underdeveloped.[^324] In a review of service user involvement in the Irish Health Service, McEvoy and others observed that “whilst it is certain that

[^322]: Mary Draper, ‘Involving Consumers in Improving Hospital Care: Lessons from Australian Hospitals’ (Department of Health and Family Services 1997).
service user involvement is gaining momentum in Ireland, it lacks a strategic approach.\textsuperscript{325} The importance of participation has been a recurring theme in a number of Irish health policy documents\textsuperscript{326} culminating in the ‘National Service User Involvement Strategy’ in 2008.\textsuperscript{327} The aim of the strategy was to ensure a systematic and consistent approach to service user involvement across health and social services. The Health Act 2004\textsuperscript{328} also provided for the establishment of the National Consultative Forum, Regional Health Fora and Advisory Panels and a National Complaints Mechanism.\textsuperscript{329} The national mental health policy strategy ‘A Vision of Change’ states that “involvement of service users and their carers should be a feature of every aspect of service development and delivery.”\textsuperscript{330} McEvoy and others proposed a number of elements for service user involvement in the Irish health services including making participation a key element of person-centred care; management commitment; open meaningful dialogue; trust and mutual respect; clear communication; appropriate supports; information and training; and accurate and timely feedback.\textsuperscript{331} The provision of information in an appropriate format, within a culture and climate where people are free to speak openly and honestly without fear of reprisal is also critical. An overview with Irish mental health service users and carers found they were reluctant to make complaints about staff because of fear of reprisal, lengthening of detention or being adversely affected in future treatment.\textsuperscript{332} The lessons learnt from service user participation initiatives must be disseminated across the health services to identify the critical success factors.\textsuperscript{333}

\textsuperscript{325} Rachel McEvoy, Celia Keenaghan, Aveen Murray, \textit{Service User Involvement in the Irish Health Service} (Department of Health and Children 2008).
\textsuperscript{327} Department of Health and Children, Health Service Executive, \textit{National Strategy for Service User Involvement in the Irish Health Service} (Department of Health and Children 2008).
\textsuperscript{328} Health Act 2004, Part 43.
\textsuperscript{331} Rachel McEvoy, Celia Keenaghan, Aveen Murray, \textit{Service User Involvement in the Irish Health Service} (Department of Health and Children 2008).
5.1.2. Service User Participation in the Irish Mental Health Services

The issue of participation warrants increased attention in mental health care. The power to curtail liberty and to treat individuals against their wishes poses significant barriers to participation. The threat of coercion can be used to limit autonomous choice. Lewis observes how the experience of using mental health services and the threat of involuntary detention creates a culture of fear and domination. Some voluntary patients in Ireland claim that they have been told their status will be changed to involuntary if they do not comply with mental health treatment. This issue was highlighted in a recent Irish case, where a voluntary patient had her status changed to involuntary because she was refusing treatment. The threat of coercion can deter individuals from seeking mental health treatment. The concept of participation is relatively new in the Irish mental health services and is being incorporated into the official discourse in conjunction with recovery. One of the strategic priorities of the Mental Health Commission is to involve service users and their families in all aspects of care and to promote user centred and recovery oriented services. The Commission has been involved in a number of initiatives to increase participation. The ‘Quality Framework for Mental Health Services in Ireland’ promotes service user involvement in care and treatment through the provision of information. The national mental health policy ‘A Vision for Change’ explicitly promotes participation and the adoption of ‘a person-centred treatment approach’. Although service user participation is increasing in Ireland, many individuals are still not involved in mental health decisions. Several reports have identified concern in relation to the low level of service-user participation and compliance with individual

337 KC v Clinical Director of St. Loman’s Hospital [2013] IEHC 310.
The importance of being involved in the decision-making process and having a choice was highlighted by a number of participants in a qualitative study with involuntary patients.\(^{343}\)

Service user participation is often at the discretion of individual mental health services.\(^{345}\) Participants in the Irish system cited the gatekeeping power of professionals to prevent service user participation and to dictate the issues that can be discussed.\(^{346}\) Brosnan contends that service user involvement highlights the hidden and invisible aspects of power in the Irish mental health system.\(^{347}\) Critics argue that without addressing these imbalances, service user involvement may simply be a way for decision-makers to legitimise their decisions.\(^{348}\) The Brosnan study showed power imbalances posed significant challenges to participation in the Irish system.\(^{349}\) Fundamentally, service users wanted to be involved in the therapeutic relationship and to have more treatment choice. One participant was angry about how individuals can be left dependent because choice and volition is removed from their lives stating that “something is deadened inside.”\(^{350}\) Another participant believed recovery and participation were interdependent and choice should include meaningful involvement. A significant theme in the study was the importance of empowering people to speak for themselves, to know their rights and

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\(^{347}\) Ibid.


\(^{350}\) Ibid 48.
take control of their lives. Despite the obstacles, service users were optimistic about
the participatory approaches being developed by some Irish mental health teams.351
Participants acknowledged the difficulties in changing a system which has been
steeped in institutional approaches to working for over a hundred years. One
participant stated that for some professionals “… it’s such an integral part of their
mind set that it’s virtually impossible to change.”352 Service user involvement was
considered to have the potential to transform the way the Irish mental health services
deliver care. One peer advocate participant in the Brosnan study surmised:

“I think the more the service-user is empowered, the more changes will happen ... 
sometimes they’re very small changes … but they will ripple out, a bit like
Armstrong on the moon, one small step for man.”353

Participation can help address the inequalities that have been traditionally endemic in
the Irish mental health system.354 ADs can facilitate empowerment, communication
and address power imbalances in clinical relationships.355 The measure has a critical
role in the transition to a more participative approach. The mental health services
need to provide meaningful participation through a range of measures based on
listening, respectful relationships and therapeutic supports. The implementation of
ADs can strengthen the framework for service user participation and assist the
cultural shift towards respect for preferences in the Irish mental health services.

5.1.3. Participation in Individual Care Plans
Individual care plans are a key mechanism by which the person’s treatment and care
goals are documented and developed.356 These plans are distinctive from ADs in that

351 Ibid 45.
352 Ibid 45, 60.
353 Ibid 45, 61.
354 Damien Brennan, ‘The Rise and Fall of Irish Asylum Utilisation: A Theoretical Exploration’ in
Pauline Prior (ed) Asylums, Mental Health Care and the Irish: Historical studies 1800-2010 (Irish
Academic Press 2012); Abbey Hyde, Maria Lohan and Orla McDonnell, Sociology for Health
Professionals in Ireland (Institute of Public Administration 2004); Lydia Sapouna, ‘Tracing Evidence
of Institutionalisation in the Process of De-institutionalisation: the Irish Case’ in Lydia Sapouna and
Peter Herrmann (eds) Knowledge in Mental Health:Reclaiming the Social (Nova Science 2006) 85-
99.
355 Penelope Weller, New Law and Ethics in Mental Health Advance Directives: The Convention on
the Rights of Persons with Disabilities and the Right to Choose (Routledge 2013) 148.
356 Mental Health Commission Ireland, Guidance Document on Individual Care Planning Mental
Health Services (Mental Health Commission 2012) 8. An individual care plan means a documented
they are not legally binding and may not involve the person. The Mental Health Commission emphasises the importance of individual care planning asserting that the essential dignity, autonomy and right to self-fulfilment of the individual is enshrined most strongly in this area. The regulations of the 2001 Act require an individual care plan for each resident. This should be completed by the multidisciplinary team in consultation with the service user. According to the regulations, it is here that the service user participates in planning his own treatment, which takes into account personality, cultural context, family, preferences, aspirations and desires. The Irish mental health policy, ‘A Vision for Change’, advocates consultation with service users and carers and states that the care plan should be written and agreed between all parties. The Independent Monitoring Group (IMG) stated that promoting best practice in care planning is one of the critical factors in shifting services towards a recovery-oriented approach. The Inspector of Mental Health Services states that if the plan was viewed in this context, the attitude that they are a ‘paperwork nuisance’ might be less prevalent. The Inspector states that the onus is on the individual members of the care team to advocate for human rights by insisting on an individual care plan. The Commission developed a guidance document to assist the development of individual care plans in 2012. The document was developed on foot of the National Mental

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359 Mental Health Act 2001 (Approved Centres) Regulations 2006, Article 15 of Statutory Instrument No 551.
360 Ibid, Article 16 of Statutory Instrument No 551.
365 Ibid.
Health Services Collaborative (NMHSC) evaluation, which was designed to facilitate the implementation of person-centred care plans to support recovery.\textsuperscript{367}

Successive reports have found low compliance with individual care plans despite the legal requirements.\textsuperscript{368} The Inspector of Mental Health Services was dismayed to find several examples of inadequate and non-existent care plans in 2012.\textsuperscript{369} In the National Inpatient survey, 30 per cent of service users indicated they did not have a care plan, while 15 per cent could not remember.\textsuperscript{370} Similarly, the National Service User Executive survey (NSUE) found one-third of service users were not involved or did not know what care plans were.\textsuperscript{371} Individual care plans were viewed as tokenistic in some services and were often developed by staff without any involvement of the person.\textsuperscript{372} A survey by the Inspectorate found 43 per cent of service users were not involved in the plan and 70 per cent did not receive a copy.\textsuperscript{373} Over a third of service users felt that care plans were not dealing with their needs.\textsuperscript{374}

The failure of many providers to ‘buy in’ to the concept of patient-centred care and the need for a cultural shift has been highlighted in several reports.\textsuperscript{375} Some consultants did not understand the legal requirements or were unaware of the human rights commitment of the State, while others were unwilling to change current practice.\textsuperscript{376} A 2009 report on end-of-life decisions found that the concept of patient

\textsuperscript{367} Mental Health Strategies, \textit{Final Report of an Independent Evaluation of the National Mental Health Services Collaborative on Individual Care Planning} (Mental Health Strategies 2011).

\textsuperscript{368} It is an offence not to comply with the regulations. Only half of mental health services were fully complying with their obligations in relation to individual care plans in 2012. Mental Health Commission, \textit{Annual Report 2012 including Report of the Inspector of Mental Health Services} (Mental Health Commission 2012) 25.


\textsuperscript{370} Mental Health Commission, \textit{Your Views of Mental Health Inpatient Services: Inpatient Survey 2011} (Mental Health Commission 2012).


\textsuperscript{372} Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2011’ (Mental Health Commission 2012).

\textsuperscript{373} Ibid.

\textsuperscript{374} Ibid.


\textsuperscript{377} Ibid.
autonomy is not well understood by many Irish health professionals.\textsuperscript{378} A gradual shift was reported in pockets of the mental health services in 2011, when there was an improvement in compliance with care planning.\textsuperscript{379} However, compliance decreased in 2012 and stagnation was reported in parts of the mental health services.\textsuperscript{380} The absence of proper care planning was considered by the Inspectorate to be symptomatic of the failure to embrace the philosophical underpinning of a modern mental health service.\textsuperscript{381}

Some providers believed there was little incentive to comply with the regulations in relation to care plans due to lack of sanctions and sought a firmer approach.\textsuperscript{382} The Inspectorate wrote to individual consultant psychiatrists who failed to comply with the requirements for individual care plans in 2012.\textsuperscript{383} Service user representatives felt professional bodies should have a role in directing providers in this area.\textsuperscript{384} The discussion of care plans at a time appropriate to the person was also considered critical.\textsuperscript{385} Some service users recommended input from the multidisciplinary team and the full involvement of the person, allowing time and space for decisions and the development of an aftercare plan.\textsuperscript{386} The development of a care plan also provides an opportune time to introduce ADs. The NMHSC evaluation found that lack of time; insufficient ‘buy-in’ from key team members; weak senior management support and limited national clinical leadership was hindering the implementation of individual

\textsuperscript{378} Conor Quinlan and C O’Neill, ‘Practitioners’ Perspective on Patient Autonomy at the End-of-Life’ (Irish Hospice Foundation, 2009).
\textsuperscript{379} 61.9 per cent or 39 of the 63 approved centres were reported to be in full compliance with individual care planning in 2011. Mental Health Commission, \textit{Mental Health Commission Annual Report including the Report of the Inspector of Mental Health Services 2011} (Mental Health Commission 2012) 91.
\textsuperscript{380} The compliance rate was 62% in 2011, but decreased to 52% in 2012. Mental Health Commission, \textit{Annual Report 2012 including Report of the Inspector of Mental Health Services} (Mental Health Commission 2012) 25, 54, 57.
\textsuperscript{382} It is an offence not to comply with the care plan but it appears that this is not enforced. Mental Health Strategies, \textit{Final Report of an Independent Evaluation of the National Mental Health Services Collaborative on Individual Care Planning} (Mental Health Strategies 2011).
\textsuperscript{384} Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2011’ (Mental Health Commission 2012).
\textsuperscript{385} Ibid.
\textsuperscript{386} Amnesty International Ireland, \textit{A Citizens’ Jury on Legal Capacity Law} (Amnesty International Ireland 2012).
care planning at local level. However, almost all team members were positive about care planning and felt it had improved communication and collaboration. Some service users felt it had helped them cope with their illness and recovery. In a recent national overview, some service user representatives believed individual care planning had improved in many areas.

The difficulties surrounding the use of individual care planning highlight some of the barriers that may arise in relation to AD implementation. The NMHSC evaluation demonstrated the difficulty in changing current practice. However, ADs can strengthen the legal framework for meaningful service user participation and assist the implementation of individual care plans. Some consultant psychiatrists referred to the potential benefit of ADs in implementing care plans in the empirical study (in chapter 6). The majority of service users who had been involuntarily detained were interested in including an AD in their care plan in a previous Irish study. The value of incorporating ADs with care plans was also referred to in a qualitative study with Irish mental health nurses. The provision of appropriate education and training; information champions; compliance mechanisms and clinical leadership from professional bodies will be critical for effectively implementing ADs into practice. ADs can form part of a wider comprehensive framework for advance care planning and participation in the Irish mental health services.

6. Service User Views on the Irish Mental Health Services

The views of Irish service users on their experience of mental health services have been addressed in a number of empirical studies. The National Inpatient Survey commissioned by the Mental Health Commission in 2011 represents the first large

in-depth nationwide survey of service users’ views of inpatient services in Ireland. Participation emerged as a key priority, indicating a need for greater focus on participative measures to increase service satisfaction. Although over three-quarters of service users believed they were involved in decisions about the care and treatment, almost one quarter desired more involvement in the process. Other priorities included person-centred care, communication and provider competencies. In a recent overview by the Inspectorate of Mental Health Services, some service users reported that attitudes were slowly evolving towards a partnership approach. The Dunne report commissioned by the Mental Health Commission in 2006 explored the views of 37 adult service users of public mental health services. The report found communication between service users and psychiatrists to be unsatisfactory; a lack of continuity of care; overreliance on medication; lack of choice; and a traumatic involuntary admission process. It recommended that choice be introduced into Irish mental health services, including choice of therapy and key workers. The consistent message still being communicated by service users in 2013 is the need to be listened to, have a consistent trusting relationship with a professional and to be offered medication alternatives. The importance of a trusting therapeutic relationship is a key theme throughout the research.

6.1. Communication and Listening in the Therapeutic Relationship

The issue of communication between service users and mental health professionals is a key theme in the Irish literature. A national overview with service users, carer and advocacy representatives identified the need for staff and managers to listen. Over a fifth of the 302 service users in the overview did not think the treatment team

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394 Ibid.


397 Ibid.

398 Orla Barry, Director of Mental Health Law Reform, ‘Mental Health Services need Long-Overdue Cultural and Structural Revamp Opinion: Progress in Implementing 2006 Reform Plan has been Painfully Slow’ *Irish Times* (Dublin 17 May 2013).

399 Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).
listened to them, while almost a third felt they did not have enough time with staff.\textsuperscript{400} The need for attitudinal change and on-going interpersonal skills training for staff was identified.\textsuperscript{401} The importance of communication and listening was also reiterated in a recent overview with service user representatives, advocates and carers.\textsuperscript{402} The findings of the Dunne report in 2006 found that treatment engagement between service users and clinicians was remote.\textsuperscript{403} Many service users felt that clinicians avoided discussion about the side effects of medication and were sometimes flippant. Although some service users felt this may be meant to protect them, the approach was viewed as paternalistic and unsatisfactory. The emphasis on medication resulted in consultations that focused on clinical symptoms rather than personal experience. Some service users communicated examples of clinicians making poor quality treatment decisions or not noticing side effects. A number of service user participants pointed out that the criticism was not directed at individual clinicians, but the system which had trained them and within which they worked.\textsuperscript{404} The therapeutic alliance between clinicians and service users is considered to be a key element of transforming practice. In a study with service users in the West of Ireland in 2002, doctors aroused more negative feelings among participants who did not feel listened to or acknowledged.\textsuperscript{405} In the Dunne study, some longer term users of mental health services believed there had been an improvement in the relationship between nursing staff and service users over the years, but others were viewed as disinterested and dismissive.\textsuperscript{406} The empirical literature in Ireland suggests that communication and listening skills should form a core part of the educational curriculum and continuing training for mental health professionals. The international research suggests that the current system of medical education could benefit by

\textsuperscript{400} Almost two-thirds felt listened to, while 10 per cent didn’t answer. Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).
\textsuperscript{401} Mental Health Commission Inspectorate, ‘National Overview of Service User, Family/Carer and Advocacy Involvement in Mental Health Services 2010’ (Mental Health Commission 2011).
\textsuperscript{402} Mental Health Commission Inspectorate, National Overview of Service User, Family/Carer, Advocacy Groups and Consumer Panels in Mental Health Services 2012 (Mental Health Commission 2013).
\textsuperscript{404} Ibid 164.
\textsuperscript{405} Liz Brosnan and others, Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective (Western Health Board 2002).
placing greater emphasis on communication and interpersonal skills. Mental health is distinct from other areas in that significant emphasis is placed on the therapeutic relationship to support recovery. Communication is, therefore, a key aspect of positive relationships. One participant in the Dunne study emphasised the importance of empathy and kindness in the therapeutic relationship:

“They don’t seem to have any kind of feeling for people at all … I mean really and truly a bit of kindness goes a long way and that’s all people need.”

The relationship between service users and staff determines how individuals engage with services. The need for respectful, empathetic relationships between service users and providers was emphasised in the National Inpatient Survey in 2011. The Dunne study recommended improving personal engagement with service users and realising the potential of the therapeutic relationship with mental health professionals. The value of the partnership approach was demonstrated by the high rating given to consultants who agreed medication in consultation with individuals. Some participants commented that participation increased trust and they had less fear of psychiatrists who adopted this approach.

“I found him [consultant] friendly and he wasn’t threatening … He was fair and I found him good-trustworthy like … I’ve built up a trust with my own psychiatrist. He is somebody that I can confide in and I do trust.”

The importance of giving the person a chance to talk about his/her concerns was also emphasised. Consultants who discussed the person’s life situation on an on-going basis.

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410 Liz Brosnan and others, Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective (Western Health Board 2002).
413 Ibid.
414 Ibid 59.
basis were given high satisfaction ratings. The report recommended that this become part of routine practice. The attitude of mental health professionals to recovery should not be underestimated. Participants in the Dunne study felt that professionals were inclined to emphasise the enduring nature of the condition and generate pessimism. A 2010 study on recovery also highlighted the domination of depersonalised and pessimistic attitudes over a person-centred approach in the Irish mental health services. The importance of listening, participation and the development of trust was highlighted. Service users pointed to the need for dialogue and support from professionals in designing recovery rather than being passive recipients of care. Coercion was perceived as traumatic and slowed down reconnection with life.

The studies clearly show the need for improved communication between service users and mental health professionals in the Irish mental health services. ADs can enhance communication by providing a forum for dialogue and the exchange of information, enhancing trust in the therapeutic relationship. Some commentators believe that the major benefit of ADs is that they force psychiatrists to listen to patients. In commenting on the opportunity to introduce mental health ADs in England and Wales, Exworthy stated that ADs are more than a reference to a person’s choices. The process of formulating an AD demands a dialogue between the individual and the mental health professional, which can be beneficial in its own right and have a wider effect on the therapeutic relationship and the person’s future ‘psychiatric career’.

415 Ibid 59.
416 Ibid 59.
419 Ibid 32.
421 Ibid 28.
424 Mental health ADs have been introduced in a limited form under the Mental Health Act 2007 in England and Wales, s 27.

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6.2. Continuity of Care

Continuity of care\textsuperscript{426} can impact on communication, treatment satisfaction and the therapeutic relationship. The lack of continuity of care in the Irish mental health system has been identified in a number of studies.\textsuperscript{427} The legal status of ADs may be more important in systems lacking continuity of care, due to the difficulty complying with treatment wishes. A recent overview with Irish service users found that six monthly rotations by non-consultant hospital doctors (NCHDs) were ineffective due to the fact that individuals had to establish a new relationship and repeat their treatment history on a continual basis.\textsuperscript{428} The national overview found that clinicians spent more time writing than actually speaking to the person.\textsuperscript{429} Moreover, some consultant psychiatrists reported that they could no longer rely on the quality of the Non-Consultant Hospital Doctors (NCHDs).\textsuperscript{430} In the Dunne report, one service user commented on the difficulty communicating or building a relationship due to a constant change in medical personnel:

"… the same doctor that you might build up … some kind of relationship with … they changed so often. I had this new doctor … and all he did was prescribe. He didn’t listen to me … just prescribed the same drugs that I was on before which were really causing me terrible trouble …"\textsuperscript{431}

The Dunne study found that the Irish mental health system was not conducive to developing therapeutic relationships.\textsuperscript{432} The study recommended changing the structure of outpatient clinics so there is continuity of care and sufficient time for discussion.\textsuperscript{433} Communication between the service user and the treating psychiatrist

\textsuperscript{426} Continuity of care is a model of care in which the same doctor serves as advisor, advocate, and friend as the patient moves through the various stages of medical care \<http://www.medilexicon.com/medicaldictionary.php?t=14539> [accessed 13 January 2014].

\textsuperscript{427} Elizabeth Dunne, Report of a Survey for the Mental Health Commission, \textit{The Views of Adult Service Users of Public Mental Health Services} (Mental Health Commission 2006); Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).

\textsuperscript{428} Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).

\textsuperscript{429} Ibid.


\textsuperscript{432} Ibid.

\textsuperscript{433} Ibid.
is undermined in the absence of a therapeutic relationship. This was reflected in a 2002 study in the West of Ireland, which found that nearly half of service users found it difficult to talk to their doctor about important issues.\textsuperscript{434} In order to facilitate open honest discussion, an environment of understanding and trust needs to be created. Service users need continuity of care to build a relationship of trust with treating professionals.\textsuperscript{435} ADs are posited to improve continuity of care by providing information on the person’s preferences and treatment history and a forum for communication.\textsuperscript{436}

6.3. Medication Use in Ireland
The Mental Health Commission identified medication as an important area of governance, which has not been sufficiently audited.\textsuperscript{437} Recent overviews with service user, carer and advocacy representatives highlighted concerns with over reliance on medication and the need for alternative therapies.\textsuperscript{438} In a survey of 302 inpatients, 42 per cent of service users stated that interventions other than medications were not discussed and 49 per cent were not given any information about side effects.\textsuperscript{439} The survey highlights the continued lack of information available to mental health service users. In 2008 and 2010, the Inspectorate of Mental Health Services\textsuperscript{440} expressed concern over the high use of sedatives and called for an ‘urgent review’ of prescribing practices. A review of prescribing practices in supervised community residences in 2011 also revealed high use of antipsychotic medication, with almost half of residents, being prescribed more than

\textsuperscript{434} Liz Brosnan and others, \textit{Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective} (Western Health Board 2002).
\textsuperscript{435} Ibid.
\textsuperscript{436} Jeffrey Swanson and others, ‘Psychiatric Advance Directives: An Alternative to Coercive Treatment’ (2000) 63 (2) Psychiatry 160.
\textsuperscript{439} Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2011’ (Mental Health Commission 2012).
\textsuperscript{440} Of the 22 hospitals or facilities visited, inspectors expressed concern over sedative use or called for an audit of drug use in half of the centres. Mental Health Commission, ‘Mental Health Services 2010, Medication’ (Mental Health Commission 2010).
one antipsychotic medication.\footnote{Twenty five per cent of residents were prescribed a long acting antipsychotic medication (a depot). Mental Health Commission, ‘Prescribing Practices in 24-Hour Supervised Community Residences’ (Mental Health Commission 2011).} The finding raises issues around the use of medication to control individuals in the community. The rate (34%) was significantly higher than that found in two inpatient surveys in the U.K. (20% to 25%), and was contrary to the recommendations of the Royal College of Psychiatrists.\footnote{Alcuin Wilkie and others, ‘High Dose Neuroleptics-Who gives them and Why?’ (2001) 25 The Psychiatrist 179; Consensus statement on high-dose antipsychotic medication, CR138, Royal College of Psychiatrists.} An audit on the use of benzodiazepines and hypnotics in the Carlow/Kilkenny Mental Health Services showed a 10 per cent decrease in usage when a multidisciplinary approach was used over a short period.\footnote{Audit on Use of Benzodiazepines and Hypnotics in Rehabilitation Psychiatry of the Carlow/Kilkenny Mental Health Services, August 2009-August 2011.}

The provision of alternatives to medication was ranked the highest priority by service users on the AI citizen jury consultation on capacity law.\footnote{Amnesty International Ireland (AI) convened a citizen’s jury to facilitate the involvement of individuals with mental health conditions in the introduction of new capacity law in early summer 2012.} The jury participants reiterated the need for choice and the right to refuse treatment based on up-to-date information on risk and side effects. The participants unanimously agreed on the right to refuse ECT treatment.\footnote{Amnesty International Ireland (AI), A Citizens’ Jury on Legal Capacity Law (Amnesty International Ireland 2012).} The provision of training and investment in alternative supports may help resolve over-reliance on medication in the mental health system.\footnote{Carl O’Brien, ‘Inspectors Seek Review of High Use of Sedatives in Mental Units’ Irish Times (Dublin 4 January 2011).} The communication of treatment preferences through ADs is pertinent given the high use of medication in the Irish mental health services and the adverse side effects. The use of ADs can decrease the use of medication by allowing service users to specify alternative treatments ‘that work’ and assist the identification of recovery strategies.

7. Views on Advance Directives in Ireland to Date

7.1. Service User Views

While the issue of ADs has not been addressed in any detail with Irish stakeholders prior to the empirical study (in chapter 6), views expressed in the context of other exploratory studies have shown strong support for ADs. The few empirical studies to
date have been qualitative in focus and conducted with small samples in specific settings. An exploratory study by Amnesty International Ireland (AI) on decision-making capacity in mental health in 2009 found a strong consensus in favour of ADs among eight service users. Participants expressed a preference to set out treatment choices in advance and the opportunity to state ‘what works’. The participants expressed a clear preference for legally binding directives. Individuals who were familiar with effective treatment strategies had particular concerns in relation to being given new treatment without their consent. Participants also wanted to be able set out life management choices so their preferences could be protected during crisis periods.

The issue of ADs was also briefly addressed in a study on the views of 67 involuntary patients towards compulsory treatment orders and ADs in a Dublin hospital one year following discharge. The results showed that 84 per cent of participants were interested in having an AD in their individual care plan. Only 8 per cent of the participants were aware of ADs and all of these stated they already had such an agreement with their consultant psychiatrist. The results of both exploratory studies indicated strong support for ADs among service users. The empirical study in this thesis with a national sample of 111 service users shows a high level of support for ADs (in chapter 6). Ireland lacks any research with consultant psychiatrists on the issue of ADs. The empirical study (in chapter 6) with consultant psychiatrists will, therefore, provide a unique contribution to knowledge.

7.2 Amnesty International Ireland (AI) Citizen Jury: Service User Views
AI convened a citizen jury to facilitate the involvement of individuals with self-experience in the introduction of new capacity law in 2012. The jury consisted

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447 This was a small-scale qualitative study with eight service users exploring views on decision-making capacity in mental health. Participants were asked two questions on advance directives. Amnesty International, Decision-making Capacity in Mental Health: Exploratory Research into the Views of People with Personal Experience (Amnesty International 2009) 50.
449 Ibid.
450 Individuals with personal experience of mental distress.
451 A citizen’s jury consists of a small panel of non-specialists, modelled on the structure of a criminal jury. The jury examines an issue of public significance and on the final day delivers a verdict based
of 16 service users and three practitioners who met to make recommendations on capacity and mental health legislation in Ireland. The report was presented to the relevant government ministers involved in drawing up capacity legislation. The citizens’ jury report provided legislators with an opportunity to consider the voice of ‘experts by experience’. The discussions included a wide range of opinions on topics concerning legal capacity and mental health.

Mental health decision-making was a common theme throughout the discussions. The jury recommended providing for the legal recognition of ADs and other supported decision-making measures to ensure the rights of the person are respected. All of the jurors reported situations where decisions regarding their capacity and treatment were taken primarily by the treating psychiatrist. The majority of jurors were opposed to the idea of another person deciding their ‘best interests’. This approach was considered overly paternalistic and subjective. The participants stated that decision-making should be supported, not substituted and appropriate supports should be provided in the law. The importance of treating individuals equally and with dignity and respect was emphasised. The jurors believed ADs could play an important role in treatment decisions during crisis periods. Some jurors felt they could depend on family members to make decisions, while others felt there should be provision for independent advocates or other support persons. A significant proportion of service users lacked a trusted person to communicate in the empirical study (in chapter 6). One juror raised the point that a person may be co-opted into expressing certain wishes so vulnerability should be taken into account.

7.3. Mental Health Nurses’ Views on Advance Directives
The views of seven Irish mental health nurses were explored in a qualitative study in one setting in 2012.\textsuperscript{452} The study found a high level of support for ADs and no ambivalence towards their use. Familiarity with ADs was low, but the most of the nurses had some awareness of the measure. Participants identified the need for more knowledge. ADs were perceived to be beneficial to both the therapeutic relationship

\footnotesize{\textsuperscript{452} The research of the author helped inform this study. Conor Quinlan, ‘Mental Health Nurses Perspectives on Advance Directives’ MSc Minor Thesis in Nursing Studies (University College Cork 2012).
and user autonomy. All of the nurse participants were positive about the increased involvement of service users in their care and recognised the need for dialogue and support with professionals.\textsuperscript{453} The participants pointed to the need for a person-centred approach with a focus on choice rather than control. One participant highlighted the need to move to a recovery ethos that includes ‘experts by training’ (staff) and ‘experts by experience’ (service users). ADs were viewed as a mechanism whereby the service user could become the ‘expert’ and assist the ‘paradigm shift’ towards user centred services. The need for education and support were identified. The perceived benefits for mental health professionals included increased transparency and direction, improved therapeutic relationships and a recovery-oriented approach. ADs were perceived to be a key driver in the transition to person-centred services promoting a better working relationship between the service user and mental health professional.\textsuperscript{454}

A number of concerns were also identified in the study. The participants strongly believed that the person should be ‘stable’ when completing the AD. In a previous Irish report, respondents had a clear sense of their preferences despite being unwell.\textsuperscript{455} Other participants referred to the difficulty reflecting on past experience. Some participants had concerns around family interference in decisions and believed they may not be appropriate decision-makers. Others suggested that the attitudes of staff and professionals may hinder AD implementation. The risk of service users being unduly influenced by mental health professionals or other parties was identified. The uncertainty around the legal status of ADs in Ireland was also perceived to be a barrier. All the participants supported a strong legal basis for ADs to protect service users and professionals. One participant contended that implementation may be difficult without education, a legislative framework or system communication and the inclusion of ADs in job descriptions and policy. Other potential barriers included resistance to change, staff and service user reluctance and the cultural backgrounds of professionals. Another participant believed provision for review should be included in the legislation in view of the

\textsuperscript{453} Ibid.
\textsuperscript{454} Ibid.
\textsuperscript{455} Liz Brosnan and others, \textit{Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective} (Western Health Board 2002).
high readmission rates in Ireland. All the participants referred to the importance of education in AD implementation.\textsuperscript{456}

7.4. \textit{End-of-Life Project on Advance Directives}

The ‘National Council of the Forum on End-of-Life in Ireland’ conducted a pilot project on end-of-life planning in 2012. The objective of the ‘Think Ahead’ project was to get individuals to ‘think about’ and record their preferences in the event of an emergency, serious illness or death, when they may be unable to speak for themselves. The public awareness initiative was developed on foot of an Irish Hospice Foundation survey, which found that six out of ten Irish people were interested in availing of advance planning.\textsuperscript{457} The most common motivation was to reduce family burden in relation to decisions.\textsuperscript{458} A number of resources were developed including a form that guides individuals through the recording of wishes and a website, which discusses end-of-life preferences.\textsuperscript{459} Pilots were conducted with 100 patients in general practitioner (GP) practices to assess individual experiences of completing the form in 2011 and 2012.\textsuperscript{460} The results indicated that over three-quarters of participants completed some or all of the form and initiated discussions with family members. Care preferences were the principal source of difficulty, while other participants experienced problems with legal information. Two regional community-based pilots were conducted between September and November 2012.\textsuperscript{461} The current project is piloting end-of-life directives in nursing homes in Kildare and includes an educational intervention. Future projects will pilot end-of-life directives in other settings such as hospitals and work with partner organisations to promote public usage.\textsuperscript{462} The previous projects generated a positive response from the public and health professionals. GPs reported that the measure had enhanced their

\textsuperscript{456} Conor Quinlan, ‘Mental Health Nurses Perspectives on Advance Directives’ MSc Minor Thesis in Nursing Studies (University College Cork 2012).
\textsuperscript{457} Irish Hospice Foundation Survey (Irish Hospice Foundation 2010).
\textsuperscript{458} Sarah Murphy, Brendan O’Shea, ‘Think Ahead: An Irish Care Planning Tool’ 3 BMJ Supportive and Palliative Care 270.
\textsuperscript{460} Sarah Murphy, Brendan O’Shea, ‘Think Ahead: An Irish Care Planning Tool’ 3 BMJ Supportive and Palliative Care 270.
\textsuperscript{461} The pilots took place in Limerick and Louth.
\textsuperscript{462} Kildare and Wexford.
relationship with patients and had reduced the potential for family conflict. Eighty per cent of participants in the regional pilots believed that the project would be of interest to the general public and would encourage individuals to discuss their end-of-life wishes. The majority of participants found the form and website easy to use, while 52 per cent stated that it had made them rethink about their end-of-life preferences and prompted them discuss their wishes. The end-of-life planning tool may assist the development of ADs in mental health settings and integrate them into a wider system of advance planning in Irish healthcare.

The limited research on the introduction of ADs in Irish mental health care suggests strong support among service users. However, the exploratory studies did not address the issue in any detail at national level or consider the views of consultant psychiatrists. The findings from these studies may therefore not be generalised. The empirical study (in chapter 6) seeks to address the dearth of research in the area and to examine the views of service users and consultant psychiatrists in regard to familiarity, support, preferences for implementation and the perceived benefits and barriers to ADs in Irish mental health care.

8. Issues in the Irish Mental Health Services
8.1. Involuntary Detention and Readmission Rates
Involuntary admissions constitute approximately 11 per cent of all admissions to Irish psychiatric units and hospitals. In 2012, 1,574 admissions were made under the 2001 Act and 567 patients had their status changed from voluntary to involuntary. The proportion of involuntary inpatients declined from 79 per cent in

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463 Sarah Murphy, Brendan O’Shea, ‘Think Ahead: An Irish Care Planning Tool’ 3 BMJ Supportive and Palliative Care 270.
464 Sarah Murphy, Brendan O’Shea, ‘The Think Ahead Project: A Public Awareness Initiative’ Poster presented at the Irish Association for Palliative Care education and Research Seminar, 7 February 2013.
466 Rates vary widely across the EU. A 2002 study found rates ranging from 6 per 100,000 in Portugal to 218 in Finland and 74 per 100,000 in Ireland. This figure is now approximately 7.7 per cent per 100,000 in Ireland according to the psychiatric unit census figures in 2013. Hans Joachim Salize and others, Compulsory Admission and Involuntary Treatment of Mentally Ill Patients: Legislation and Practice in EU Member-States (European Commission 2002).
1963 to 15 per cent in 2013. The involuntary admission rate decreased significantly after the mental health tribunals were established in 2006, the admission rates returned to 2007 levels in 2012. The involuntary admission rates for approved centres increased by five per cent between 2010 and 2011 and four per cent from 2011 to 2012. The use of coercion and seclusion is still common in the Irish mental health services and was deemed unacceptable in a recent report.

In a 2006 study, service users identified enforced compliance with treatment and the use of seclusion and restraint as areas that needed urgent attention and alternative responses. For many service users, involuntary admission was traumatic and included excessive force. The report recommended reducing the trauma of the involuntary admission process and making it a more dignified experience for service users, families and professionals. Voluntary admissions also needed to be dealt with more sensitively, taking into account the concerns of the service user and his or her family. The McGuinness study illustrated the difficulties experienced by those who are admitted involuntarily, and suggests that the service needs to be more caring and acknowledge the person’s experiences. The study concludes that listening to the person, providing information, being cared for and seeing the person beyond their illness can help achieve this goal. The findings identified the various

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468 The number of involuntary patients on census night increased from 13% in 2010 to 15% in 2013, representing a rate of 7.7 per 100,000 population. Health Research Board, Irish Psychiatric Units and Hospitals Census 2013 (Health Research Board 2013).
474 Ibid.
475 Ibid.
476 Ibid.
478 Ibid.
meanings of detention and highlighted the need for renewed responses in this area.\textsuperscript{479} The impact of forced treatment and lack of choice was encapsulated by one participant:

“I didn’t have a choice and that was made clear to me when the guys came to inject me. I didn’t have a choice.”\textsuperscript{480}

Some participants fought the system initially, but in time learned to conform in order to regain their liberty and leave the approved centre. ADs can reduce the need for involuntary readmission and provide treatments acceptable to the person. The need for coercion can be reduced by moving towards the recovery approach and the use of participative responses. ADs are at the forefront of measures to reduce the need for coercion and readmission.\textsuperscript{481} Individuals who believe they have a ‘voice’ experience less coercion during the hospital admission process.\textsuperscript{482} ADs provide the opportunity to redefine the legal model of treatment from one of coercion to collaboration.\textsuperscript{483}

Readmissions accounted for 66 per cent of the 18,173 admissions to Irish psychiatric units and hospitals in 2012.\textsuperscript{484} While readmissions have decreased slightly, the rate remains high, suggesting a ‘revolving door syndrome’, where service users are discharged and readmitted on a continuing basis.\textsuperscript{485} A study on first admissions in 2001 showed that 37 per cent of individuals had one or more readmissions in the

\textsuperscript{479} Ibid.
\textsuperscript{480} Ibid 730.
\textsuperscript{485} The ‘revolving door syndrome’ describes the pattern of repeated hospitalisation, subsequent non-compliance and decompensation experienced by many mental health service users. A total of 40 patients had three or more involuntary admissions in 2012. Mental Health Commission, \textit{Annual Report 2012 including Report of the Inspector of Mental Health Services} (Mental Health Commission 2013) 33.
subsequent five years. Depressive conditions represent the highest proportion of admissions in Ireland, accounting for 30 per cent of all admissions. The use of anti-depressant medication has failed to reduce the admission rate in this group, suggesting a need for more effective recovery strategies. The international STAR*D study showed that antidepressant strategies had low efficacy in major depression, while the CATIE study showed low effectiveness for antipsychotics. The repeated use of ineffective treatment and recovery strategies can lead to high readmission rates. ‘A Vision for Change’ provides for a holistic, person-centred approach to recovery where the need for hospital admission is greatly reduced. The impact of readmission on the person is detrimental to recovery. One service user asserted that:

“A lot of things got lost during those admissions. There was a loss of self-confidence, trust and dignity … I felt isolated and alone, never knowing if I’d get through what I felt I was going through … it was just an incredible feeling of not knowing.”

The readmission rate should, therefore, be urgently addressed. High readmission rates can also block the admission of new patients and impact on quality of care. The AD development process can reduce the need for readmission by assisting the identification of relapse triggers and facilitating engagement. ADs are also hypothesised to reduce hospitalisation lengths by providing more expeditious

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486 1,274 of 3,473 patients were readmitted in Antoinette Daly, Donna Tedstone Doherty and Dermot Walsh, Readmissions to Irish Psychiatric Units and Hospitals, HRB Research Series 3 (Health Research Board 2007).
488 Dermot Walsh and Antoinette Daly, Mental Illness in Ireland 1750 - 2002: Reflections on the Rise and Fall of Institutional Care (Health Research Board 2004); Antoinette Daly and Dermot Walsh, Activities of the Irish Psychiatric Units and Hospitals 2008 (Health Research Board 2009).
492 Fiona Keogh and others, ‘We have no Beds … ‘An Enquiry into the Availability and Use of Acute Psychiatric Beds in the Eastern Health Board Region (Health Research Board 1999).
treatment. This is particularly pertinent given that life in the inpatient facility has been described as deskilling, anti-therapeutic and likely to promote institutionalisation if admissions are long or frequent. Over a third of patients were in hospital for one year or more in the 2013 census of Irish psychiatric units and hospitals. ADs can help empower service users towards self-directed care and avert the need for hospitalisation.

8.2. Economic Factors

The societal cost of on-going mental health difficulties is high, pervading all aspects of life including physical health, family relationships, social networks and employment status. In addition to the trauma and distress, hospital admission incurs considerable economic cost. A 2008 report found mental health problems cost the Irish economy over €3 billion per year. ADs are associated with a reduced need for readmission conferring economic and other benefits. An economic valuation of joint crisis plans (a form of AD) in the U.K. found a 78 per cent probability that they were more cost-effective than standard service information in preventing hospital admissions. A recent U.K. report suggests that savings can be realised by the use of crisis intervention strategies. ADs are a form of crisis intervention that can mitigate the cost of hospitalisation and involuntary admission.

496 Health Research Board, Irish Psychiatric Units and Hospitals Census 2013 (Health Research Board 2013).
499 Eamon O’Shea and Brendan Kennelly, The Economics of Mental Health Care in Ireland, Irish Centre for Social Gerontology and Department of Economics, NUI Galway (Mental Health Commission 2008).
503 Paul McCrone and others, Paying the Price-The Cost of Mental Health Care in England to 2026 (King’s Fund 2008).
Spending on Irish mental health services fell from 11 per cent of the overall health budget in 1991 to 5.2 per cent in 2010. The Programme for Government committed to investing €35 million annually in community mental health services, but the bulk of this money has not been invested and there have been lengthy delays in appointing staff. In 2011, the Inspector of Mental Health Services found the Irish mental health services had been adversely affected by the economic conditions. The report stated that services could be more efficiently governed and with an increased emphasis on psychosocial supports if they were under the remit of a National Directorate of Mental Health Services with executive and budgetary powers. A new national director for mental health was appointed in May 2013. The challenge for the director will be to continue to progress structural and cultural change. Mental health professionals have expressed concerns about the lack of resources to implement legislative changes. The importance of resources and ‘political will’ in the implementation of mental health legislation and policy was highlighted by the WHO which stated that:

“… unless there is also political will, adequate resources, appropriately functioning institutions, community support services and well trained personnel, the best policy and legislation will be of little significance …”

The opportunity to reorient the mental health services towards good governance and international human rights standards is still possible, even in the context of limited resources. While the initial implementation of ADs requires some investment, cost savings can be accrued in the longer term through reduced readmissions and involuntary detention. At a time when the Irish healthcare system is chronically under resourced, ADs can have significant economic benefits.

504 Health Service Executive (HSE), National Service Plan 2010 (Department of Health 2010).
8.3. Recovery Ethos in the Irish Mental Health Services

The concept of recovery first appeared in the official Irish discourse in 2005 with the publication of a discussion paper by the Mental Health Commission. The Commission describes the concept of recovery “in terms of the human right to autonomy and the self-fulfilment of the individual.” A recovery-focused approach to care is one of the standards identified in the ‘Quality Framework for Mental Health Services in Ireland’ and is central to the Irish mental health policy framework ‘A Vision for Change’. The policy describes the approach in the foreword:

“A ‘recovery’ approach should inform every level of service provision so service users learn to understand and cope with their mental health difficulties, build on their inherent strengths and resourcefulness, establish supportive networks, and pursue dreams and goals that are important to them and to which they are entitled as citizens.”

The recovery approach encapsulates many of the CRPD principles by focusing on the strengths of the person and support to promote full and equal participation. ‘A Vision for Change’ identified the need for a shift within the mental health services from the biomedical model to a recovery orientation. The chairman of the Irish Mental Health Commission asserted “the concept of recovery is central to modern thinking and practice in the area of mental health.”

8.4. Implementation of the Recovery Approach in the Irish Mental Health Services

The implementation of the recovery approach poses significant challenges to traditional mental health services. The transition requires a cultural re-orientation.
from the medical model to a social and personal conception of recovery. The lobby group, Mental Health Reform identified five core components of a recovery-oriented service including choice, listening, partnership, hope and social inclusion. The recovery orientation makes services more user-centred and recognises different ways to overcome mental distress. The need for a national implementation plan to translate recovery principles into practice has been identified. A qualitative study with Irish service users found the main expectation for recovery-oriented services was the provision of greater choice. The importance of participation, the therapeutic relationship and allowing individuals the opportunity to learn and develop by taking responsibility for choices was emphasised. In the absence of choice, individuals are effectively denied the right to make decisions over their own care. In a previous Irish study, the main barriers to recovery related to the medical model including: the lack of someone to talk to; medication side effects; pessimism; being treated as a disease rather than a person and hostility and stigma in the community.

The Mental Health Commission pointed to serious deficiencies in the development of recovery-oriented services in a recent report. Despite the recommendations for recovery services under ‘A Vision for Change’, several catchment areas still have few or no recovery services. A report by the Inspectorate of Mental Health Services in 2011 found that there were insufficient recovery teams to provide a

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518 Shari McDaid, *Recovery ... What you should Expect from a Good Quality Mental Health Service* (Mental Health Law Reform Ireland 2013) 3.
519 Ibid 9.
520 Regional Director of Operations, HSE South, ‘Moving West Cork Mental Health Service in a Recovery Direction: Developing an Integrated Mental Health Service in Line with A Vision for Change’ (HSE 2011).
523 Ibid.
526 A rehabilitation and recovery service provides specialised mental health care for people with severe and enduring mental health problems which cannot be adequately met by general adult services. Inspectorate of Mental Health Services, *Rehabilitation and Recovery Mental Health Services* (Mental Health Commission 2011).
comprehensive national service.\textsuperscript{527} In the areas where teams did exist, the Inspectorate found evidence of service user involvement and care planning within the constraints of limited resources. The Inspectorate recommended the implementation of fully staffed recovery teams for each catchment area as outlined in ‘A Vision for Change’.\textsuperscript{528} The slow pace of implementation means that many mental health services are still based on the medical model and lack multidisciplinary input and supports.\textsuperscript{529} The level and variety of services varies widely and largely depends on budgetary constraints leadership and staff attitudes and support. Recovery based mental health services are still largely underdeveloped in Ireland and remain inaccessible to the majority of service users in the community.\textsuperscript{530} The lack of legislative provisions for ADs was also viewed as increasing service user vulnerability.\textsuperscript{531}

Attitudinal, cultural and organisational change are core to the recovery philosophy and involve a shift away from treating illness towards promoting wellness.\textsuperscript{532} ADs are an important part of this approach. Mental health services have traditionally focussed on adherence to medication, which can result in passivity and compliance with the wishes of the health professionals. The implementation of the recovery approach and the supported decision-making model will require fundamental changes to existing structures and processes and will involve training in the attitudes and communication skills required for person-centred planning.\textsuperscript{533} The proportion of ADs executed provides a useful performance measure for the implementation of a recovery based system.\textsuperscript{534}

\begin{itemize}
\item \textsuperscript{527} Ibid.
\item \textsuperscript{528} A Vision for Change recommends one rehabilitation and recovery team per 100,000 of population with a minimum of 39 teams nationally.
\item \textsuperscript{529} Ena Lavelle and others, Mental Health Rehabilitation and Recovery Services in Ireland: A Multicentre Study of Current Service Provision, Characteristics of Service Users and Outcomes for those with and without Access to these Services (Mental Health Commission 2011).
\item \textsuperscript{530} Ibid.
\item \textsuperscript{531} Consultation Meeting in Dublin on 30\textsuperscript{th} of April 2012, Notes from Workshops for Sixth Annual Report of the Independent Monitoring Group for a Vision for Change-the Report of the Expert Group on Mental Health Policy April 2012.
\item \textsuperscript{532} Regional Director of Operations, HSE South, ‘Moving West Cork Mental Health Service in a Recovery Direction: Developing an Integrated Mental Health Service in Line with A Vision for Change’ (HSE 2011).
\item \textsuperscript{533} Ann Sheridan and others, Enabling Recovery: The Benefits of Supporting Socialisation. Report of a Randomised Controlled Trial (University College Dublin 2012).
\item \textsuperscript{534} Ibid.
\end{itemize}
ADs need to be viewed as recovery tools that confer developmental benefits. WRAP (Wellness Recovery Action Planning) is being increasingly used by service users and practitioners in the Irish mental health system. The main goal of WRAP is to increase empowerment and recovery through self-management. The Irish Mental Health and Recovery Education Consortium (IMHREC) introduced the WRAP programme across Ireland in 2010. The National Learning Network has also successfully introduced WRAP as part of the response to ‘A Vision for Change’ and has trained over 100 facilitators. A recovery programme commenced in St. Patrick’s hospital in 2008 with dedicated WRAP staff. The self-reflection and crisis planning process provide a basis for AD completion. The international research suggests choice and control in the care plan leads to an increased willingness to participate in WRAP. WRAP engagement was found to be most effective when the person was well and required belief, time, motivation and understanding of the benefits. WRAP is being used to facilitate the completion of legally binding ADs in mental health settings in the U.S.

The implementation of ADs can assist the ‘paradigm shift’ towards recovery-oriented care and the supported decision-making model in the Irish mental health services. Staff can assist the identification of recovery goals by using person-centred planning, supporting AD development and completing their own directives to promote experiential learning and to reduce stigma. ADs can help achieve many of the goals of recovery by enabling the identification of personal values and aspirations and empowering the person towards self-directed care.

536 IMHREC successfully delivered 2 day WRAP workshops to 197 participants and delivered a further 5 day advanced facilitation training for 68 participants. Agnes Higgins and others, Evaluation of the Mental Health Recovery and WRAP Education Programme, Report to the Irish Mental Health and Recovery Consortium (Trinity College Dublin 2010).

537 More than 13,000 people with mental health and other disabilities are supported by the National Learning Network all over Ireland to achieve their goals every year. National Learning Network, NLN invited to Share Experience of WRAP Mental Health Programme at US Conference’ [accessed 11 December 2013].

538 St Patrick’s Mental Health Services, ‘Recovery Programme’ [accessed 11 December 2013].


540 See chapter 5. State of Virginia.
8.5. Cultural Change in the Irish Mental Health Services

The effective implementation of ADs will largely depend on the culture in the mental health services and the attitudes of providers. The need for structural and cultural change in the mental health services has been identified in several reports. The IMG report suggested cultural change can be achieved by embedding recovery principles into the legislation; providing leadership at national and local level; designing recovery-oriented planning; involving service users and their families; training and disseminating best practice. A recent overview with service user representatives, carers and advocates found ongoing paternalism and lack of choice. The overview suggested that middle management in some mental health services were responsible for resistance to change. Participants felt the key to service user involvement was to establish ‘buy-in’ from a wide range of staff from consultants to nurses to security staff. Previous overviews recommended treating services users and carers with dignity and respect. In the National Inpatient Survey in 2011, over a third of service users did not feel encouraged to voice their opinions by hospital staff.

The Irish lobby group Mental Health Reform contend that a modern mental health service requires staff to adopt the role of ‘facilitators’ and to work in partnership with the person to support recovery. The challenge is for staff to embrace the new paradigm and recognise the different types of expertise including the ‘lived experience’ of the person. The attitudes of clinical staff with respect to recovery, person-centred care and collaboration were reported to be improving gradually in

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544 Ibid.
545 Ibid
546 Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2011’ (Mental Health Commission 2012).
548 Shari McDaid, Recovery ... What you should Expect from a Good Quality Mental Health Service (Mental Health Law Reform Ireland 2013) 28.
2011, but services stagnated again in 2012.\textsuperscript{549} Some nurses felt the mental health services were slowly moving away from the control approach.\textsuperscript{550} The importance of progressive human rights legislation in achieving attitudinal change was emphasised repeatedly by service user participants on the AI citizen jury.\textsuperscript{551} Mental Health Reform recommended incorporating the values of hope, respect, empathy, equality and human rights into job specifications and performance measures.\textsuperscript{552} However, structural conditions must also be favourable for staff. In a recent report, the Inspector of Mental Health Services referred to the enormous pressure on mental health services staff, putting them at risk of mental ill-health.\textsuperscript{553} The development of a service where the ‘voice’ of the individual is heard and respected, and consistently supported by trusted professionals does not have to be costly.\textsuperscript{554} The introduction of ADs can help drive the cultural shift towards dignity and respect in Irish mental health care.

8.6. Education and Training

Education and training are needed to ensure a cultural shift in the Irish mental health services. The provision of education in human rights standards and recovery is critical.\textsuperscript{555} Murray highlights the need to engage and educate those with responsibility for implementing rights-based legislation.\textsuperscript{556} ‘A Vision for Change’ emphasised the need for staff training on recovery principles,\textsuperscript{557} but the monitoring group found little or no evidence of in-service training or reconfiguration of


\textsuperscript{550} Conor Quinlan, ‘Mental Health Nurses Perspectives on Advance Directives’ MSc Minor Thesis in Nursing Studies (University College Cork 2012).

\textsuperscript{551} Amnesty International Ireland, \textit{A Citizens’ Jury on Legal Capacity Law} (Amnesty International Ireland 2012).

\textsuperscript{552} Shari McDaid, \textit{Recovery … What you should Expect from a Good Quality Mental Health Service} (Mental Health Law Reform Ireland 2013) 15.


\textsuperscript{554} Shari McDaid, \textit{Recovery … What you should Expect from a Good Quality Mental Health Service} (Mental Health Law Reform Ireland 2013) 15.

\textsuperscript{555} Agnes Higgins and others, \textit{Evaluation of the Mental Health Recovery and WRAP Education Programme, Report to the Irish Mental Health and Recovery Consortium} (Trinity College Dublin 2010).


services. The Inspector of Mental Health Services identified training opportunities as limited and was “shocked by the lack of understanding of basic aspects of mental health legislative requirements” in the most recent report. A previous report noted “a lack of much needed training among clinicians” in areas such as human rights; recovery; individual care planning; and the operation of the 2001 Act. A national overview with service user representatives suggested a need for interpersonal skills training for staff. The Inspector of Mental Health Services also noted problems in recruiting health and social care professionals from national panels where staff sometimes had little interest in mental health. The potential for continuous professional development in this area was welcomed.

Education plays a key role in AD implementation. The need for stakeholder education has been identified in other jurisdictions. The perceived barriers increased for stakeholder groups that were not educated on their use in Virginia. The empirical study (in chapter 6) also showed that barriers increased among service users who were not familiar with the measure. The implementation of the legislative provisions for ADs under the 2013 Bill will require training for providers, service users and families. This should be incorporated in a Code of Practice. Previous research suggests clinicians are more willing to support ADs if they are educated about the parameters of the legislation. The Scottish experience also demonstrated the need for guidance on the legislation to maximise use.

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560 Ibid 79.
564 Ibid.
8.7. Education and Recovery Programmes in Ireland

8.7.1. Advancing Recovery in Ireland (ARI)

The ‘Advancing Recovery in Ireland’ (ARI) project funded by Genio Trust,\(^\text{567}\) may facilitate the implementation of organisational change in the Irish mental health services. The ARI project proposes to effectively implement recovery-oriented services on eight selected sites using ImROC (Implementing Recovery through Organisational Change).\(^\text{568}\) The ImROC programme supports mental health service providers to become more ‘recovery orientated’. It is envisaged that the project will support the selected services to implement recovery-oriented delivery in the Irish mental health services. A Recovery Context Inventory (RCI) has been developed for the purpose of tracking individual progress towards recovery goals and service planning.\(^\text{569}\) The ‘Recovery Planning Workbook and Facilitator Training Programme’ may assist training for AD facilitators. The ARI project has the potential to provide the basis for a system-wide programme for cultural change in the Irish mental health services. It also provides the unique opportunity to incorporate ADs into recovery practice in Ireland.

8.7.2. Irish Mental Health and Recovery Education Consortium (IMHREC)

The Irish Mental Health and Recovery Education Consortium (IMHREC) was established to deliver a facilitated education programme on mental health recovery across Ireland in 2009.\(^\text{570}\) The aim of the programme was to promote recovery strategies to individuals with self-experience, family members and practitioners. The initiative involved a two-step education programme, which sought to educate individuals on recovery and WRAP, followed by a five day facilitator training.

\(^{567}\) Genio is a non-profit organisation rooted in the belief that by valuing diversity both the individual and society can benefit from the unique contribution of all. The organisation is currently working in the disability, mental health and dementia fields supported by Atlantic Philanthropies and in collaboration with the Department of Health, the HSE, and non-governmental advocacy and service-providing organisations.

\(^{568}\) The ImROC methodology is currently being tested by the rehabilitation team in Castlebar.

\(^{569}\) EVE is a programme within the HSE, the primary ethos is to provide community-based recovery-orientated programmes. Eve provides a range of person-centred and recovery-oriented community services in Dublin, Wicklow and Kildare on behalf of the HSE [www.eve.ie] [accessed 13 March 2014].

\(^{570}\) Agnes Higgins and others, Evaluation of the Mental Health Recovery and WRAP Education Programme, Report to the Irish Mental Health and Recovery Consortium (Trinity College Dublin 2010).
The evaluation found that participant knowledge increased and attitudes towards recovery improved.\textsuperscript{571} The focus on self-management, responsibility and control was perceived to be empowering and challenged the assumption that service users are passive recipients of care. One of the most valuable aspects of the programme was reported to be the mix of participants. The shared education model was viewed as pivotal for future recovery education. The process helped to equalise relationships, normalise mental distress and communicate a message of partnership. The major challenge in developing recovery services was perceived to be overcoming the medical model and shifting the philosophy of care from illness to wellness. The evaluation report made a number of recommendations including: developing a national strategy for recovery education; assigning responsibility for education to an autonomous person or group; including recovery principles on the programmes of educational accrediting bodies for mental health professionals; the establishment of a national recovery collaborative by the Mental Health Commission and mentorship programmes for facilitators.\textsuperscript{573}

The study concluded that providing practitioners and service users with systematic education and training in recovery principles using the WRAP approach can lead to positive changes in knowledge, skills and attitudes and the ability to teach these skills to others. The project provides a blueprint for the development of AD education in Ireland and the incorporation of the measure into existing recovery training programmes. The IMHREC project demonstrated the importance of engaging with local communities from the start and the power of a tripartite model of education, which includes a mixture of stakeholders. The consortium trained 67 WRAP facilitators, providing a pool of facilitators for the completion of ADs.\textsuperscript{574}

8.7.3. West Cork Mental Health Services

The West Cork mental health services have been cited in a number of submissions as exemplars of the changes that occur when the recovery-ethos is implemented into

\textsuperscript{571} IMHREC successfully delivered 2 day WRAP workshops to 197 participants and delivered a further 5 day advanced facilitation training for 68 participants.

\textsuperscript{572} Agnes Higgins and others, \textit{Evaluation of the Mental Health Recovery and WRAP Education Programme, Report to the Irish Mental Health and Recovery Consortium} (Trinity College Dublin 2010).

\textsuperscript{573} Ibid.

\textsuperscript{574} Ibid.
every aspect of practice.575 This involved a gradual move away from the traditional medical model and a genuine commitment by clinical staff to engaging with service users and their families to formulate an individualised plan for recovery, which is not led by diagnosis.576 WRAP facilitation is now being offered routinely in the approved centre and may provide for AD completion. The combination of individualised care planning, WRAP and legally binding ADs can strengthen the framework for service user participation. These services may provide an appropriate location for a pilot project on ADs.

8.7.4. Peer Advocacy in Ireland

Individuals who are in similar situations can be powerful advocates for each other (peer advocacy). The word advocacy comes from the Greek word ‘ad vocare’ and means ‘towards a voice’.577 The right to advocacy is not enshrined in Irish legislation, but several non-statutory bodies are involved in providing services.578 The Irish Advocacy Network (IAN) has been active in developing and providing peer support in the Irish mental health services in Ireland. Peer advocates are people who have personal experience of mental health difficulties who have achieved a sufficient level of recovery to complete an accredited training course.579 IAN has peer advocates in most health board areas in Ireland who regularly attend acute units and day centres.580 The main function of peer advocates is to provide continual support and information to people with mental health difficulties. This support succeeds through the establishment and development of trust between the peer advocate and the person. Peer advocacy helps individuals to take control of their lives and empowers them to do things for themselves with support. The main concerns brought to IAN by service users are information deficits and request for support in influencing their care and treatment. IAN has also been involved in developing service user involvement in training and educating professionals in

580 IAN now has 16 full time staff, seven part time staff, four trainees, five volunteers in the South and two full time staff and one part time staff in the North of Ireland.
conjunction with Dublin City University (DCU). Peer advocates can provide an appropriate support for the development of ADs within the existing service.

8.8. System Transformation
The analysis suggests that the medical model still underpins many parts of the Irish mental health services and cultural change is slow. The system militates against the progression to greater autonomy and independence through the lack of participative responses, support measures and community services. This perpetuates the process of institutionalisation and overuse of medication in the community. The transition to the supported decision-making model and recovery-oriented practice may not occur naturally in the Irish mental health system. The move towards a human rights based approach requires fundamental system transformation and cultural change. The introduction of non-discriminatory legislation for ADs can help achieve this attitudinal change.

The successful implementation of ADs is dependent on a co-ordinated strategy of system and law reform accompanied by education, resources and support. Monitoring and compliance mechanisms should be included within the legislation and the organisation to ensure these changes are being implemented. The focus on recovery and respect for the person’s preferences requires a paradigm shift, which challenges the dominant medical model and traditional roles. Staff education and the support of management are critical in the cultural shift. The mental health services management need to clearly communicate the need to implement legislative changes and include them in internal audits and staff appraisals. Information champions are also critical to promote the adoption of new approaches. Some Irish hospitals have compliance officers to ensure the provisions of mental health legislation are implemented by staff. Slade asserts that embarking on a recovery journey is profound for both service users and staff. The recovery and supported decision-

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583 St. Patrick’s Hospital, Dublin.
making models have the potential to empower service users and to liberate staff from unachievable expectations in relation to risk and curing illness.  

The introduction of ADs can help cultivate a culture of respect for individual preference and help drive system transformation in the Irish mental health services.

9. Stigma and Discrimination in Ireland
The experience in other jurisdictions highlights the systemic and attitudinal barriers surrounding the introduction of ADs in mental health care.  

The exclusion of legally binding ADs during involuntary detention, in the proposed Irish legislation, reinforces stigma and limits their use in mental health settings when they are most needed. The exception is reflective of inherent stigma and discrimination in the legislation, courts, the mental health system and wider Irish society and poses significant challenges to participation in mental health care. The inclusion of ADs in the legislative framework requires an attitudinal shift in the conceptualisation of individuals with mental health conditions and how they are treated. The CRPD stresses the importance of awareness to combat unfounded prejudices and stereotypes and to foster equal respect.

The Health Research Board contends that public attitudes to mental health need to change from ‘us’ and ‘them’ to the knowledge that mental health difficulties can affect everyone. Bartlett and Sandland observe that the dividing line between ‘them’ and ‘us’ is largely illusory.

National and international studies suggest that 25 per cent of the population will experience a mental health difficulty at some point in their lives. Policy and programmes that address stigma and encourage people to seek support may assist. The anti-stigma study in the U.K. highlighted the need...
for education to address discrimination. The National Disability Authority (NDA) found attitudes to people with mental health difficulties were more negative than those relating to intellectual, physical or sensory disabilities in Ireland. In 2010, a research study with more than 300 Irish people with a history of poor mental health found discrimination in every domain of life including friends; neighbours; family; health service staff; police; housing; education; work and welfare. The international research shows that individuals with mental health conditions experience even higher levels of stigma from psychiatrists, mental health professionals and families than the general public. A national survey by St. Patrick’s Mental Health Services revealed that stigma is still deeply ingrained in Irish society. The disturbing findings revealed that 41 per cent of participants believed that getting treatment for a mental health issue was a sign of personal failure; 22 per cent perceived that those suffering from a mental health condition were of below average intelligence and 30 per cent stated that they would not accept someone with a mental health problem as a friend, even though 37 per cent had a family member and 52 per cent had a close friend with a mental health difficulty. The survey, which has been conducted since 2009, indicates only small attitudinal improvements in Irish society over the five year period. According to the CEO of St. Patrick’s Mental Health Services, Paul Gilligan, “At the heart of most stigma and prejudice is fear and misunderstanding.” This lack of understanding is fuelling stigma and preventing individuals accessing support. The former President of the United States Bill Clinton asserted:

594 National Disability Authority, Public Attitudes to Disability in Ireland (National Disability Authority 2002).
595 Liam MacGabhann and others, Hear My Voice: The Experience of Discrimination by People with Mental Health Problems (Amnesty International Ireland 2010).
597 The survey was undertaken with 500 members of the public on a nationwide basis in 2013. St Patrick’s Mental Health Services, ‘Stigma still a Significant Factor’ 10 September 2013 <https://www.stpatricks.ie/stigma-still-significant-factor> [accessed 12 December 2013].
598 Ibid.
600 Ibid.
“Mental illness is nothing to be ashamed of, but stigma and bias shame us all … these myths don’t just harm people with mental disorders; they hurt all of us.”

10. Conclusions

The integration of mental health ADs into the legislative framework on an equal basis for all persons is important symbolically and practically in reducing stigma and discrimination. Advocacy organisations recommend providing for mental health ADs with general legislation rather than in specific provisions to prevent discrimination and promote participation. ADs for mental health treatment decisions should therefore operate in the same way as other directives during involuntary admission. The National Disability Authority asserts:

“This legislative and policy context provides significant opportunities to realise the social and human rights model of disability and embed values such as equality, participation, quality and inclusion within policy, provision and wider Irish society as part of an integrated social change agenda.”

Ireland is working towards an international human rights standard, which includes the recovery approach and the CRPD model, which requires equal recognition before the law for all persons. The new approach will require the introduction of support measures, which facilitate the exercise of legal capacity, the identification of recovery strategies and equal respect for the ‘will and preferences’ in mental health treatment decisions. The transition to the human rights based approach will require education, a shift in philosophical focus and a commitment to change. The establishment of equal respect for individuals with mental health conditions in the legislation can help achieve these objectives. According to the Director for International Programmes at Atlantic Philanthropies, Martin O’Brien, the creation of

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a better society is most effectively achieved by changing government policies and practices. One of the most important areas for securing change is the law, but this alone cannot achieve change in society. O’Brien asserts that there is a need for public awareness, support for vulnerable groups and for rights to be asserted both inside and outside the courts. The fundamental premise of ADs, the CRPD and the recovery approach is that individuals are capable of making choices given the opportunity and support to develop, but these rights must be enforceable in the mental health system, the courts and society. One service user asserted that “When people not used to speaking are heard by people not used to listening then real changes can be made.”

The impassioned plea made by an Irish service user at a 2012 conference on the impending capacity legislation illustrated the need for legally binding ADs in Ireland. The female service user relayed how she lived in constant fear of being treated ‘against her will’ or in her ‘best interests’ ‘following her experience of involuntary detention. In order to avoid this, she has developed an AD and given it to her former psychiatrist. In this she has clearly articulated her preference for psychological supports and specified the medications she is willing to take in certain circumstances. Despite clearly communicating her preferences, she is concerned that her AD might be disregarded and she may be forcibly treated while pregnant. The draft legislation for ADs proposes to provide exceptions to enforceability for treatment decisions during involuntary detention and pregnancy. ADs will not be legally binding for treatment governed by the 2001 Act. Even if she is admitted voluntarily, her status may be changed to involuntary rendering her AD non-legally

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605 Martin O’Brien, Director for International Programmes with Atlantic Philanthropies, ‘Atlantic Philanthropies’ $1.1bn is ‘drop in ocean’ next to what State can Invest’ Irish Times (Dublin 5 December 2013).
606 Ibid.
609 Mental Disability Advocacy Center (MDAC), Legal Capacity in Europe: A Call to Action to Governments and the EU (MDAC 2013) 58, 59.
binding. This situation has been highlighted in a recent Irish court decision. The introduction of legally binding ADs that apply during involuntary detention can prevent her ‘voice’ from being disregarded and protect her from unwanted treatment. The inclusion of ADs for mental health treatment decisions in the legal framework can assist the shift towards meaningful participation and inclusion. Ultimately, the implementation of ADs under the Irish legal framework requires equal respect for the ‘voice’ of all persons.

611 KC v St. Loman’s Hospital [2013] IEHC 310.
CHAPTER 5
The Implementation of a Legal Framework for Advance Directives in Virginia: A Comparative Case Study

1. Introduction
This chapter will examine the introduction and implementation of a legal framework for ADs in the State of Virginia in the United States, with a view to informing the Irish State at a critical juncture in the legislative process. The State of Virginia is at the forefront of international efforts to successfully implement a legal framework for ADs into mental health care. An innovative new healthcare law integrates a broad range of healthcare decisions, including mental health treatment decisions, into a single directive. Virginia is undertaking an unprecedented attempt to successfully implement ADs in mental health settings and achieve higher levels of participation. The chapter will consider features of the Virginia legislation and implementation into mental health practice. This will be achieved by describing the development of the legislation; the features of the Virginia directive; the implementation of the law and associated barriers and opportunities. The Virginia model provides valuable lessons for other jurisdictions considering the implementation of ADs under the recovery approach and the UN Convention on the Rights of Persons with Disabilities (CRPD). The U.S. has signed the CRPD, but has not yet ratified it.\(^1\)

The Virginia legislation will be considered in the context of the new Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill) in Ireland and the CRPD. The 2013 Bill proposes to provide a modern statutory framework for those who need assistance in making decisions in Ireland and is viewed as a key step towards Irish ratification of the CRPD.\(^2\) The Committee on the Rights of Persons with Disabilities (CRPD Committee) will specifically examine the legislation to determine whether Ireland meets the legal capacity obligations under Article 12. Ireland currently lacks legislation for ADs, but it is planned to incorporate a framework into the 2013 Bill. The Virginia legislation complies with many of the features of the supported

\(^1\) The United States Senate failed to ratify the CRPD in December 2012. Ratification received 61 of the 67 votes required for ratification.

\(^2\) The Irish Government committed to introducing capacity legislation that complies with the CRPD in the Programme for Government. The CRPD has been a driving force in the development of the 2013 Bill, which will replace the ward of court system.
decision-making model in the CRPD. The legislation in Virginia was informed by the recovery approach, which is a guiding principle of mental health policy in Ireland. The comparative analysis will help inform the introduction of an appropriate legal framework for ADs in Ireland.

This chapter is based on published material and meetings with key stakeholders involved in the Virginia law reform and implementation process during a research visit by the author in 2012. As part of the visit, the author visited the Bazelon Centre for Mental Health Law in Washington DC, the University of Virginia, the State of Virginia mental health services and AD pilot sites and the National Resource Centre for Psychiatric Advance Directives at Duke University. The visit was funded by a National University of Ireland (NUI), Travelling Studentship Award in the Humanities and Social Sciences.  

A shorter version of this chapter was published in the Medico-Legal Journal of Ireland in December 2013 to help inform the legislative proposals for ADs in Ireland. The stakeholders referred to throughout the chapter include leading academic and legal experts from the University of Virginia and the National Resource Centre for Psychiatric Advance Directives at Duke University. Other stakeholders include system stakeholders; peer facilitators and mental health services staff in the State of Virginia. The meetings undertaken with various stakeholders were recorded and transcribed and subjected to line coding to identify significant statements and themes. The Virginia legislation specifies an inclusive AD for general health and mental health care so the term advance directive (AD) rather than psychiatric advance directive (PAD) is used in the chapter.

2. Development of ADs in the United States

ADs for mental health treatment originated in the U.S. and are commonly referred to as ‘psychiatric advance directives’ (PADs). Twenty-six U.S. States have statutes explicitly authorising stand-alone PADs or proxy decision-making, and nearly all the others permit them through general healthcare ADs or power of attorney statutes. All the statutes provide for legally enforceable PADs, but the provisions can

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3 See appendix.
generally be superseded by involuntary admission. The upholding of treatment preferences during involuntary detention varies between States. The failure to respect AD treatment refusals during involuntary commitment has been litigated as discriminatory under the Americans with Disabilities Act (ADA) 1990 in the U.S. Court of Appeal. The decision in *Hargrave v Vermont* suggests ADs should be respected during detention. ADs were originally adapted to the mental health context as a way for service users to exert more control over treatment and avoid coercion. The emphasis on recovery and person-centred care expanded the focus of ADs towards effective implementation and efficacy. However, only a limited number of individuals are benefiting from ADs due to lack of knowledge regarding their availability. General healthcare ADs have progressed dramatically in the U.S. in the past decade and experts suggest they will be embedded into mental health settings in a similar manner. The challenge in Virginia and other jurisdictions is to foster a greater level of engagement and participation in ADs for mental health treatment decisions. The Virginia directive provides a legislative model for jurisdictions seeking more ethical approaches to mental health decision-making. The implementation project is the subject of ongoing research supported by international experts at Duke University and the University of Virginia. This knowledge will help inform the implementation of an appropriate legal framework for ADs in Ireland and other jurisdictions.

3. Background to Virginia Law Reform

The major objective of the Virginia mental health law reform was to promote recovery and to reduce the need for coercive treatment. The Commission on Mental Health Law Reform was established in 2006 in response to widespread

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7 Ibid.
9 3.9 to 12.9 per cent of mental health outpatients had completed a PAD but 66 to 77 per cent reported a desire to execute one. Jeffrey Swanson and others, ‘Psychiatric Advance Directives among Public Mental Health Consumers in Five US Cities: Prevalence, Demand and Correlates’ (2006) 34 (1) Journal of the American Academy of Psychiatry and Law 43.
10 Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 14 August 2012).
dissatisfaction with mental health services and involuntary commitment. The death of 33 students in the Virginia Tech shooting in 2007 accelerated the law reform process. The Commission sought a non-coercive response to the tragedy and viewed ADs as a key element of person-centred services. The Virginia legislation only provided for end-of-life directives prior to the amendments of the Health Care Decisions Act in 2009. The new law is explicit in the inclusion of all types of healthcare decisions, including mental health treatment decisions. The reform process was preceded by a three-year period of consensus-building with key stakeholder groups and substantial participation by service users. The importance of stakeholder support was recognised for the successful introduction of the law. The revisions to the Virginia legislation were enacted in 2009 and 2010 based on the proposals of the Commission and deliberations with stakeholders. The legislation provided a strong legal foundation for empowerment and self-determination under the recovery approach. The recovery ethos has also been explicitly adopted as the guiding principle of mental health policy and service planning in Ireland. The approach supports the introduction of laws that respect a person’s treatment choices and avoid the need for coercion. The Virginia experience suggests that a planned consensus-building approach with substantial participation by stakeholders can break down barriers, facilitate mutual understanding and create a shared vision of reform. The introduction of legislative provisions for ADs in Ireland will require

12. The 25 member Commission was established by Virginia Supreme Court Chief Justice Hassel and chaired by Professor Richard Bonnie of the University of Virginia, Law School.
13. The movement to enact reform began in 2008 but the economic recession slowed the process.
14. The Virginia Tech shooting tragedy in 2007 reinforced the need for reform.
16. The term ‘consensus-building’ refers to a variety of approaches in which the participants seek a mutually acceptable resolution of their differences. See Gail Bingham, ‘What is Consensus Building and Why is it Important for Resource Management?’ [accessed 7 October 2013].
consultation and discussion with stakeholders to address concerns. The CRPD requires State Parties to consult with and involve persons with disabilities and their representative organisations in the development and implementation of policies and other decision-making processes.\(^{22}\)

### 4. Features of the Virginia Directive

#### 4.1. Integration

Comparative jurisdictions have a range of legal frameworks for ADs, with some adopting provisions under mental health legislation and others providing for them with general ADs. The Virginia directive provides for all types of healthcare decisions, including mental health treatment decisions, thus eliminating the need for separate ADs. The Virginia Commission decided that a stand-alone statute perpetuated the practice of singling out mental health for differential treatment.\(^{23}\) The integration of healthcare decisions was considered important symbolically in reducing stigma and discrimination. Integration also addresses the physical and other life choices of the person. The Virginia legislation limits the circumstances in which ADs can be overridden by mental health law. These exceptions include involuntary admission and clearly defined emergency treatment.\(^{24}\) Treatment preferences are still respected during periods of detention. The integrated directive is regarded as an innovative and successful aspect of Virginia law, which promotes the principle of equality and non-discrimination espoused in the CRPD.\(^{25}\) The Virginia directive also informs providers of the physical health and other life choices of mental health service users.\(^{26}\) The increased incidence of physical health conditions among individuals with mental health conditions requires a more holistic and integrated approach. The use of general healthcare ADs has been neglected in this population

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\(^{22}\) Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) 11.


\(^{24}\) Emergency treatment is generally considered as treatment to prevent imminent or irreversible harm: Va Code s 37.2-1101.

\(^{25}\) Article 5, Article 12.

\(^{26}\) A demand for end-of-life treatment preferences by individuals with serious mental illness (SMI) was found in previous research. Mary Ellen Foti and others, ‘End-of-Life Treatment Preferences for People with Serious Mental Illness’ (2005) 56 Psychiatric Services 585.
Despite the increased risk of physical health problems, the draft Irish legislation proposes a single legislative framework for general and mental health care ADs, but limits their legal enforceability for treatment decisions during involuntary detention. The legislative provisions should provide for legally binding ADs during involuntary detention and limit the extent to which directives can be overridden by mental health legislation to defined life-saving emergency treatment.

4.2. Presumption of Capacity
The Virginia legislation provides for a presumption of capacity for all adults to execute an AD, thus making them available to everyone. A capacity assessment is not required unless the person executes a self-binding Ulysses clause, which can be used by individuals who wish to override their own future objections during crisis periods. The presumption of capacity in the Virginia directive can only be rebutted by a legally recognised measure such as a court order or a clinical determination of incapacity. The burden of proof is placed on the party challenging the directive to prove that the person lacked capacity or was under duress at the time it was executed. The presumption of capacity is considered to be a positive aspect of the Virginia legislation. Individuals with mental health conditions can be excluded from using ADs in other jurisdictions due to the requirement for a capacity assessment at execution. The CRPD provides for a presumption of capacity and recognises that persons with mental disabilities have a right to legal capacity on an equal basis with others in all aspects of life. Article 12 requires State parties to provide access to appropriate support measures if needed. In Ireland, the principles of the 2013 Bill include a presumption of capacity with due regard for the rights to dignity, bodily integrity, privacy and autonomy in respect to interventions for relevant persons.

30 Louisiana requires a physician or psychologist ‘mental status examination’ that attests to the person’s ability to make reasoned treatment decisions. La Rev Stat Ann § 28:224. Eight US states have definitions of capacity which the person must meet for the AD to be valid.
31 Article 12(2).
32 Article 12(3). Supported decision-making must be available to all. The level of support needs should not be a barrier.
33 Assisted Decision-Making (Capacity) Bill 2013, s 8(2) and (6)(b).
The draft legislative scheme for ADs confirms that a presumption of capacity applies to all adults to execute a directive.\textsuperscript{34}

4.3. Types of Directive
ADs can take varying forms, enabling different decisions to be made. Some directives are legally binding whereas others are accorded consideration. Preferences can be expressed through an instructional directive, which provides directions regarding treatment, or a proxy directive, where the authority to communicate choices is given to a designated person, or a hybrid which includes a combination of both features.\textsuperscript{35} The appointment of a proxy is the most frequently used component of ADs and attracts the highest level of support from clinicians.\textsuperscript{36} The majority of service users are interested in appointing a proxy decision-maker.\textsuperscript{37}

4.3.1. Proxy Directives
The importance of a trusted proxy decision-maker is recognised in the Virginia directive. The legislation provides for a legally binding proxy directive, a stand-alone instructional directive or a hybrid directive, which includes both instructions and a proxy. In the Virginia stakeholder survey, all but one of the service users who completed a directive appointed a proxy decision-maker.\textsuperscript{38} The appointment of a proxy was reported to be the most popular feature of ADs in Virginia, even though some mental health service users did not have a trusted person to act on their behalf. The proxy decision-maker can be used to respond to changes in treatment, participate in research or to communicate visitor preferences during crises. The

\textsuperscript{34} Head 3(2).
\textsuperscript{38} A survey of Virginia stakeholders was undertaken during the introductory phase of the legislation including service users, clinicians, administrators, families and advocates determine opinions, knowledge and barriers. Christine Wilder and others, ‘A Survey of Stakeholder Knowledge, Experience, and Opinions of Advance Directives for Mental Health in Virginia’ (2013) 40 (3) Administration and Policy in Mental Health 232.
legislation allows different proxies to be appointed for mental health and other decisions. The appointment(s) can be reversed at any time, unless the person empowers the proxy to act over objection during crisis periods.\(^39\) The proxy can also terminate the position if he/she is unwilling to carry out the instructions.\(^40\) A distinction is drawn between proxy decision-making and ‘best interests’ in the Virginia statute to safeguard against substituted decision-making.\(^41\) The legislation places an obligation on proxy decision-makers to make decisions based on the person’s ‘values and preferences’ and efforts must be made to identify these. A decision can only be made in the person’s ‘best interests’ where these are unknown. Several Virginia stakeholders held the view that training for proxy decision-makers would help ensure that the person’s ‘will and preferences’ are reflected in treatment and other decisions.

The CRPD requires a decision-making system based on the ‘will and preferences’ of the person.\(^42\) The principles for legal capacity law state that advance planning representatives should reflect the ‘will and preferences’ of the person, and include the meaningful ability to reverse the appointment at any time.\(^43\) In Ireland, the 2013 Bill provides that decision-makers must give effect to the ‘will and preferences’ of the person, in so far as they are reasonably ascertainable.\(^44\) The Office of the Public Guardian will also have a role in supervising decision-makers and attorneys under the proposed legislation.\(^45\) This role may extend to AD proxies. The draft legislative scheme for ADs provides for the appointment of a patient-designated decision-making representative.\(^46\) The person can place limitations on the powers of the

\(^{39}\) The statutory and integrated forms provide that the proxy retains authority over objection unless the person removes it in Virginia.
\(^{40}\) Va Code s 54.1-2986.1(b).
\(^{41}\) Va Code s 54.1-2986.1(b).
\(^{42}\) Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—EQUAL RECOGNITION before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) 6.
\(^{44}\) Assisted Decision-Making (Capacity) Bill 2013 s 8(7)(b) and s 8 (7)(c)(i).
\(^{45}\) The function of the Office of the Public Guardian is to supervise the implementation of the new legislation, promote awareness of the CRPD, and monitor decision-making assistants, co-decision-makers and decision-making representatives. Assisted Decision-Making (Capacity) Bill 2013 s 56(2) (a).
\(^{46}\) Head 7.
representative if he/she wishes and the scheme excludes healthcare providers from acting unless they are related to the person.\textsuperscript{47} However, the proposed legislation does not explicitly oblige the representative to make decisions based on the ‘will and preferences of the person or make efforts to identify them where they are unknown. These form part of the overall principles of the 2013 Bill.

4.3.2. \textit{Lack of Trusted Proxy Decision-Maker}

The lack of a trusted proxy decision-maker was identified as a barrier to the use of ADs in mental health settings in Virginia.\textsuperscript{48} The Virginia legislation provides the option of instructional directives for individuals who lack a trusted person to act on their behalf. Peer facilitators\textsuperscript{49} are also being used to assist service users to identify proxy decision-makers and to build support networks. In the absence of an instructional AD or a proxy decision-maker, the Virginia legislation provides a list of surrogate decision-makers in descending order of blood relatives to make healthcare decisions when the person is deemed to lack capacity.\textsuperscript{50} The surrogate has a duty to identify the ‘values and preferences’ of the person when making decisions. The difficulty appointing a trusted person suggests a need for proxy and instructional directives in the legislation. A ‘one-size-fits all’ approach is unlikely to accommodate varying needs and preferences. The CRPD requires State Parties to facilitate the creation of supports, for individuals who are isolated or may lack access to natural-occurring supports in the community.\textsuperscript{51} The Virginia facilitators reported referring individuals to support groups to build networks. Submissions on the Irish capacity legislation suggest placing obligations on State bodies to develop opportunities for natural supports.\textsuperscript{52} The 2013 Bill provides for the appointment of decision-making assistants and co-decision makers under supported decision-making

\textsuperscript{47} Head 7 (2)(3).
\textsuperscript{48} The issue was particularly problematic in Virginia Beach Mental Health and Substance Abuse Service and Norfolk Community Service Board (CSB), Region 10 and the jail settings.
\textsuperscript{49} A peer facilitator is a person with personal mental health experience who is trained to support AD completion.
\textsuperscript{50} Va Code s.54.1-2986.
\textsuperscript{51} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention-Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013), para 25(d).
agreements. These decision-makers may also be able to act as proxy decision-makers for ADs. The draft legislation states that other decision-makers will not have power where the treatment decision is specified in the AD or a decision-making representative has been appointed to make such decisions. The Office of the Public Guardian will also have responsibility for nominating a decision-making representative(s) from a panel, where no suitable or willing representative is available to the person. The provision of a panel of independent persons could also be used for ADs until identifies a suitable support person.

4.4. Informality for Execution and Forms
The Virginia legislation adopted an informal and flexible approach to AD execution to minimise exclusion. The legislation minimises formalities so that legally binding ADs are available to everyone. The AD is easily executable, requiring the signature of the person and two adult witnesses to be valid. The legislation does not place any limitations on adult witnesses or require legal certification. The document is normally in writing, but an oral AD is authorised if a person has been diagnosed with a terminal condition and is unable to write the directive. The oral AD must be communicated to the attending physician, in the presence of two adult witnesses, and documented in the person’s medical record. The CRPD requires an informal and flexible approach to support measures, requiring them to be accessible and inexpensive. Some persons with disabilities or literacy difficulties may be unable to communicate through a written AD, suggesting a need for oral ADs with independent witness safeguards or recorded evidence in limited circumstances. The

53 Assisted Decision-Making (Capacity) Bill 2013, s 11 and s 21.
54 Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013. Head 8(5)
55 Assisted Decision-Making (Capacity) Bill 2013 s 23(3) and s 61(1). Decision-making representative (s) will be appointed where a person is deemed to lack capacity by the court and is unable to make a co-decision making agreement. Section 61 requires the Public Guardian to establish panels of suitable persons willing and able to act as decision-making representatives.
56 It is best practice for heirs and proxy decision-makers not to act.
57 John Oliver, Advance Health Care Directives in Virginia: New Improved and Expanded: How Recent Innovations Improve Planning and Outcomes for General Care, End-of-Life Care and Mental Health Care (Virginia Pro Bono Legal Project 2012).
58 Va Code s 54.1-2983.
informality of the Virginia directive minimises the barriers to AD completion and is appropriate for use under the CRPD.

The AD form was viewed as an important feature of the Virginia directive. The legislation does not require a statutory form but a number of templates have been developed i.e. a statutory form, a short form, and an integrated form (which includes mental health and other decisions). The Ulysses clause allows the individual to prioritise the AD wishes over his/her own objections during future crisis periods on the form. The form confers many advantages, including recognition by providers, clear articulation of treatment choices and the granting of authority to proxy decision-makers. The form was also found to alleviate concerns in relation to the role of the peer facilitator. One service user representative believed mental health decisions should be documented separately to physical health decisions to avoid stigma in general health settings. This suggests a need to develop separate and integrated forms to accommodate these concerns.

The simplification of the form is considered a vital part of the implementation process in Virginia. The complexity of the form has been identified as a barrier to completion in previous research. The Virginia facilitators reported that service users with lower educational levels needed support to complete the form and individuals with literacy difficulties required a significant amount of assistance. Other mental health service users were reported to be experiencing concentration problems, but visual brochures were improving completion rates on one Virginia site. Some peer facilitators believed that the AD form was overwhelming at the

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60 Va Code s 54.1-2984.
61 The short form is a simplified version of the statutory form but does not include a Ulysses clause.
62 Each of the forms includes presumed powers for the proxy.
63 Roundtable meeting with peer facilitators and other stakeholders (Chesapeake Community Service Board 10 August 2012).
64 Meeting with service user representative (University of Virginia 7 August 2012).
66 Meeting with service user representative (University of Virginia 7 August 2012).
67 Chesapeake Community Service Board (CSB). Community mental health agencies are referred to as Community Service Boards in Virginia. A number of CSBs have been recruited to pilot the implementation of ADs in the public mental health system, including Chesapeake.
early stages of recovery process. The CRPD requires an exploration of ways of providing information adapted to the needs of the individual. The information should, therefore, be delivered in a format appropriate to the individual and include support for completion.

4.5. Invoking the Advance Directive and Capacity Determinations

The procedure for invoking an AD is set out in the Virginia legislation. The directive is activated by the attending physician who certifies that the person lacks the capacity to make a healthcare decision. The determination is independently reviewed by a second physician or licensed psychologist and the person is informed of the finding. The legislation sets out a legal definition of ‘incapacity’ and outlines the content of the evaluation, similar to the functional definition proposed in the 2013 Bill in Ireland. A communication disorder or a clinical diagnosis alone cannot form the basis of a capacity determination. In some jurisdictions, being subject to capacity or mental health legislation automatically invokes an AD. While this confers advantages, it can create an assumption that individuals who are involuntarily detained lack decision-making capacity. In Virginia, the physician must consult the proxy decision-maker or a relative from the default list if the person cannot make a healthcare decision. Decision-making authority can be restored when one physician certifies that the person has regained capacity. The Virginia procedure was designed to provide greater efficiency, ease of use and fairness in decision-making in relation to capacity assessment and treatment. However, some providers appear to be still using court authorised treatment in preference to appointing two capacity assessors and allowing the surrogate to make a decision.

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68 Roundtable meeting with peer facilitators and other stakeholders (Chesapeake Community Service Board 10 August 2012).
70 Va Code s 54.1-2983.
71 Va Code s 54.1-2983.2.
72 Incapacity to make an informed decision is defined as being unable to understand the nature, extent or probable consequences of the proposed healthcare decision, or to make a rational evaluation of the risks and benefits of alternatives to that decision: Va Code s 54.1-2982.
73 Va Code s 54.1-2983.2.
74 Mental Health (Care and Treatment) (Scotland) Act 2003.
76 Va Code s 54.1-2983.2(d).
77 In Virginia, an application can be made to the court to authorise treatment under statute because the person is incapacitated and no surrogate exists if it is in the person’s ‘best interests’.

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In Ireland, the capacity to consent to treatment is currently determined by the responsible consultant psychiatrist without independent review and treatment decisions are made in the ‘best interests’ of the person if he/she is deemed to lack capacity.\(^{78}\) The CRPD requires the abolition of substitute decision-making regimes based on the individual’s ‘best interests’, which lead to denials of legal capacity, and requires State Parties to replace them with a range of supported-decision-making options.\(^{79}\) The 2001 Act should be amended to reflect the principles of the CRPD and the 2013 Bill. The draft scheme for ADs provides for a presumption of capacity for all adults to execute a directive.\(^{80}\) In the absence of an AD or designated decision-making representative to make the decision, the High Court will decide on more serious matters such as the withdrawal of life-sustaining treatment.\(^{81}\) The draft scheme does not specify who will determine decision-making capacity for the purpose of invoking and revoking ADs. The CRPD requires a re-evaluation of capacity determinations for the activation and deactivation of ADs. ADs should be separated from legal frameworks, which use capacity determinations as a threshold. The requirement that an individual must be declared incapable in order for an AD to be invoked or revoked limits their use and fails to comply with the presumption of capacity.\(^{82}\)

4.6. Revoking and Reviewing the Advance Directive

In some U.S. jurisdictions, the person must have decision-making capacity to revoke the directive, while others allow the AD to be revoked at any time. Other jurisdictions allow the person to choose whether the document is to be revocable during crisis periods.\(^{83}\) A proportion of mental health service users prefer the

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\(^{78}\) Mental Health Act, 2001. The Act is currently under review so the interface with the proposed capacity legislation is still unclear.


\(^{80}\) Life-saving treatment decisions must be accompanied by a written statement from the person stating that the AD is applicable in these circumstances. Department of Health, ‘Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 3(2)(a), Head 5(3).

\(^{81}\) Assisted Decision-Making Bill 2013 s.4; Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 6(2). Decisions relating to life-saving treatment must be accompanied by a written statement from the person stating this intention for it to be applicable. Head 5(3).

\(^{82}\) Article 12(2).

\(^{83}\) Arizona and Washington.
directive to be revocable at any time. The CRPD Committee states that the person should have the right to end the support measure at any time he/she chooses. The presumption of capacity implies that the AD can be revoked at any time. While this confers autonomy, issues arise in mental health where a person knows he/she will object to the previously expressed wishes when unwell and wants to override his/her own future objections to avoid deterioration and damage to interpersonal relationships.

The Virginia directive resolves the revocability issue by allowing a person to change AD preferences at any time, unless a Ulysses clause has been executed. The Ulysses clause allows the person to clearly specify in the directive if he/she wishes the AD preferences to stand in the face of his/her own subsequent objections during crisis periods. Many individuals self-bind to avoid deterioration and the need for involuntary admission. The optional clause must be attested to by two physicians or a physician and a licensed psychologist at the time of execution as a safeguard. The clause can be revoked at any time unless a declaration of incapacity has been made. An objection to the withholding or withdrawal of life-prolonging treatment is respected even if a Ulysses clause has been executed due to the gravity of the decision. The legislation also allows a person to empower a trusted proxy decision-maker to authorise hospitalisation for mental health treatment for up to ten days, subject to safeguards. The admission is subject to independent review by a physician and a special judge in the hospital after the ten day period.

Some Virginia service users expressed a desire for a Ulysses clause in the legislation to avoid the trauma of involuntary admission and police transportation. The Irish mental health legislation confers power on the police to take a person into custody

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84 In one study of 106 service users with ADs and 487 crisis events, the directive was never revoked as a whole, although in 105 (22 per cent) of the crises, service users changed their minds about some specific instructions: Debra Srebnik and Scott Kim, ‘Competency for Creation Use and Revocation of Psychiatric Advance Directives’ (2006) 34(4) Journal of the American Academy of Psychiatry and the Law 501.
86 Article 12.
87 Self-binding directives are available in a number of U.S. States, Canadian provinces and the Netherlands.
88 Va Code s 54.1-2982.
and to enter a dwelling or other premises by force if necessary.\textsuperscript{89} Almost a quarter of the applications for involuntary admissions in Ireland in 2010 were made by police officers, a rise from 16 per cent in 2007, suggesting an increase in coercion.\textsuperscript{90} This can further exacerbate stigma and distress and the notion of criminality. The trauma of involuntary admission is conveyed in the service user statements in the empirical study (in chapter 6). The Ulysses clause allows the person’s prior consent to be used over involuntary admission and is a valuable tool in avoiding coercion.

Approximately 50 per cent of service users in Virginia are reported to be executing the clause. The Ulysses clause is reported to be successful with both service users and psychiatrists in Virginia and is a unique feature of mental health ADs.

In some jurisdictions, the directive is only valid for a specific period after which the person has to revalidate it.\textsuperscript{91} The Virginia directive is valid until the person decides to revoke it. The merit of revisiting the AD after each crisis was recognised, but it was decided that an inbuilt statutory review would impact on the validity of the directive.\textsuperscript{92} The frequency or responsibility for review is not specified, but service users can change the AD at any time if they wish to do so. The successful Gundersen Lutheran health system programme for end-of-life directives in Wisconsin suggests that advance care planning is an ongoing communication process, which becomes more specific over time.\textsuperscript{93} The AD should be reviewed after each mental health episode so new preferences can be incorporated.\textsuperscript{94}

\textsuperscript{89} Mental Health Act 2001, s 12.
\textsuperscript{91} Pennsylvania and Tennessee provide for two-yearly reviews; Louisiana, Texas, Utah, Illinois, Ohio, Oregon and South Dakota provide for three-yearly reviews.
\textsuperscript{92} Meeting with legal expert, Virginia (Virginia Beach 9 August 2012).
\textsuperscript{93} Gundersen Lutheran Health System provides an innovative advance directives program that provides patient-centred healthcare in the end stages of life: Bernard Hammes and others, ‘A Comparative, Retrospective, Observational Study of the Prevalence, Availability and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem’ (2010) 58 (7) Journal of the American Geriatrics Society 1249.
4.7. Access to Advance Directives

The issue of provider access was identified in the Virginia stakeholder survey.\textsuperscript{95} Stakeholders are unlikely to invest time in ADs if they are sceptical about accessing the document in a crisis.\textsuperscript{96} The Virginia stakeholders pointed to the need to make ADs accessible to emergency services staff and to embed them into staff consciousness.\textsuperscript{97} Service users are advised to distribute copies of the directive to local mental health services and emergency staff after the facilitation process. A crisis plan card has also been developed, which alerts providers as to the existence of the directive and informs them where the AD is located and details of the proxy decision-maker.\textsuperscript{98} The card is available to download from the registry and other sites. An online registry was established in Virginia in 2011 and plans are underway to include ADs in electronic medical records.\textsuperscript{99} The Virginia legislation directed the Department of Health to establish a secure online registry.\textsuperscript{100} Only the person executing the document may submit it to the registry, but the failure to register an AD does not invalidate it.\textsuperscript{101} The Department of Health is working with stakeholder groups to make the registry more accessible.\textsuperscript{102} Electronic medical records also provide an ideal landscape for ADs and help build self-directed care into practice. The successful Gundersen Lutheran programme for end-of-life directives in Wisconsin provides advance planning information in electronic records wherever they need to be accessed.\textsuperscript{103}

\begin{footnotes}
\item\textsuperscript{95} Christine Wilder and others, ‘A Survey of Stakeholder Knowledge, Experience, and Opinions of Advance Directives for Mental Health in Virginia’ (2013) 40 (3) Administration and Policy in Mental Health 232.
\item\textsuperscript{96} Ibid.
\item\textsuperscript{97} The emergency services staff currently lack access to ADs, but electronic medical records may help rectify this anomaly. Emergency services staff are responsible for screening individuals before they are admitted voluntarily or involuntarily to state and private hospitals. Approximately 50,000 emergency evaluations are conducted by CSB staff each year. Almost 50 per cent of evaluations involve people who are not currently in treatment.
\item\textsuperscript{98} Virginia Crisis Plan Card, \url{http://www.virginiaadvancedirectives.org/Crisis_Card.html} [accessed 23 February 2014].
\item\textsuperscript{99} Virginia Department of Health, Advance Health Care Directive Registry, available at: \url{https://www.virginiaregistry.org/} [accessed 13 March 2014]. The adoption of electronic medical records is a key aspect of healthcare reform in the U.S.
\item\textsuperscript{100} § 54.1-2994 et seq 2008
\item\textsuperscript{101} § 54.1-2995.
\item\textsuperscript{102} Some stakeholders felt the registry is cumbersome and could result in digital exclusion.
\item\textsuperscript{103} Gundersen Lutheran System, \textit{Respecting Choices: Advance Care Planning} \url{http://www.gundersenhealth.org/respecting-choices} [accessed 30 October 2014].
\end{footnotes}
In Ireland, the 2013 Bill proposes to establish a register of decision-making agreements through the Office of the Public Guardian, but it is not clear whether this will be accessible by healthcare providers or include ADs. The draft scheme for ADs does not propose a registry, but the issue has been raised as part of the public consultation on the legislation and may form part of the Code of Practice. The need to establish a national electronic information system is recognised in the HSE service plan and a web-based information system for mental health services (WISDOM) has been piloted, but an AD registry will also be needed. The Minister for Health published an ehealth strategy for Ireland in December 2013 and published a Health Identifiers Bill.

5. Implementing Law into Practice

The transition from law into practice poses a myriad of challenges. Once ADs are enshrined into legislation, considerable attention must be given to implementation. A co-ordinated effort using a multi-pronged approach was undertaken in Virginia immediately after the Health Care Decisions Act was enacted. A number of community mental health vanguard pilot sites were recruited to identify an effective implementation model. System transformation and the implementation of ADs are part of an ongoing project in Virginia. The three-phase implementation study focuses on knowledge, attitudes to facilitation, content and completion and the impact on recovery and coercion. A survey of stakeholder groups undertaken during the introductory phase provided critical information on implementation.

104 Assisted Decision-Making (Capacity) Bill 2013 s 56(2)(b).
109 Vanguard means the leading position in a movement. A number of community mental health sites have been recruited to pilot the implementation of ADs in the public mental health system, including Region Ten, Prince William and Chesapeake. Norfolk CSB and Virginia Beach are participating informally in the project. Middle Peninsula/Northern Neck CSB recently joined the project. The main statutory function of CSBs is to serve as the single point of entry to the public mental system.
The findings suggested that many of the barriers could be addressed through support and education. The second stage of the research examines AD completion in community mental health settings and their effect on empowerment, self-esteem, treatment engagement and service satisfaction. It is envisaged that the research will yield further recommendations for facilitation and increase AD usage by persons with mental health conditions. The research will help inform Ireland and other jurisdictions seeking to follow the Virginia model.

5.1. Support for Developing Advance Directives

A major theme in developing a model for ADs is whether they are made independently or with support. The low uptake of ADs in the U.S. resulted in the introduction of several features, including facilitated support for completion. Structured facilitation is a process that emphasises the use of reflective listening and non-directive discussion to help the individual clarify and articulate values and choices. The research found mental health service users preferred support to develop ADs and had significantly better health outcomes. The need for support is recognised in the CORD, which promotes a system whereby appropriate support measures are provided to enable individuals to exercise their legal capacity where needed. The CRPD requires recognition of naturally-occurring supports including friends and families, as a key part of decision-making.

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111 Ibid.
117 Article 12(3).
5.2. Peer Facilitation Model

The Virginia project adopted facilitated ADs and is currently focusing on the effectiveness of the process. Facilitated peer support forms a core component of the AD completion process. Peer support refers to the process whereby a person of equal standing supports another person who shares the experience. The peer support model is also being used to support the development of ADs in other U.S. States. The peer facilitation model was initiated by a group of service users on a community mental health site after the Virginia legislation was enacted. The pilot sites initially adopted a model whereby case managers were facilitating ADs on an individual basis. However, issues arose in relation to legal liability and time constraints. Resistance was higher where prior training had not been undertaken with staff. Some sites are now using peer specialist workers, while others are using volunteer peer facilitators. Other projects are using a combination of case managers and peer facilitators. One stakeholder suggested case managers have a key role in introducing ADs to service users and making referrals to facilitators for completion.

Several peer facilitators reported that the AD development process was more difficult than anticipated. The failure to attend follow up facilitations was reported to be problematic at a number of sites. A number of strategies were being used to overcome this problem including outreach services, out of hour appointments and AD completion days. One peer felt that service users were not attending follow up appointments due to the overwhelming nature of the document. The provision of

121 Norfolk CSB.
122 Case managers were selected as a common point of contact for service users.
123 Peer specialists are employed by community mental health agencies to provide services for people with mental health conditions.
124 Middle Peninsula/Northern Neck.
125 Meeting with stakeholder, Virginia (Charlottesville 6 August 2012).
126 Roundtable meeting with peer facilitators and other stakeholders (Chesapeake CSB 10 August 2012).
peer office hours increased the number of referrals, staff awareness and agency commitment. One peer facilitator felt more consistency was needed in the facilitation process. Data from 26 service users who completed ADs indicated strong interest, but inconsistent knowledge and practice implementation. The majority of service users specified treatment preferences and the strongest response was in relation to ECT treatment. Many service users requested to be left alone during a crisis. The anecdotal feedback from the pilot sites suggested service users were gaining enormous value from documenting their preferences. Peer facilitators communicated that service users felt a sense of accomplishment and control after completion, which improved well-being.

Facilitator certification is viewed as an important component of the Virginia model. Certification confers recognition and credibility for peers. An in-house certification programme was developed for peer facilitators on one mental health site after the legislation was introduced. A state-wide curriculum is currently being developed for mental health services staff, peer specialists, case managers and other facilitators. The materials will provide guidance for other jurisdictions. Lawyers are also being trained to support AD development on a pro bono basis. The Virginia experience demonstrates the need for adequate training, recognition and support for peer facilitation to be effective. The CRPD reaffirms the importance of peer support to attain maximum independence and refers to them as an example of a support under Article 12. State parties are required to provide access to support for

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128 Roundtable meeting with peer facilitators and other stakeholders (Chesapeake 10 August 2012).
130 It was reported that most service users did not require additional treatment information.
131 Meeting with service user representative (University of Virginia 7 August 2012).
132 Meeting with legal expert, Virginia (Virginia Beach 9 August 2012).
133 Norfolk CSB developed an in house certification process.
135 Professional services given on a voluntary basis at no cost to the recipient.
legal capacity.\textsuperscript{137} The development of peer run services and support is also a key part of the recovery approach.

6. Implementation Issues and Barriers

6.1. Education

Education plays a key role in the successful implementation of ADs. The perceived barriers increased for groups that were not educated on ADs in the Virginia stakeholder survey.\textsuperscript{138} Each of the stakeholder groups (service users, clinicians, administrators, families, and advocates) had specific educational needs or areas where additional training was needed. The need for on-going targeted education for clinicians was identified in the survey.\textsuperscript{139} The development of an AD does not generally involve the treating psychiatrist in Virginia unless a Ulysses clause has been executed, but the research shows an association between clinician support and service user interest in directives.\textsuperscript{140} Eighteen per cent of Virginia stakeholders perceived that ADs would lead to an increase in malpractice lawsuits.\textsuperscript{141} This is consistent with the rate of concern among Irish consultant psychiatrists (in chapter 6). Tailored education programmes, champions and professional bodies were viewed as important to garner the support of psychiatrists.\textsuperscript{142} The Virginia survey findings suggested educating stakeholders about the opinions of other groups to reduce barriers.\textsuperscript{143} The inclusion of peers in education programmes has been critical in promoting the use of ADs across the stakeholder groups in Virginia and reducing stigma. The message was considered more profound when the feedback was coming

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\textsuperscript{137} Ibid para 25(e).
\textsuperscript{139} Seventeen per cent of in-patient clinicians, 16 per cent of out-patient clinicians, and 30 per cent of in-patient and out-patient providers reported had received AD training. Christine Wilder and others, ‘A Survey of Stakeholder Knowledge, Experience, and Opinions of Advance Directives for Mental Health in Virginia’ (2013) 40 (3) Administration and Policy in Mental Health 232.
\textsuperscript{141} Christine Wilder and others, ‘A Survey of Stakeholder Knowledge, Experience, and Opinions of Advance Directives for Mental Health in Virginia’ (2013) 40 (3) Administration and Policy in Mental Health 232.
\textsuperscript{142} Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 15 August 2012)
\textsuperscript{143} Christine Wilder and others, ‘A Survey of Stakeholder Knowledge, Experience, and Opinions of Advance Directives for Mental Health in Virginia’ (2013) 40 (3) Administration and Policy in Mental Health 232.
\end{flushright}
from a service recipient. The involvement of peers in AD facilitation and education provides an entry path to peer participation in the provision of mental health services.

Provider education is viewed as critical for the effective implementation of ADs. The Gundersen Lutheran programme in Wisconsin achieved over 90 per cent participation and compliance by providers through 40 hours of training on communicating with patients and families about advance planning.\(^{144}\) The ‘Respecting Choices’ programme at Gundersen Lutheran provides six modules of online training for health professionals.\(^{145}\) Virginia is attempting to replicate the model by identifying an organisation to increase participation and compliance rates. The Scottish framework also demonstrated the need to provide ongoing community and professional education.\(^{146}\) A series of educational conferences were undertaken in Virginia after the Health Care Decisions Act was enacted.\(^{147}\) The initial programme included providing information, education and training on the new law to case managers, supervisors and advocates.\(^{148}\) Presentations were also made to regional management groups, executive directors and mental health services staff throughout the State. The programme highlighted the need for provider education to secure support.\(^{149}\) A website was also created to provide information for professionals, families and service users.\(^{150}\) Many stakeholders considered provider education to be the missing piece in the Virginia implementation effort and believed understanding could be dramatically increased with consistent training. The inclusion of ADs on educational curricula for trainee mental health professionals, staff induction and continuing professional development (COD) programmes was

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148 The programme included a short session with Duke University staff on structured facilitation.
150 [http://www.virginiaadvancedirectives.org/]
The Virginia stakeholders suggested the need for legal compliance training for providers after the new law is enacted in Ireland. Canadian healthcare systems are using staff completion to embed ADs into the belief system. Provider completion can promote understanding and support for ADs.

In a recent report, the Inspector of Irish Mental Health Services found a lack of understanding of basic aspects of mental health legislation and limited training opportunities. The Office of the Public Guardian will have an educational role under the 2013 Bill. These duties will include providing advice and guidance, promoting public awareness of the legislation and the CRPD and establishing a website. This educational role may extend to mental health ADs or the Mental Health Commission may assume responsibility. The draft legislation does not refer to education, but this may form part of the Code of Practice. The CRPD Committee referred to the need for training and awareness for professionals such as police, social workers and the judiciary to ensure respect for the legal capacity of persons with disabilities.

Family members were also considered to be an important part of the AD process in Virginia. The Virginia stakeholders held the view that a State wide education programme with families would be beneficial to implementation and in ensuring the person’s wishes are respected. Some family members in Virginia initially expressed concern that ADs would be used to refuse all treatments, but this was alleviated through the research evidence, which shows refusal of all treatment is rare. Family

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151 Meeting with system stakeholders (Richmond 8 August 2012).
152 Ibid.
153 Wendy Wainright, ‘Key Issues in Staff Education to Support Advance Care Planning in the Hospital Settings’ Vancouver Health Authority <https://www.researchgate.net/post/Key_issues_in_staff_education_to_support_advance_care_planning_in_the_hospital_setting> [accessed 9 October 2013].
155 Assisted Decision-Making (Capacity) Bill 2013 s 56 (1)(a) and (2)(p).
156 Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) 35.
157 Some family members facilitate the completion of ADs.
groups were viewed as an ideal place to discuss the Ulysses clause. A recent study in the U.K. found mental health service users experienced high levels of discrimination from those with whom they had regular contact including mental health professionals and families. This reinforces the need for education. As one of the characters in Virginia Woolf’s Mrs Dalloway asserts “the people we are most fond of are not good for us when we are ill.” One peer facilitator in Virginia felt many families are not educated sufficiently about mental health difficulties.

6.2. Overriding Advance Directives and Accountability Mechanisms

The potential for ADs to be overridden or ignored by medical staff can lead to low completion rates among service users. The Virginia survey found that service users and families needed to feel confident that the AD will be respected by clinicians. The legislation places an obligation on providers to follow the AD unless it is illegal, unethical or medically inappropriate. A person cannot be treated against the directive instructions without legal authority. The person or proxy decision-maker must be advised if the AD cannot be followed and given the opportunity to identify another provider. The override should be input on the patient’s chart and may have to be reported to the human rights committee in some facilities. One service user representative believed that the failure to follow a validly executed AD would cause further disempowerment and distrust in the system. The inclusion of reasons for treatment decisions was viewed as important in ensuring


Roundtable meeting with peer facilitators and other stakeholders (Chesapeake Community Service Board 10 August 2012).


Virginia Woolf, Mrs Dalloway (Harcourt 2002) 147.


The decision-maker gets a minimum of 14 days to find an alternative provider and the doctor must provide care in the interim: Va Code s 54.1-2990(a).

Meeting with service user representatives (Richmond 8 August 2012).
respect for the AD.\textsuperscript{166} The publication of figures showing the low number of ADs being overridden has been used to alleviate fears in other jurisdictions,\textsuperscript{167} but Virginia currently lacks statistics in this area. One Virginia stakeholder suggested the need for test cases so that a clear procedure can be established.\textsuperscript{168} The establishment of a clear monitoring mechanism whereby treatment in conflict with a valid AD is reported to an independent authority may increase accountability and instil service user confidence.\textsuperscript{169}

6.3. Resources
The research points to the importance of accompanying the introduction of ADs with appropriate resources.\textsuperscript{170} The resources required to implement ADs are often underestimated.\textsuperscript{171} According to international experts, the implementation of ADs as a meaningful alternative to involuntary detention requires investment to gain long-term savings.\textsuperscript{172} Many of the goals of the Virginia law reform are not being met due to resource difficulties.\textsuperscript{173} Virginia currently lacks accurate completion figures, but AD uptake appears lower than expected and implementation is slow. In the 2010 stakeholder survey, 49 per cent of service user respondents reported having an AD and 75 per cent of those who did not a directive expressed a desire to complete one.

\textsuperscript{166} Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 15 August 2012); Jeffrey Swanson and others, ‘Facilitated Psychiatric Advance Directives: A Randomized Control Trial of an Intervention to Foster Advance Treatment Planning among Persons with Severe Mental Illness’ (2006) 163 American Journal of Psychiatry 1943.

\textsuperscript{167} Figures from the Scottish Mental Welfare Commission show that the vast majority of advance statements are adhered to and few are overridden. The Commission received 25 notifications of overrides in 2013 but only 12 of these were valid. Mental Welfare Commission for Scotland, Mental Health Act Monitoring 2012/2013 (Mental Welfare Commission 2013) 44.

\textsuperscript{168} Meeting with service user representative (University of Virginia 7 August 2012).

\textsuperscript{169} The Scottish review recommended requiring responsible medical officers to review any treatment in conflict with an AD and provide a written record of efforts to address the person’s wishes: Jim McManus and others, Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: Report: As Presented to Scottish Ministers March 2009 (Scottish Government 2009).


\textsuperscript{171} Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 15 August 2012).

\textsuperscript{172} Ibid.

\textsuperscript{173} Meeting with Virginia law reform expert, University of Virginia (Charlottesville 7 August 2012).
but these figures may be inflated due to response bias.\textsuperscript{174} Previous studies in other states reported completion rates of 3.9 to 12.9 per cent for mental health ADs.\textsuperscript{175}

The mental health system in Virginia is under-funded and pressure on staff is increasing.\textsuperscript{176} Several Virginia stakeholders considered provider capacity and resources to be barriers to progress. Without additional funding, providers are less willing to embrace ADs, staff are reluctant to take on responsibility and the system lacks sufficient numbers of facilitators. The responsibility for introducing ADs needs to be assigned to specific members of staff.\textsuperscript{177} The system stakeholders suggested designating responsibility for ADs, but identifying staff members has proven difficult and many agencies do not have anybody acting in the role.\textsuperscript{178} Case managers and psychiatrists were reported to be under time constraints. The public health system in Virginia lacks the flexibility to build ADs into job descriptions and the process was viewed as disjointed due to lack of consistent staff capability. Stakeholders suggested the need for new strategies to incorporate ADs into ‘best practice’.\textsuperscript{179} Recommendations from other jurisdictions included designating explicit responsibility to recovery staff.\textsuperscript{180} The relevance of the AD to care and a written record of efforts made to address the person’s wishes were also recommended.\textsuperscript{181} The opportunity to complete an AD with support should be introduced at various stages of the recovery process. Some stakeholders held the view that AD development should form part of the care plan recovery goals.\textsuperscript{182} Care plans are generally completed with the clinician or case manager at both inpatient and

\textsuperscript{176} Richard Bonnie and others, ‘Tragedy and Mental Health System Transformation in Virginia’ (2009) 28 (3) Health Affairs 793.
\textsuperscript{177} Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 15 August 2012).
\textsuperscript{178} Meeting with system stakeholders, Department of Behavioral Health and Developmental Services (Richmond 8 August 2012).
\textsuperscript{179} Meeting with system stakeholders, Department of Behavioral Health and Developmental Services (Richmond 8 August 2012).
\textsuperscript{180} Jim McManus and others, \textit{Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: Report: As Presented to Scottish Ministers March 2009} (Scottish Government 2009).
\textsuperscript{181} Ibid.
\textsuperscript{182} Roundtable meeting with peer facilitators and other stakeholders (Chesapeake 10 August 2012).
outpatient level in Virginia. Some Virginia stakeholders suggested the possibility of introducing ADs in inpatient settings.

The Irish mental health services have been similarly affected by resource issues (see chapter 4). An Irish Medical Organisation (IMO) survey of GPs and consultant psychiatrists found inadequate funding, lack of leadership and planning, a lack of community multi-disciplinary mental health teams (CMHTs) and stigma to be the major issues impacting mental health treatment. The Irish mental health system is characterised by high readmission rates, and involuntary admissions have been increasing again since 2010. The figures suggest a need for alternative responses in the Irish mental health services. ADs are associated with a reduced need for readmission and involuntary detention conferring economic and other benefits. The implementation of ADs will require some investment, but cost savings can be accrued in the longer term. The legislation is destined to fail if a support system is not built around ADs prior to implementation.

6.4. Reduced Involuntary Admission and Treatment

ADs are considered to provide an alternative response to involuntary admission in Virginia. The Virginia Commission recognised the lack of opportunity for self-determination in the involuntary admission process and sought a more service user oriented experience. The legislation requires the court to inquire if the person has an AD or if a proxy decision-maker is available to make a treatment decision. AD

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189 More than 80 per cent of CSB admissions were estimated to be involuntary.
treatment refusals are normally honoured during involuntary detention outside of defined emergencies. Emergencies are defined as a situation that requires the provider to take immediate action to avoid harm, injury, or death to an individual or to others. The need for coercion is expected to decrease in Virginia as ADs increase engagement with recovery and facilitate advance consent to treatment. 

The absence of less restrictive responses and accessible community services can lead to system disengagement. ADs have been found to increase treatment engagement and reduce the need for coercion in previous research. Advance planning can transform the way families, providers and police respond to mental health crises by allowing them to provide treatment in accordance with the person’s wishes. Bonnie asserts that ADs represent an opportunity to change the legal model of care from one of ‘coercion to contract’.

In Ireland, it is proposed to incorporate legislative provisions for ADs into the 2013 Bill at Committee stage, but differential standards are proposed for those who are detained under mental health legislation. AD treatment decisions will be non-legally binding and taken into consideration during involuntary detention. The CRPD requires respect for the legal capacity of all persons, including those detained under mental health legislation. Several concluding observations of the CRPD Committee have stated that forced treatment by mental health and other professionals is a violation of the right to equal recognition before the law, the right to personal integrity (Article 17), freedom from torture (Article 15), freedom from violence, exploitation and abuse (Article 16) and the right to the legal capacity.

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190 HB 638, effective July 1, 2012 amending Va Code s.37.2-1101(g)(4).
191 Department of Behavioral Health and Developmental Services (DBHDS) Human Rights Regulations, 12VAC35-115-70; Va Code s 37.2-1101.
192 Ibid.
198 Article 12 provides for equal recognition before the law, Article 14 provides for the right to liberty, and Article 17 provides a right to physical and mental integrity.
(Article 12). The 2001 Act, which is currently under review, should be amended to reflect the provisions of the 2013 Bill and to ensure ADs are equally available to all persons and enforceable during involuntary detention.

6.5. System Barriers
The structure of the health system in Virginia was viewed as a barrier to AD implementation. The State lacks an integrated healthcare system or centralised authority for funding mental health services making it difficult to access decision-makers. The greatest challenges were reported at the middle level of the system. Wide variations in organisational culture and programmes exist, which impact on staff attitudes. Stakeholders suggested that paternalism is still common in the mental health system despite training for law enforcement officers, special judges, community services and hospital staff. The premise that individuals with mental health conditions can participate in treatment decisions is not widely accepted and cultural change is slow. It is difficult for many staff to envisage themselves in a shared decision-making relationship with service users. Information champions and site preparation were viewed as critical in achieving a cultural shift in mental health practice. Several stakeholders were surprised at the general lack of awareness of ADs in Virginia. One service user representative commented on the dearth of knowledge in medical settings where ADs rarely formed part of educational programmes or materials. Low awareness was also reported in the service user population. Peer leadership was viewed as key to securing service user support. Service user fear and distrust in the system can act as barriers to AD use. The delivery of awareness campaign by peer leaders was suggested to increase service

200 Meeting with system stakeholders, Department of Behavioral Health and Developmental Services (Richmond 8 August 2012).
202 Community mental health agencies are referred to as Community Service Boards in Virginia. The main statutory function of CSBs is to serve as the single point of entry to the public mental system.
203 The level of knowledge was perceived to be low in both public and private hospital settings.
204 Meeting with service user representative (University of Virginia 7 August 2012).
205 Meeting with consumer representatives (Richmond 8 August 2012).
user trust in the process. One service user representative stated that individuals have ‘nothing to lose and so much to gain’ through the AD development process.\(^{206}\)

Some Virginia stakeholders suggested the biggest challenge was changing public attitudes in relation to mental health.\(^{207}\) One service user representative suggested it ‘takes time to re-educate people’.\(^{208}\) The National Alliance on Mental Illness (NAMI) undertakes public anti-stigma campaigns in Virginia, but stakeholders believed that programmes also need to be undertaken in the education system for children and adolescents.\(^{209}\) The participation of individuals with mental health conditions in treatment decisions was regarded as a paradigm shift for lawmakers and society.\(^{210}\)

Structural and cultural change is also needed in the Irish mental health services.\(^{211}\) The Independent Monitoring Group (IMG) for Irish mental policy, found resources and a cultural shift in attitudes are needed.\(^{212}\) Stigma was reported to be an issue in the Irish mental health services\(^{213}\) and middle management were viewed as responsible for resistance to change in some areas.\(^{214}\) A number of reports have identified concerns in relation to low levels of service-user participation and compliance with individual care planning.\(^{215}\) The implementation of ADs requires an

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\(^{206}\) Roundtable meeting with peer facilitators and other stakeholders (Chesapeake 10 August 2012).
\(^{207}\) Meeting with system stakeholders, Department of Behavioural Health and Developmental Services (Richmond 8 August 2012); Roundtable meeting with peer facilitators and other stakeholders, (Chesapeake 10 August 2012).
\(^{208}\) Roundtable meeting with peer facilitators and other stakeholders, (Chesapeake 10 August 2012).
\(^{209}\) Meeting with service user representatives (Richmond 8 August 2012).
\(^{210}\) Ibid.
\(^{211}\) Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).
\(^{213}\) Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).
attitudinal shift among providers, law makers and wider society. Societal attitudes pose significant challenges to AD implementation. Community education is crucial in achieving a wider attitudinal shift towards individuals with mental health conditions.

6.6. Leadership and Oversight
Leadership was considered to be an instrumental part of the AD implementation process in Virginia. The support of senior management was viewed as key to the adoption of ADs. Stakeholders suggested a need for mental health leadership to communicate an expectation and rationale for using ADs to staff. The lack of accountability in the Virginia system was viewed as problematic by system stakeholders. The need for a ‘bottom up’ desire and ‘top down’ incentive for implementation was identified in the stakeholder survey. Some stakeholders suggested ADs should form part of accreditation and performance evaluations. ADs became an explicit part of one community service after an expectation was created by management that service users are referred for facilitation. Quality improvement initiatives such as the ACCEPT audit can help sites measure performance in relation to advance planning processes. The implementation of ADs requires a care philosophy where the use of ADs is incentivised and measured.

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217 Roundtable meeting with peer facilitators and other stakeholders (Chesapeake Community Service Board 10 August 2012).
218 Meeting with system stakeholders, Department of Behavioural Health and Developmental Services (Richmond 8 August 2012).
220 Discussions have taken place at one site to include referrals in annual evaluations.
221 Norfolk CSB.
A designated implementation body was also viewed as crucial to sustain progress in Virginia. The Co-ordinating Committee for Promoting Use of Advance Directives by People with Mental Illness provides oversight, but stakeholders suggested implementation would be more effective with a dedicated body to oversee the process. Virginia lacks a regulatory agency so the various representatives have taken responsibility based on personal interest. Consistency and oversight were viewed as important, particularly when resources are needed for progress. The Scottish framework demonstrates the value of linking innovative legislation to independent accountability and oversight mechanisms. In Ireland, the Office of the Public Guardian will have a supervisory role under the 2013 Bill, but the Mental Health Commission may provide independent oversight for ADs in the mental health services. The Virginia experience suggests that a monitoring body will be crucial to sustain progress.

6.7. Legal Barriers

Legal guidance was considered an instrumental part of the implementation process in Virginia. However, the unauthorised practice of law (UPL) was an unforeseen barrier in the AD facilitation process. The Virginia State Bar Association found support for the development of ADs by a non-lawyer to be an unauthorised practice of law. The legislation provides exceptions for healthcare providers, their employees or agents, but the issue has prevented many peers, professionals and advocacy organisations from facilitating AD completion. The Co-ordinating Committee is now focussing on peer specialists and pro bono lawyers who can legally facilitate ADs.

223 University of Virginia, ‘UVA Law Professor Richard Bonnie Testifies before Sandy Hook Panel’ [accessed 9 Ocober 2013].
224 The Committee includes representatives from public mental health agencies, key private organisations and other individuals with specialised knowledge.
226 Assisted Decision-Making (Capacity) Bill 2013 s 56(2).
227 University of Virginia, ‘UVA Law Professor Richard Bonnie Testifies before Sandy Hook Panel’ [accessed 10 February 2013].
228 Va Code Section 54.1-2988 provides an exception: ‘The distribution to patients of written advance directives in a form meeting the requirements of § 54.1-2984 and assistance to patients in the completion and execution of such forms by health care providers shall not constitute the unauthorized practice of law pursuant to Chapter 39 (§ 54.1-3900 et seq.).’ Under Virginia Code Section 8.01-581.1, health care providers include health care entities such as community service boards, hospitals and their employees, contractors and agents who are acting within the scope of their employment or engagement as related to health care or professional services.
The possibility of contractual or agency relationships between advocacy organisations and health care providers is also being explored.

7. Opportunities to Embed Advance Directives into Practice in Ireland
A number of opportunities exist to embed ADs into mental health practice. The recovery approach and the supported decision-making model are part of the context in which ADs can develop. Virginia formally adopted the recovery approach with the goal of maximising autonomy and independence. The CRPD and the recovery approach share many common principles underpinning ADs, including participation, autonomy, choice and empowerment. ADs are multifaceted measures that confer a variety of benefits at the development and invocation stage of the process. Providers need to view ADs as recovery tools that confer developmental and capacity building benefits beyond the legislative aspects. The proportion of ADs executed provides a performance measure for the implementation of a recovery-oriented system. Virginia stakeholders held the view that ADs are not yet perceived as part of the recovery approach and transition from the medical model is slow. One Virginia representative is looking forward to a time when “ADs are expected and respected” and every person is given a voice.

7.1. WRAP (Wellness Recovery Action Planning)
The recovery process provides a natural environment for AD completion. The WRAP (Wellness Recovery Action Planning) programme is being used to support the completion of ADs in mental health settings in Virginia. The self-reflection, crisis planning and support in the WRAP programme provide an ideal foundation for AD development. WRAP has been successfully implemented in many parts of the mental health system and is attracting a large number of participants. The group momentum combined with mutual peer support accelerates completion. Some Virginia stakeholders found the group setting ineffective for the medical aspect of

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229 Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 14 August 2012).
230 Article 12(3). A supported decision-making regime is a cluster of various support options which give primacy to a person’s will and preferences and includes ADs.
232 Meeting with service-user representative (University of Virginia 7 August 2012).
the document due to the personal nature of the content. This suggests a need for both individual and group support. WRAP provides an opportunity to embed ADs into the recovery approach and garner stakeholder support.

7.2. Criminal Justice Population
The Virginia law reform also aimed to reduce criminalisation by diverting individuals to mental health services and providing support. The prevalence of individuals with mental health conditions in the criminal justice system has led to increasing pressure on services. Treatment engagement and discharge planning were viewed as key to reducing recidivism. In a Washington study of individuals with mental conditions convicted of felonies, only 16 per cent received any form of treatment after release and nearly 40 per cent were rearrested within 3 years. The use of ADs can help divert individuals away from the criminal justice system and provide better outcomes in future crises without the need to use more coercive measures such as community treatment orders. The WRAP programme is being offered in Virginia diversion residences, jails and State hospitals. It is envisaged that the majority of inmates in one region will be completing an AD as part of the WRAP programme. This population are faced with a myriad of life management and other decisions when they are sentenced e.g. childcare. The use of ADs for diverting individuals with mental health conditions from the criminal justice system is viewed as one of the contexts in which they can develop.

7.3. Persons with Intellectual Disabilities
Individuals with intellectual disabilities are also being supported to complete ADs in Virginia. The presumption of capacity in the legislation ensures they are not precluded from executing ADs. The monumental impact of guardianship on the

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234 Meeting with service-user representative (University of Virginia 7 August 2012).
236 Approximately 16 per cent of inmates in Virginia have a severe mental health condition. Richard Bonnie and others, ‘Mental Health System Transformation after the Virginia Tech Tragedy’ (2009) 28 Health Affairs 793.
238 Meeting with expert, National Resource Centre for Psychiatric Advance Directives, Duke University (Durham 15 August 2012).
239 Twenty five per cent of advance directives being completed by one facilitator are with people with intellectual disabilities.
person warranted the consideration of less restrictive alternatives in Virginia. The health care proxy section of the form is often used by this population. The AD facilitation process may involve spending time with parents or carers to determine the best way to communicate with the person. A range of verbal and nonverbal supports are used tailored to the needs of the person. The person chooses whether they want a parent or guardian present at the facilitation. A simplified one page AD providing for the appointment of a proxy decision-maker was suggested. Peer facilitators are not currently trained to facilitate ADs with this population.

8. Conclusions-Lessons for Ireland
The Virginia Health Care Decisions Act is a progressive and comprehensive piece of legislation, which provides for ethical and person-centred approaches to ADs. The enabling legislation provides a strong legal foundation for system reform in jurisdictions promoting the recovery approach and encapsulates many of the CRPD principles. The legislation shows the value of adopting a consensus-building approach with stakeholders and for system and law reform to proceed in tandem with each other. The Virginia directive promotes the principles of equality and non-discrimination through the integration of a broad range of healthcare decisions into a single AD and provides an appropriate support for the exercise of legal capacity. The legislation provides for a presumption of capacity and minimises exclusion by providing legally binding ADs that are easily executable and revocable by all persons. The framework provides for flexibility and choice in relation to the revocability of the directive and the appointment of a proxy decision-maker. The directive is non-discriminatory and can only be overridden in defined emergencies or for involuntary admission to hospital. The AD preferences are honoured for treatment during involuntary detention. While ADs cannot supersede involuntary admission, advance consent to hospitalisation can be provided subject to safeguards. The Virginia model provides a participative response to mental health crises, reducing the need for coercion and readmission. The provision of peer support for completion is a critical feature of the model, which complies with the supported decision-making model in the CRPD. The implementation of ADs is an ongoing process in Virginia, but the prospects for success are still promising with high levels
of enthusiasm. The implementation points to the importance of accompanying ADs with system reform, resources, education and support.

The innovative and flexible features of the Virginia directive complies with many of the CRPD principles and the recovery approach, which are key drivers of Irish law reform. The proposal to incorporate ADs into the 2013 Bill at Committee stage means the final legal framework is still uncertain in Ireland. The proposal to incorporate ADs for general and mental health decisions into a single legislative framework is positive. However, the draft legislation proposes differential standards for the enforceability of ADs during involuntary detention. The structure of the legislation can perpetuate stigma and limit the use of ADs in mental health care. The proposal for non-legally binding ADs during involuntary detention reinforces discrimination and fails to instil confidence in a system, where lack of respect for treatment preferences is endemic. The CRPD requires equal recognition before the law and respect for the legal capacity of all persons. State Parties are, therefore, required to provide equal access to legally binding ADs for all persons. The 2001 Act will have to be amended to reflect the principles of the CRPD and to ensure equal respect for ADs during involuntary detention. The limitations on witnesses and the requirement for the person to have capacity to revoke the directive may also act as barriers to execution. The CRPD requires the removal of barriers that prevent participation in supported decision-making. The features of the Irish system suggest a need for legally binding ADs with accountability mechanisms to provide confidence until a cultural shift towards participative responses is established. The Virginia model provides valuable lessons for the introduction of legislative provisions for ADs in Ireland.

CHAPTER 6
The Introduction of Advance Directives in Irish Mental Health Care: The Views of Irish Service Users and Consultant Psychiatrists—An Empirical Study

1. Introduction:
The preceding chapters in the thesis assessed the AD literature and the theoretical, international, comparative and domestic legal frameworks in which they operate. This chapter will examine the views and preferences of service users and consultant psychiatrists towards the introduction of ADs in Irish mental health care. These views will be presented through an empirical study conducted with 111 Irish service users and 100 consultant psychiatrists. The effective implementation of a legal framework for mental health ADs is dependent on key stakeholder groups involved in development and enforcement. It is therefore essential to have a greater understanding of the views and concerns of service users and consultant psychiatrists. While much has been written internationally concerning ADs, there is a dearth of Irish literature on the topic. Empirical research addressing stakeholder views of ADs is lacking in Ireland and has never been examined in detail prior to this current research. To date, no known quantitative or mixed methods study has surveyed Irish stakeholders in relation to ADs in Irish mental health care. The application of research from other jurisdictions is useful, but limited by the context. The empirical study seeks to address this vacuum by undertaking a survey of the views of Irish service users and consultant psychiatrists towards the introduction of ADs in mental health care. The study will make a novel contribution to knowledge by considering the implementation of ADs from an Irish perspective.

2. Aims and Objectives
The aim of the empirical research was to determine the views and preferences of Irish service users and consultant psychiatrists towards the proposed use of ADs and the extent to which they will be supported in Ireland. This was achieved by examining the views and preferences of both stakeholder groups, and the perceived benefits and barriers to implementation.

The study sought to address these aims through the following objectives:

1. Examine the extent to which Irish service users and consultant psychiatrists are willing to support the introduction of ADs in mental health care.
2. Identify the views of service users and consultant psychiatrists towards their proposed use.
3. Assess familiarity with ADs.
4. Identify the preferences of both stakeholder groups for AD implementation.
5. Describe the main perceived benefits and barriers to ADs in the Irish context.
6. Compare disparities in knowledge, perceptions, preferences, perceived benefits and barriers between the stakeholder groups and within the stakeholder groups.
7. Determine which legal framework, if any, is most appropriate for implementation in Ireland based on the views and preferences of stakeholders.
8. Identify how ADs may be effectively implemented into Irish mental health care.

3. Study Design

The empirical study used a mixed methods design to synthesise both quantitative and qualitative data to provide a robust understanding of participants’ preferences and choices. Mixed methods research has been previously used in mental health research to examine delivery of services, management of medication and coping strategies. The philosophical partner for mixed method research is pragmatism. Pragmatists argue that it is justifiable to combine qualitative and quantitative methods of data collection in a single study if this provides the most appropriate means of answering the research questions.

The rationale for the use of mixed methods in this project is that neither quantitative nor qualitative methods alone are sufficient to capture the complexity of the issue. ADs are complex social interventions that occur in an intricate web of personal and professional relationships and are characterised by contested and competing values. Mixed methods have been used in previous studies of mental health and general ADs. Coupling qualitative and quantitative methods can illuminate phenomena that cannot be captured using a singular approach. Mixed methods are an appropriate means to answer the research questions. Crawford and others recognised the value of qualitative research in exploring and describing the process and outcomes of psychological and other complex interventions in mental health. Qualitative methods can further explore quantitative findings to put them in context or provide a more in-depth understanding. A major advantage of mixed methods research is that it enables researchers to simultaneously ask confirmatory and exploratory questions. In an exploratory context, the qualitative approach will help document views towards the proposed use of ADs. While the nature of the research design in this study is exploratory as it has never been researched in any detail in Ireland, it is also explanatory in that it seeks to explain why some groups may be more supportive of ADs than others. Mixed methods are logically congruent with this goal.

3.1. Participants

The participants in the study were 111 mental health service users and a 100 consultant psychiatrists in Ireland. Service user participants were required to be over 18 years old and be current or past users of Irish mental health services. Consultant psychiatrist participants were required to be registered in the Republic of Ireland and have experience of working in the Irish mental health services.

10 June Crawford and others, Emotion and Gender: Constructing Meaning from Memories (Sage 1992).
3.2. *Survey Instrument*

The views of both stakeholder groups towards the introduction of ADs in Irish mental health care were measured by self-completed questionnaires. Two separate paper based questionnaires were developed for service users and consultant psychiatrists. Opinions were collected using a newly developed questionnaire, based on pre-existing stakeholder surveys on mental health ADs and the hypothesised benefits and concerns in the literature.

In developing the questionnaires, core questions were developed across both stakeholder groups, in addition to more tailored questions. Some questions were specific to the personal experience of service users whereas others were specific to the clinical experience of consultant psychiatrists. The core questions enabled comparisons between the groups, while specific questions provided detail on personal experience, knowledge and perceived impact, motivations and barriers. The questionnaires were divided into six major sections to measure familiarity and opinions regarding ADs and involvement in mental health treatment; preferences for implementation; perceived impact; demographics and open ended questions and comments. The service user questionnaire included an additional section on personal experience, while the consultant psychiatrist questionnaire included a section on capacity and legal issues. The questionnaires consisted of 46 questions for consultant psychiatrists and 47 questions for service users. Participants were given the opportunity to describe their views through two open-ended questions on the perceived helpfulness of ADs and their potential impact. A third open ended question was included for consultant psychiatrists allowing this group to specify why they may be willing or unwilling to use ADs in clinical practice. Both questionnaires

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included categorical\textsuperscript{12} and ordinal\textsuperscript{13} questions to measure familiarity, views towards involvement in mental health treatment and support for ADs. Copies of the research instruments for both stakeholder groups are included in Appendix B of the thesis.

3.3. \textit{Sampling Strategies}

3.3.1. \textit{Service Users}

Service user participants were recruited through a variety sources due to significant difficulties accessing this group. A total population figure for service users in Ireland was unavailable. The researcher liaised with a variety of service user groups at national and local level to gain access to participants and build trust. This required substantial engagement by the researcher and provided a greater understanding of the issues. The U.S. Civil liberties lawyer, Bryan Stevenson asserted that in a just society it is important to be close to the group that require changes to be made to understand their experience.\textsuperscript{14} Resistance was encountered from some service user leaders, which created additional access barriers. In order to recruit for the study, gain an understanding of the issues and build trust the researcher attended service user meetings, outpatient support groups, local forums, recovery and advocacy training and national conferences over a two-year period. The meetings and forums attended included:

- August 2011: National Service User Executive (NSUE) Regional Meeting
- November 2011: Clifden Mental Health Forum
- January 2011: See Change Forum
- May 2011: Peer Advocacy Training
- November 2011: Critical Voices Network Conference, UCC, Information stand/workshop on advance directives and survey

\textsuperscript{12} A categorical variable or nominal variable is one that has two or more categories, but there is no intrinsic ordering to the categories e.g. gender.

\textsuperscript{13} An ordinal variable is similar to a categorical variable, but has some order to it e.g. education.


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• June 2011-May 2012: Weekly ‘Out and About’ Outpatient Recovery Group
  Galway
• March 2011- Present: Trialogue Regional Monthly Mental Health Meetings
  Galway
The researcher built a relationship of trust with service user groups and
representatives through this engagement. Service users were recruited through a
variety of outpatient and community mental health settings, support groups, mental
health networks, service user representatives, peer advocacy workers, occupational
therapists and service user contacts. Ethical approval was required for distribution of
questionnaires through national mental health organisations and support groups.
Applications were also made to distribute questionnaires through a number of
national mental health organisations including ‘Aware’\textsuperscript{15} ‘Grow’\textsuperscript{16} and the National
Service User Executive (NSUE). The application to ‘Aware’ was approved, but
‘Grow’ and ‘NSUE’ did not grant access to their membership for the purpose of the
research.\textsuperscript{17} Convenience and snowball sampling techniques were employed, yielding
118 service user participants. Snowball sampling is a widely used sampling
technique that involves using survey participants to identify additional cases for the
study.\textsuperscript{18} Convenience sampling is defined as the use of the most conveniently
available individuals in the study.\textsuperscript{19} The advantage of convenience sampling include:
accessibility, lower expense and faster acquisition in the recruitment phase.
However, it provides fewer opportunities to control for biases.\textsuperscript{20} A service user
representative assisted the distribution of questionnaires in community mental health
settings in the Western region. Regional service user representatives and peer
\begin{footnotes}
\item Aware is a national voluntary organisation that provides support services and groups for depression and related conditions. The organisation has over 48 support groups.
\item GROW is a mental health organisation, which helps people who have suffered, or are suffering, from mental health problems in Ireland and internationally.
\item Grow had reached a full complement of research projects for that year. The NSUE board did not grant access to their membership list for research purposes.
\item Denise Polit and Bernadette Hungler, Nursing Research: Principles and Methods (Lippincott Williams and Wilkins 1999); Mental Health Commission, Your Views of Mental Health Inpatient Services: Inpatient Survey 2011 (Mental Health Commission 2012).
\item Nancy Burns and Susan Grove, Understanding Nursing Research: Building an Evidence Based Practice (Elsevier 2011); Mental Health Commission, Your Views of Mental Health Inpatient Services: Inpatient Survey 2011 (Mental Health Commission 2012).
\end{footnotes}
advocates also assisted recruitment of service user participants. Response rates were lower where there was no engagement with the researcher or a representative. The questionnaires distributed through the ‘Aware’ support groups yielded extremely low response rates. Service user representatives and participants were also used to identify other participants. The difficulty accessing the service user group resulted in a larger percentage of participants from the HSE West region. The degree to which the results represent the population as a whole is therefore unclear. Fear was also found to be a barrier to questionnaire completion in some community mental health settings.

3.3.2 Consultant Psychiatrists

Complete collection was employed due to low response rates for consultant psychiatrists and the relatively small population. In this technique, all members of the population of interest who meet a special criterion are selected. A number of difficulties were encountered identifying a comprehensive listing and a total population size for consultant psychiatrists in Ireland. This information was not available from the College of Psychiatrists in Ireland and the researcher was denied permission to distribute questionnaires through the professional body. Consultant psychiatrist participants were identified through various sources including the 2011/2012 edition of the Irish Medical Directory, the Irish Medical Council listing and commercial databases. The Irish Medical Council listing did not provide an accurate figure for the total population of registered consultant psychiatrists in Ireland, which is estimated to be approximately 350. According to the 2009 OECD

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22 The College of Psychiatrists of Ireland is the professional body for psychiatrists in Ireland and the sole body recognised by the Medical Council and the HSE. The human rights committee of the College of Psychiatrists in Ireland denied access to their membership list for research purposes.


report, Ireland had nine psychiatrists per 100,000 of population. However, this figure may have reduced due to the recruitment moratorium, high number of vacancies and retirements in the HSE since 2009.

3.4. Data Collection
Data collection was by means of two separate self-administered questionnaires for consultant psychiatrists and service users. A service user representative assisted the data collection with service users. The data collection phase was longer for service users due to access difficulties. A pilot study was undertaken with five service users and five consultant psychiatrists prior to the commencement of the main survey, after which suggested changes were made to the format and ambiguities were clarified. The questionnaires were piloted twice with the same participants to ensure reliability and validity. The pilot ensured that the survey questions and information sheets were pitched at an appropriate level to maximise understanding of ADs.

A total of 350 questionnaires were distributed through the various service user sources. A total of 118 questionnaires were returned through a variety of postal ($n = 40$) and face to face ($n = 78$) channels between September 2011 and August 2012. This yielded a response rate of approximately 34 per cent. A total population size for service users was not available. Questionnaires were distributed through service user representatives, community mental health settings, conferences, peer advocates, advocacy organisations (Critical Voices Network), support groups (Aware) and outpatient groups (Out and About Group, Galway). Incentives were provided at two service user conferences, which included a book prize for completed questionnaires. An evening with food was provided for a local outpatient group which participated in completion of the questionnaires in February 2012. Seven returned questionnaires were excluded from the results due to incompletion.

A survey was also conducted to determine the views and preferences of consultant psychiatrists ($n = 330$). Data collection was by means of self-administered postal questionnaires for consultant psychiatrists. A total of 330 questionnaires were

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distributed and 100 were returned between February and August 2012, yielding a response rate of 30 per cent. A book token draw was provided for the early return of questionnaires and reminder letters were sent after a two week interval in repeat envelopes.

3.5. Statistical Data Analysis
The quantitative survey data was collated, coded and entered into SPSS version 20 and analysed, while open-ended questions were coded and analysed in NVIVO version 10. Data cleaning was undertaken after entry into SPSS. The preliminary analysis of the data involved running descriptive statistics and frequency tables and cross tabulations for comparison between the variables. Non-parametric tests are used to measure categorical (nominal) and ordinal data, where the data does not meet the assumptions of parametric techniques and for small samples.27 Categorical or nominal variables include distinct categories, whereas ordinal variables have some form of ranking. Chi-square tests, Fisher’s exact test, Spearman’s rank-order correlations, and Mann-Whitney U tests were used to measure associations, correlations and variations within and between the groups, and statistical significance was set at $p < 0.05$. Chi-square tests and Fisher’s Exact Test were used to measure associations between nominal data and Spearman’s rank-order correlations were used to measure correlations between ordinal variables. Mann-Whitney U tests were used to measure differences between groups for ordinal and nominal variables. Independent variables such as gender, marital status, familiarity, educational levels, diagnoses, involuntary detention and hospitalisation and use of WRAP were used to compare differences in familiarity, opinions, personal experience, preferences for implementation and the perceived benefits and barriers of ADs for service users. Variables such as gender, familiarity and length of experience, prior use of ADs or WRAP plans were used to compare preferences and perceptions for consultant psychiatrists. The results for familiarity and opinions, preferences for implementation, perceived benefits and barriers were compared within and between the consultant psychiatrist and service user groups.

3.5.1. Qualitative Analysis

The qualitative data from the questionnaire was imported into NVIVO and open coded to identify relevant themes. All process and stages of coding were tracked to demonstrate rigour. Data was organised into a folder hierarchy by group type and question (example: service users, consultant psychiatrists) to track the sources. The case nodes were physically linked to the demographics tables and returns from the quantitative survey, which facilitated integration between the qualitative and quantitative aspects of the data. Case nodes allow qualitative data to be gathered in one place to allow the researcher to look for emerging patterns. Nodes can be created for themes or cases such as people. The coding framework involved three stages of coding i.e. broad coding; grouping by theme and cross coding to create further subcategories. The qualitative statements were linked to the literature and the quantitative data and were distilled and synthesised to generate themes. Other tools within the database were used to enhance understanding of the data during the various stages of analysis. Conceptual mapping was assisted by the coding stripes and the modeller, which provides a visual representation of the relationships. Coding stripes are coloured bars displayed beside the node, which allow the researcher to see how the comments are coded. The results of the qualitative analysis have been grouped by question and theme to identify support for ADs, preferences for implementation and the perceived benefits and barriers for service users and consultant psychiatrists. The views of service users and consultant psychiatrists were categorised into four main headings under which the themes were grouped:

1. Support for Introduction.
2. Preferences for Implementation.
4. Perceived Barriers.

Qualitative themes will be discussed under the above headings before the discussion section along with ‘verbatim’ quotes used throughout the quantitative results section to affirm findings or variations in the data. The verbatim quotes are in italics to distinguish them from other published quotations in the thesis. As this study involved an embedded mixed methods survey prioritising quantitative methods, the quantitative results are presented with qualitative results from the qualitative open
ended questions. The qualitative statements can help explain and confirm perceptions and preferences in the quantitative data.

4. Ethics
The empirical research with service users and consultant psychiatrists received full ethical approval from the Research Ethics Committee (REC) at NUI Galway. The Irish Advocacy Network (IAN) agreed to provide support in the event of any service user distress from recalling traumatic experiences when answering the questionnaire. The researcher used information sheets and consent forms to ensure participants freely consented to participating in the survey. Separate information sheets were developed for service users and consultant psychiatrists based on the REC template at NUI Galway. A sample of both forms can be found in Appendix B. Participants were asked if they had read the information sheet and were given time to consider the information and ask questions before signing the consent form. They were also informed that they were not required to participate and could withdraw from the study at any time. Consent forms were returned separately from the questionnaire to protect anonymity and were stored in a secure cabinet. Participants could use initials on the consent form if they did not wish to reveal their full identity. Face-to-face surveys were completed in the presence of the researcher or the representative. The full contact details of the researcher including phone number were provided on the information sheet for postal surveys.

5. Results
The results for both stakeholder groups will be organised around the research questions and questionnaire themes which included: familiarity and opinions; preferences for implementation; the perceived impact of ADs; perceived benefits and barriers and support for their use in the Irish mental health context. The comparisons between the stakeholders groups, differences within the service user and consultant psychiatrist groups will also be examined. The results for service users who were involuntarily detained will be considered as a subsample in the analysis. The implications of the findings for the implementation of a legal framework for ADs in

29 See Appendix A.
Irish mental health care will be addressed in a discussion section at the end of this chapter.

5.1. Sample Characteristics: Service Users
The sample included 111 service user participants. Table 1 presents the demographic profile for service users. The participants ranged in age from 18 to over 61 years of age, with 54.2 per cent of participants aged between 41 and 60 years old (59/109). Over half of service users were female (55%, 60/109), and 45 per cent were male (49/109). Almost two-thirds (64.2%, 70/109) of participants lived in urban areas, while over a third (35.8%, 39/109) lived in rural areas. Over half (55.2%, 58/105) of participants were in the HSE West region, while the remainder were in Dublin Mid-Leinster (17.1 %, 18/105); HSE South (21%, 22/105) and Dublin North East (6.7%, 7/105). More than three-quarters (76.1%) of the sample were single, separated, widowed or divorced. Over half of service user participants had a third level education (54.6%, 59/108), a quarter had a primary or lower secondary education (27/108) and one fifth (22/108) had higher secondary level education.

Table 1: Service User Demographics

<table>
<thead>
<tr>
<th>Service Users</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>5</td>
<td>4.6%</td>
</tr>
<tr>
<td>31-40</td>
<td>33</td>
<td>30.3%</td>
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<tr>
<td>41-50</td>
<td>33</td>
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<tr>
<td>51-60</td>
<td>26</td>
<td>23.9%</td>
</tr>
<tr>
<td>61 or over</td>
<td>12</td>
<td>11.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>109</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49</td>
<td>45.0%</td>
</tr>
<tr>
<td>Female</td>
<td>60</td>
<td>55.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>109</td>
<td></td>
</tr>
<tr>
<td><strong>Place of Residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>70</td>
<td>64.2%</td>
</tr>
<tr>
<td>Rural</td>
<td>39</td>
<td>35.8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>109</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>66</td>
<td>60.6%</td>
</tr>
<tr>
<td>Married</td>
<td>19</td>
<td>17.4%</td>
</tr>
<tr>
<td>Cohabiting</td>
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<td>6.4%</td>
</tr>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>----------------</td>
<td>--------</td>
<td>------------</td>
</tr>
<tr>
<td>Separated</td>
<td>7</td>
<td>6.4%</td>
</tr>
<tr>
<td>Divorced</td>
<td>8</td>
<td>7.3%</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>1.8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>109</td>
<td></td>
</tr>
</tbody>
</table>

### Educational Level

<table>
<thead>
<tr>
<th>Educational Level</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary/Lower Secondary Level</td>
<td>27</td>
<td>25.0%</td>
</tr>
<tr>
<td>Higher Secondary Level</td>
<td>22</td>
<td>20.4%</td>
</tr>
<tr>
<td>Third Level</td>
<td>59</td>
<td>54.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>108</td>
<td></td>
</tr>
</tbody>
</table>

5.1.1. *Use of Mental Health Services*

Table 2 reveals the use of mental health services among service users. The table indicates that almost three-quarters (73.7%, 81/110) of service users were hospitalised more than once and over half (54.9%, 56/102) were long term users of mental health services. The majority of participants (83%, 88/105) were using public mental health services. Service users were asked if they had received a diagnosis or misdiagnosis of the listed mental health conditions. In the pilot study, some service users indicated that they had been misdiagnosed. Participants selected multiple responses to the diagnosis question. The majority of participants had a diagnosis for depressive disorder (60.8%, 62/102); more than a third indicated that they had bipolar disorder (36.3%, 37/102); while over a quarter reported being diagnosed with schizophrenia (25.5%, 26/102). Those with a diagnosis of schizophrenia and bipolar disorder had a higher rate of hospital readmission. These differences were statistically significant [Mann-Whitney U test, $U = 542$, $z = -3.37$, $p = .001$] [Mann-Whitney U test, $U = 852$, $z = -2.52$, $p = .01$].

---

30 Long term users were categorised as those using mental health services for ten years or more.  
31 There is an absence of data in relation to psychiatric misdiagnosis. The international literature suggests that bipolar disorder is often misdiagnosed. Hickling found a misdiagnosis rate of 45 per cent for schizophrenia among African Caribbean’s in a London hospital. Frederick Hickling and others, ‘A Jamaican Psychiatrist Evaluates Diagnoses at a London Psychiatric Hospital’ (1999) 175 British Journal of Psychiatry 283.  
32 The Mann-Whitney U Test is used to test for differences between two independent groups on a continuous measure.
Table 2: Use of Mental Health Services. Service Users

<table>
<thead>
<tr>
<th>Use of Mental Health Services</th>
<th>Freq.</th>
<th>%</th>
<th>Case %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Hospital Admissions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 3 times</td>
<td>49</td>
<td>44.6%</td>
<td></td>
</tr>
<tr>
<td>2-3 times</td>
<td>32</td>
<td>29.1%</td>
<td></td>
</tr>
<tr>
<td>Once</td>
<td>12</td>
<td>10.9%</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>17</td>
<td>15.5%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>110</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length Using Mental Health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services</td>
<td>Less than 1 year</td>
<td>4</td>
<td>3.9%</td>
</tr>
<tr>
<td></td>
<td>1-2 years</td>
<td>3</td>
<td>2.9%</td>
</tr>
<tr>
<td></td>
<td>3-5 years</td>
<td>17</td>
<td>16.7%</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>22</td>
<td>21.6%</td>
</tr>
<tr>
<td></td>
<td>More than 10 years</td>
<td>56</td>
<td>54.9%</td>
</tr>
<tr>
<td></td>
<td>102</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sector</td>
<td>Public MH Services</td>
<td>88</td>
<td>83.0%</td>
</tr>
<tr>
<td></td>
<td>Private MH Services</td>
<td>11</td>
<td>10.4%</td>
</tr>
<tr>
<td></td>
<td>Public/Private Services</td>
<td>6</td>
<td>5.7%</td>
</tr>
<tr>
<td></td>
<td>105</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnoses*</td>
<td>Depressive disorder</td>
<td>62</td>
<td>33.9%</td>
</tr>
<tr>
<td></td>
<td>Anxiety Disorder</td>
<td>39</td>
<td>21.3%</td>
</tr>
<tr>
<td></td>
<td>Bipolar Disorder</td>
<td>37</td>
<td>20.2%</td>
</tr>
<tr>
<td></td>
<td>Schizophrenic Disorder</td>
<td>26</td>
<td>14.2%</td>
</tr>
<tr>
<td></td>
<td>Eating Disorder</td>
<td>7</td>
<td>3.8%</td>
</tr>
<tr>
<td></td>
<td>Other Disorder</td>
<td>12</td>
<td>6.6%</td>
</tr>
<tr>
<td>Total</td>
<td>183</td>
<td>100%</td>
<td>179.4%</td>
</tr>
</tbody>
</table>

* Per cent refers to per cent of responses. Case per cent refers to the percentage of respondents who selected the diagnosis. Number of valid cases in multiple response variable = 102.

5.1.2. Involuntary Admission Group Characteristics

The characteristics of service users who were subject to involuntary admission under mental health legislation are presented in Table 3. Over a quarter (25.5%, 28/110) of service user participants had been subject to involuntary admission under mental health legislation, while a further 5.5 per cent (6/28) were not sure. A third of the involuntary admission group (33.3%, 9/27) specified that they were admitted under the Mental Health Act, 2001, but over a third (37.7%, 10/27) were unsure. Over a third (37%, 10/27) had received a diagnosis or misdiagnosis for schizophrenic disorder, while over half (55.6%, 15/37) had been diagnosed with bipolar disorder. A
significant association was found between involuntary admission and schizophrenia [Fisher’s Exact Test, \( p = .03, \phi = -.23 \)] and bipolar disorder [\( p = .04, \phi = -.22 \)]. The majority of those who were involuntarily detained had been treated with medication (70.4%, 19/27); seven were placed in seclusion (25.9%, 7/27) and over a fifth (22.2%, 6/27) had been treated with electroconvulsive therapy (ECT).

Table 3: Involuntary Admission Group: Legislation, Diagnostic Categories and Treatment

<table>
<thead>
<tr>
<th>Involuntary Admission Group</th>
<th>Frequency</th>
<th>%</th>
<th>% of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involuntary Admission</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28</td>
<td>25.5%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>76</td>
<td>69.1%</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td>6</td>
<td>5.5%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>110</td>
<td></td>
</tr>
<tr>
<td>Legislation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health Act 2001</td>
<td>9</td>
<td>33.3%</td>
<td></td>
</tr>
<tr>
<td>Mental Treatment Act 1945</td>
<td>4</td>
<td>14.8%</td>
<td></td>
</tr>
<tr>
<td>Both Acts</td>
<td>2</td>
<td>7.4%</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td>10</td>
<td>37.0%</td>
<td></td>
</tr>
<tr>
<td>Other Jurisdiction outside Ireland</td>
<td>2</td>
<td>7.4%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Diagnoses*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive Disorder</td>
<td>19</td>
<td>30.2%</td>
<td>70.4%</td>
</tr>
<tr>
<td>Anxiety Disorder</td>
<td>14</td>
<td>22.2%</td>
<td>51.9%</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>15</td>
<td>23.8%</td>
<td>55.6%</td>
</tr>
<tr>
<td>Schizophrenic Disorder</td>
<td>10</td>
<td>15.9%</td>
<td>37.0%</td>
</tr>
<tr>
<td>Eating Disorder</td>
<td>2</td>
<td>3.2%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Other Disorder</td>
<td>3</td>
<td>4.8%</td>
<td>11.1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>Involuntary Treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECT</td>
<td>6</td>
<td>13.0%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Medication</td>
<td>19</td>
<td>41.3%</td>
<td>70.4%</td>
</tr>
<tr>
<td>Seclusion</td>
<td>7</td>
<td>15.2%</td>
<td>25.9%</td>
</tr>
<tr>
<td>Psychotherapy</td>
<td>4</td>
<td>8.7%</td>
<td>14.8%</td>
</tr>
<tr>
<td>Other Treatment</td>
<td>8</td>
<td>17.4%</td>
<td>29.6%</td>
</tr>
<tr>
<td>Not sure</td>
<td>2</td>
<td>4.3%</td>
<td>7.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>46</td>
<td></td>
</tr>
</tbody>
</table>

* The total figure exceeds 100% in the diagnoses and treatment fields due to multiple diagnoses and treatments. Case per cent refers to percentage of respondents who responded to multiple response question. Number of valid cases for diagnoses and involuntary treatment = 27.
The demographic characteristics of the involuntary admission group were similar to other service users, with over half (53.5%, 15/28) aged between 41 and 60 years old. Over half of those who were detained were female (55.6%, 15/27), while 44.4 per cent were male. Almost two-thirds (60.7%, 17/28) were using mental health services for 10 years or more. This group also had significantly higher levels of readmissions to hospital, with over two-thirds (64.3%, 18/28) hospitalised more than three times, compared to 34.2% (26/76) of other service users [Mann-Whitney U Test $U = 596, z = -3.53, p < 0.001, r = -.34$].

5.1.3. Sample Characteristics: Consultant Psychiatrists

The survey sample consisted of 100 consultant psychiatrists working or recently working in the Irish mental health services. Table 4 shows the demographic profile of the consultant psychiatrist group and the relevant specialities. Almost two-thirds (63.3%, 62/98) of the sample were male and over a third were female (36.7%, 36/98). Three-quarters (74.5%, 73/98) of the participants had between 11-30 years’ experience, while one fifth (20.4%, 20/98) had over 30 years’ experience. Over three-quarters (76.3%, 74/97) of participants worked in the public sector and the majority (68%, 66/97) were general adult consultant psychiatrists.

Table 4: Consultant Psychiatrist Demographics

<table>
<thead>
<tr>
<th>Consultant Psychiatrists</th>
<th>Frequency</th>
<th>%</th>
<th>% of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>31-40</td>
<td>11</td>
<td>11.2%</td>
</tr>
<tr>
<td></td>
<td>41-50</td>
<td>45</td>
<td>45.9%</td>
</tr>
<tr>
<td></td>
<td>51-60</td>
<td>30</td>
<td>30.6%</td>
</tr>
<tr>
<td></td>
<td>Over 61</td>
<td>12</td>
<td>12.2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>98</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>62</td>
<td>63.3%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>36</td>
<td>36.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>98</td>
<td></td>
</tr>
<tr>
<td>Length</td>
<td>6-10 years</td>
<td>5</td>
<td>5.1%</td>
</tr>
<tr>
<td></td>
<td>11-30 years</td>
<td>73</td>
<td>74.5%</td>
</tr>
<tr>
<td></td>
<td>&gt;30 years</td>
<td>20</td>
<td>20.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>98</td>
<td></td>
</tr>
<tr>
<td>Sector</td>
<td>Public sector</td>
<td>74</td>
<td>76.3%</td>
</tr>
<tr>
<td>-----------------</td>
<td>---------------</td>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>Private Sector</td>
<td>23</td>
<td></td>
<td>23.7%</td>
</tr>
<tr>
<td></td>
<td><strong>97</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Speciality*</th>
<th>General Adult</th>
<th>66</th>
<th>60.6%</th>
<th>68.0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liaison</td>
<td>7</td>
<td>6.4%</td>
<td>7.2%</td>
<td></td>
</tr>
<tr>
<td>Older Persons</td>
<td>12</td>
<td>11.0%</td>
<td>12.4%</td>
<td></td>
</tr>
<tr>
<td>Addiction</td>
<td>4</td>
<td>3.7%</td>
<td>4.1%</td>
<td></td>
</tr>
<tr>
<td>Forensics</td>
<td>7</td>
<td>6.4%</td>
<td>7.2%</td>
<td></td>
</tr>
<tr>
<td>Learning Disability</td>
<td>2</td>
<td>1.8%</td>
<td>2.1%</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>5</td>
<td>4.6%</td>
<td>5.2%</td>
<td></td>
</tr>
<tr>
<td>Other Speciality</td>
<td>6</td>
<td>5.5%</td>
<td>6.2%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>109</strong></td>
<td>100%</td>
<td>112.4%</td>
<td></td>
</tr>
</tbody>
</table>

* Total figure exceeds 100% in the speciality field due to multiple specialities. Per cent refers to percentage of responses. Per cent of cases refers to the percentage of respondents who selected the speciality. Number of valid cases in the multiple response variable = 97.

### 5.2. Familiarity and Understanding of Advance Directives

Familiarity varied substantially between the stakeholder groups, with consultant psychiatrists significantly more familiar with ADs than service users. Figure 1 reveals that seventy per cent (70/100) of consultant psychiatrists were familiar with ADs, compared to 27.5 per cent (30/109) of service users. The differences between the groups were statistically significant [Mann-Whitney test $U = 2746$, $z = -6.38$, $p < 0.001$, $r = -.44$]. While the majority of consultant psychiatrists reported they were familiar with ADs, less than a quarter (24%, 24/100) stated they were very familiar and over three-quarters (76%, 76/100) identified lack of staff training or knowledge as a barrier. The need for information and training emerged in the qualitative statements.
Familiarity levels varied within the service user group, with 40.5 per cent (11/27) of participants who were involuntarily detained reporting that they were either very familiar (22%) or somewhat familiar (18.5%) with ADs, compared to 21.1 per cent (16/76) of other service users. No significant differences were found between involuntary detention and familiarity. Limited understanding was a lower barrier for those who were involuntarily detained. This may be linked to the higher level of familiarity. Service users with third level education (53.4%, 31/58) had significantly higher levels of familiarity with ADs, than those with primary/lower secondary (18.5%, 5/27) or higher secondary education (28.6%, 6/21). Lower educational levels had a significant negative correlation with familiarity [Spearman’s rank order correlation $r = -.34$, $n = 106$, $p < 0.001$].
Service users were given a simplified information sheet describing ADs to read before completing the survey. The first section of the survey included an open ended question, which asked them to describe their understanding of ADs. Almost three-quarters (73.9%, 82/90) of service user participants demonstrated an understanding of ADs, while 18.9 per cent did not provide an answer. Almost all of those who lacked understanding had primary or lower secondary education (7/8). In a subsequent question, over a third (35.5%, 39/110) of service users identified limited understanding as a barrier to completing an AD.

5.2.1. Psychiatrists’ Familiarity with the UN CRPD
The CRPD requires State Parties to adopt measures that support the exercise of legal capacity and implicitly promotes the use of ADs. The Irish Government has committed to introducing capacity legislation that complies with the CRPD. The CRPD has been a key driver in the development of the Assisted Decision-Making (Capacity) Bill 2013 (2013 Bill). ADs will be incorporated into the Bill at the Committee stage of the legislative process and a draft general scheme was published in February 2014. Consultant psychiatrists were asked about their familiarity with the CRPD in the survey. Over half (52.1%, 51/98) reported that they were very familiar (8.2%) or somewhat familiar (43.9%) with the CRPD. However, over a third (34.7%) were somewhat unfamiliar (16.3%), or not familiar with it all (18.4%). A positive association was found between knowledge of the CRPD and familiarity with ADs in the consultant psychiatrist group [Spearman’s rank order correlation rho = .25, n =98, p =.01].

5.3. Perceived Helpfulness and Willingness to Use Advance Directives
Table 5 reveals the perceived helpfulness of ADs in future mental health crises and in clinical practice. Service users displayed higher levels of perceived helpfulness than consultant psychiatrists. The qualitative analysis confirmed higher levels of

---

34 7.2 per cent were excluded due to lack of understanding.
38 Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.
perceived helpfulness among service users, with psychiatrists conveying more concerns.

Table 5: Perceived Helpfulness of ADs. Service User and Consultant Psychiatrists

<table>
<thead>
<tr>
<th>Service Users</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helpful in Future Crisis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely helpful</td>
<td>69</td>
<td>64.5%</td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>29</td>
<td>27.1%</td>
</tr>
<tr>
<td>Don't know</td>
<td>7</td>
<td>6.5%</td>
</tr>
<tr>
<td>Somewhat unhelpful</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Not helpful at all</td>
<td>2</td>
<td>1.9%</td>
</tr>
<tr>
<td>Total</td>
<td>107</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consultant Psychiatrists</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helpful in Clinical Practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely helpful</td>
<td>15</td>
<td>15.3%</td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>64</td>
<td>65.3%</td>
</tr>
<tr>
<td>Neither</td>
<td>12</td>
<td>12.2%</td>
</tr>
<tr>
<td>Somewhat unhelpful</td>
<td>4</td>
<td>4.1%</td>
</tr>
<tr>
<td>Not helpful at all</td>
<td>3</td>
<td>3.1%</td>
</tr>
<tr>
<td>Total</td>
<td>98</td>
<td></td>
</tr>
</tbody>
</table>

Some variations in perceived helpfulness were found within the service user and consultant psychiatrist groups. Service users who were involuntarily detained (74.1%, 20/27) perceived ADs to be more helpful than other service users (64.4%, 47/73). Female service users also perceived ADs to be more helpful than male service users. Almost two-thirds of female service users (68.3%, 41/60) perceived ADs to be extremely helpful, compared to 58.7% of male service users (27/46). No significant differences were found between these variables. Consultant psychiatrists with longer professional experience perceived ADs to be more helpful than other psychiatrists. While this was not statistically significant, 90 per cent (18/20) of consultant psychiatrists with more than 30 years’ experience perceived ADs to be either extremely helpful or somewhat helpful, compared to 79% (58/73) with 11 to 30 years’ experience.

When asked if they would consider making an AD if the measure becomes legally available in Ireland, 88.9 per cent (96/108) of service users stated that they would be willing to use them. Almost three-quarters (72.9%, 70/96) of consultant psychiatrists also stated that they were either very willing (35.4%) or somewhat willing (37.5%) to use ADs in practice. Over half (56.7%, 55/97) of consultant psychiatrists approved
of proposals for enduring power of attorney for mental health decisions, but one third (34%, 33/97) were unsure. An enduring power of attorney (EPA) enables a capable person to delegate decision-making power to an appointed person in the event of future incapacity and is sometimes used as a form of AD. The 2013 Bill proposes to extend the EPA to healthcare decisions. The provisions will amend the Power of Attorney Act 1996, which currently applies to property and finance decisions and limited personal care decisions. In the qualitative statements, some consultant psychiatrists and service users stated they were already using ADs informally:

“Have several people already who have clearly and unambiguously indicated their future treatment wishes and expectations. I have one person who has provided me with a titled AD.” Consultant Psychiatrist

One service user was in the process of developing an AD with his psychiatrist:

“I am in the process of making an advance directive with my psychiatrist and would like to make it legally binding.” Service User

The qualitative statements confirmed support for the introduction of ADs with consultant psychiatrists expressing some reservations. Examples of statements of support from service users and consultant psychiatrists included:

“I would dearly like to see advance directives become legal in Ireland, having a say in my treatment and recovery is very important to me.” Service User

“Overall, I support the idea, but I do feel in mental health care area, it is difficult to ensure illness itself doesn't influence decision making and therefore I believe it has to come under capacity legislation ...” Consultant Psychiatrist.

5.4. Involvement in Planning for Future Mental Health Treatment

The majority of service users (89.9%, 98/109) and consultant psychiatrists (80.6%, 79/98) believed individuals with mental health conditions have a right to make
decisions about future mental health treatment. When asked if it would be helpful to have treatment preferences or other life choices stated in advance of a mental health crisis, the majority of service users (86.2%, 94/109) and consultant psychiatrists (83%, 83/100) perceived it would be helpful. Almost all consultant psychiatrists (99%, 99/100) stated that service user involvement was important. However, satisfaction with treatment involvement varied significantly between the groups. Figure 2 reveals that 34.6 per cent (37/107) of service users were somewhat dissatisfied (14%) or very dissatisfied (20.6%) with current involvement in mental health treatment, compared to 16.7 per cent of consultant psychiatrists (16/96). Service users were found to have significantly lower satisfaction with treatment involvement than consultant psychiatrists. [Chi-square test for independence, $\chi^2 (4, n = 203) = 22.9, p < 0.001, \text{phi} = .34$].

![Fig 2: Satisfaction with Service User Involvement in Planning for Future Mental Health Treatment: Service Users and Consultant Psychiatrists](image)
Variations in satisfaction levels were also found within the service user group. Table 6 shows the satisfaction levels for those who were involuntarily detained. Satisfaction levels were lower in the involuntary admission group (50%, 14/28), compared to other service user participants (30.6%, 22/72). These differences were statistically significant [Mann-Whitney U test, \( U = 717, z = -2.29, p = .02, r = .23 \)].

Table 6: Satisfaction with Involvement in Planning for Mental Health Treatment: Involuntary Admission group and other Service Users

<table>
<thead>
<tr>
<th>Satisfaction Ranking</th>
<th>Service Users</th>
<th>%</th>
<th>Involuntary Detention Group</th>
<th>%</th>
<th>( p )-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>17</td>
<td>23.6%</td>
<td>3</td>
<td>10.7%</td>
<td>( p = .02^* )</td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td>19</td>
<td>26.4%</td>
<td>7</td>
<td>25.0%</td>
<td></td>
</tr>
<tr>
<td>Neither satisfied nor</td>
<td>14</td>
<td>19.4%</td>
<td>4</td>
<td>14.3%</td>
<td></td>
</tr>
<tr>
<td>dissatisfied</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat dissatisfied</td>
<td>12</td>
<td>16.7%</td>
<td>2</td>
<td>7.1%</td>
<td></td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>10</td>
<td>13.9%</td>
<td>12</td>
<td>42.9%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>72</td>
<td>28</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Mann-Whitney U test \( p \)-value

The preference to refuse certain medications/treatments in the AD was significantly higher among service users who were dissatisfied with involvement in treatment (44%, 29/66) than those who were satisfied (33.4%, 22/66) [Chi-square test for independence, \( \chi^2 (4, n = 103) = 13.3, p = 0.1, phi = .36 \)]. Over half of female service users (51.7%, 30/58) were satisfied with involvement in mental health treatment, compared to 42.6% per cent of male service users (20/47). No significant differences were found between satisfaction and gender. Male service users also had significantly lower levels of perceived control than female service users.

5.5. Personal Experiences

5.5.1. Communication and Listening

One third (33%, 34/103) of service users perceived that their treating psychiatrist did not listen to their treatment wishes, while almost a quarter (23.3%, 24/103) were not sure. The perception of not being listened to was significantly higher among service users who were involuntarily detained (59.3%, 16/27) than other service users (26.1%, 18/69) [Chi-square test for independence, \( \chi^2 (2, n = 96) = 13.2, p = .001, \).
Cramèr’s $V = .37]$. These differences were statistically significant. The provision of a forum for listening (72.4%, 76/105) was a major perceived benefit of ADs for service users. Communication and listening also emerged as a theme in the qualitative statements, with service users commenting on the value of ADs for communicating treatment wishes and concerns to doctors. Service users were interested in communicating their wishes and treatment history to treating doctors and family to provide greater understanding and to avoid harmful side effects. ADs were perceived to enhance communication, engagement and trust in both stakeholder groups. Examples of corresponding statements referring to the development of mutual trust included:

“Agreements, discussion, review of listening means real engagement and listening on both sides-hence mutual trust where the patient I hope, trusts me, and I trust them too!” Consultant Psychiatrist

Service user perceived ADs would enhance communication and continuity of care:

“Helpful because my wishes would be listened to.” Service User.

“It would communicate my wishes in a situation where I would find it difficult to stand my own.” Service User

“Would help if change in GP services or psychiatrist family member/carer may not be available in the future.” Service User

Service users perceived ADs could assist professionals in making treatment decisions and to communicate harmful side effects:

“It would draw on all the past experience of my illness and help the professionals dealing with me.” Service User

“With regard to a particular medication because I reacted badly e.g. lithium. No. Never again. Nearly died.” Service User
5.5.2. WRAP (Wellness Recovery Action Plans)

The Wellness Recovery Action Plan (WRAP) is a planning tool that supports individuals towards recovery and involves crisis planning.\textsuperscript{42} WRAP is being used in the Irish mental health system\textsuperscript{43} and is being used to support AD completion in other jurisdictions.\textsuperscript{44} The majority of service users (70.4%, 76/108) were interested in including an AD in the WRAP crisis plan in the survey. Almost a third (31.8%, 35/110) of service users in the survey had a WRAP plan, while over a quarter had never heard of it (26.4%, 29/110). A quarter (25%, 7/28) of those who were involuntarily detained had a WRAP plan, compared to over a third (35.5%, 27/76) of other service users. Those who had a WRAP plan reported higher levels of perceived control over treatment (43.8%, 14/32) than other service users (30.4%, 14/46). The variations in terms of control and WRAP were not statistically significant.

Sixty per cent (57/95) of consultant psychiatrists reported that their patients had a WRAP plan. The majority of consultant psychiatrists (86%, 49/57) using WRAP perceived ADs to be helpful and were more willing (43.9%, 25/57) to use them in practice than other psychiatrist participants (26.7%, 8/30). These variations were not found to be statistically significant. Consultant psychiatrists (13.3%, 13/98) who had worked in other jurisdictions with ADs reported that the measure had improved relationships and understanding and took less time than they originally perceived. Several consultant psychiatrists referred to the benefits of WRAP when commenting on the value of ADs in the qualitative statements:

\textit{“I have experienced ADs being very effective using WRAP where the patient works with a team member to develop a workable care plan.”} Consultant Psychiatrist

\textit{“WRAP crisis plan very helpful to patient and their concerns i.e. info warning signs, expectations clarified.”} Consultant Psychiatrist


\textsuperscript{43} The IMHREC consortium developed a website and education resources and trained 67 WRAP facilitators, who have the skills to facilitate the development of ADs in Ireland.

\textsuperscript{44} See chapter 5.
“Use WRAP-very useful approach … Overall very useful but have to adapt with the individual and sometimes their partner/family who may be allowed to be involved by patient in plan.” Consultant Psychiatrist

ADs were also perceived as strengthening the framework for participation in individual care plans in the qualitative statements. Several consultant psychiatrists referred to the role of ADs in enhancing individual care planning and involving the person, family and relatives. The Mental Health Act, 2001 requires that an individual care plan is completed by the multidisciplinary team in consultation with the service user.  

5.5.3. Autonomy, Control and Choice

Autonomy refers to the opportunity to make decisions according to one’s own values and preferences.  

The ability to exercise autonomous choice and control over life decisions is pivotal to social and mental well-being. ADs are perceived as giving greater control and choice. Autonomy was measured by asking service users about control and choice in the survey. Figure 3 reveals the perceptions of control over treatment in the service user group. Overall 60.4 per cent (64/106) of service users perceived they were somewhat lacking in control (21.7%) or not in control (38.7%) of treatment when being treated by the Irish mental health services.

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47 The Roeher Institute, Social Well-Being (Roeher Institute 1993).
49 Terms such as independence, choice, control or freedom are often used to refer to the concept of autonomy. Daniel Ambrosini and others, ‘Narratives of Individuals Concerning Psychiatric Advance Directives: A Qualitative Study’ (2012) Journal of Ethics in Mental Health 1.
Fig 3: Service User Perceived Control over Treatment

Higher levels of satisfaction with involvement in planning for future mental health treatment had a significant positive correlation with control [Spearman’s rank-order correlation $r = .26$, $n = 103$, $p < .007$]. Table 7 reveals the level of perceived control among those who were involuntarily detained, compared to other service users. The perception of control over treatment was significantly lower in the involuntary admission group, with 57.1% (16/28) lacking total control, compared to 32.4% of other service users (23/71). These variations were statistically significant [Mann-Whitney $U = 699$, $z = -2.40$, $p = .02$, $r = .24$].

Table 7 reveals the impact of hospitalisation on the service user perception of control over treatment. The perception of control was significantly lower among service users who were hospitalised (63.8%, 58/91) than those who were never hospitalised (35.7%, 5/14). These differences were statistically significant [Mann-Whitney U test $U = 403.5$, $z = -2.31$, $p = .02$, $r = .23$].
Table 7: Perceived Control over Treatment: Comparison between Involuntary Admission Group and other Service Users and those who were Hospitalised and Never Hospitalised.

<table>
<thead>
<tr>
<th>Control Ranking</th>
<th>SU %</th>
<th>Invol. %</th>
<th>Hosp %</th>
<th>Never Hosp %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very in control</td>
<td>7</td>
<td>9.9%</td>
<td>7</td>
<td>7.7%</td>
</tr>
<tr>
<td>Somewhat in control</td>
<td>23</td>
<td>32.4%</td>
<td>3</td>
<td>10.7%</td>
</tr>
<tr>
<td>Neither</td>
<td>3</td>
<td>4.2%</td>
<td>1</td>
<td>3.6%</td>
</tr>
<tr>
<td>Somewhat lacking control</td>
<td>15</td>
<td>21.1%</td>
<td>6</td>
<td>21.4%</td>
</tr>
<tr>
<td>Not in control at all</td>
<td>23</td>
<td>32.4%</td>
<td>16</td>
<td>57.1%</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>28</td>
<td>91</td>
<td>14</td>
</tr>
<tr>
<td>p-value</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Mann-Whitney U Test

Service users who were hospitalised were more interested in using ADs to reduce the need for hospitalisation (62.1%, 54/87) than those who were never hospitalised (47.1%, 8/17). The hospitalisation group (90.8%, 79/87) were also more interested in using ADs to increase control over treatment than those who were never hospitalised (70.6%, 12/17). These motivational differences were not statistically significant $p = .06$. Service users distinguished between control over treatment during hospitalisation to other contexts in the qualitative research. Some qualitative statements suggested a fear of loss of control during hospitalisation. One service user who was never hospitalised stated:

“I am scared of what could happen if I ever needed or became 'supposed to need' severe treatments especially hospitalisation.” Service User

Others perceived that ADs could provide them with a voice when hospitalised:

“That when I'm unwell and hospitalised, I would have a say in my treatment.”

Service User
Table 8 shows the perception of control over treatment among male and female service users. Over half of male service users perceived they were not in control at all (56.8%, 25/44), compared to less than a quarter of female users (23.3%, 14/60). These differences were statistically significant. [Mann-Whitney U test, $U = 958.5$, $z = -2.49$, $p = .01$, $r = .24$.] Male service users were also more dissatisfied with involvement in future mental health treatment (40.4%) than female service users (31%). The differences in satisfaction levels were not statistically significant. Table 8 also reveals that service users with schizophrenia (72%, 18/25) and bipolar disorder (67.5%, 25/37) had lower perception of control over treatment, than other service users (58.1%). The differences between the diagnostic groups in terms of control were not statistically significant.

**Table 8: Control over Treatment for Male/Female Service Users and those with Diagnoses of Schizophrenia and Bipolar Disorder**

<table>
<thead>
<tr>
<th>Control</th>
<th>Male</th>
<th>%</th>
<th>Fem</th>
<th>%</th>
<th>Schiz</th>
<th>%</th>
<th>Bipol</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very in control</td>
<td>4</td>
<td>9.1%</td>
<td>5</td>
<td>8.3%</td>
<td>3</td>
<td>12.0%</td>
<td>4</td>
<td>10.8%</td>
</tr>
<tr>
<td>Somewhat in control</td>
<td>9</td>
<td>20.5%</td>
<td>20</td>
<td>33.3%</td>
<td>2</td>
<td>8.0%</td>
<td>8</td>
<td>21.6%</td>
</tr>
<tr>
<td>Neither</td>
<td>1</td>
<td>2.3%</td>
<td>3</td>
<td>5.0%</td>
<td>2</td>
<td>8.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Somewhat lacking control</td>
<td>5</td>
<td>11.4%</td>
<td>18</td>
<td>30.0%</td>
<td>7</td>
<td>28.0%</td>
<td>9</td>
<td>24.3%</td>
</tr>
<tr>
<td>Not in control at all</td>
<td>25</td>
<td>56.8%</td>
<td>14</td>
<td>23.3%</td>
<td>11</td>
<td>44.0%</td>
<td>16</td>
<td>43.2%</td>
</tr>
</tbody>
</table>
**Total**                  | 44   | 60  | 25  | 37  |       |       |       |     |

$p$-value = .01

The potential for increased control over treatment (87.6%, 92/105) was the most frequently cited motivation for developing ADs for service users. Over three-quarters of consultant psychiatrists (75.5%, 71/94) identified increased patient control as a motivating factor for ADs, compared to 87.7 per cent of service users. Significant differences were found between the stakeholder groups in endorsing control as a motivating factor. [Fisher’s Exact Test, $p = .04$, $phi = -.16$.]
The development of an AD can provide the opportunity to have choices respected. Over a third of service users (34.3%, 36/105) in the survey perceived they had no choice in regard to future treatment, while 29.5 per cent (31/105) were not sure. The perception of lack of choice was over twice as high among those who were involuntarily detained with over half (57.1%, 16/28) perceiving they had no choice, compared to a quarter of other service users (25.7%, 18/70). These differences were statistically significant [Chi-square test for independence, $\chi^2 (2, n = 98) = 8.72, p = .01$, Cramer’s $V = .30$]. Almost two-thirds of service users (69.2%, 74/107) in the survey felt confident to manage their mental health. The level of confidence was higher in the involuntary admission group (78.6%, 22/28), but this difference was not statistically significant. Autonomy and control also emerged as themes in the qualitative data. Examples of corresponding statements from service users in relation to the perceived benefit of ADs to autonomy include:

“In the event of a future mental health crisis such a directive would help give me a sense of autonomy, during what would otherwise be a very traumatic and vulnerable time.” Service User

The perceived value of ADs to control emerged in service user statements. The need for security and control was more common among those who were involuntarily detained:

“It would give a sense of security and control over treatment, thus preserving one's sense of autonomy and identity.” Service User

“I think that having an advance directive would be a good idea because I would have control over my treatment.” Service User

One service user stated that it would allow her voice to be heard:

“An advance directive would make it easier for others to hear my voice even if I am unwell.” Service User

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Another service user who was involuntarily detained described succinctly the sense of control a legally binding AD would provide:

“I would finally feel safe if my advance directive was legally binding—it is an awful feeling to know your liberty and rights can be taken away from you at any time and that you have no say whatsoever in your treatment.” Service User

5.6. Preferences for Implementation

5.6.1. Content

ADs can take varying forms, enabling different decisions to be made. Comparative jurisdictions have a range of legal requirements, with some adopting a more formalised approach. The basic content typically includes treatment or hospitalisation preferences, crisis information, relapse symptoms, persons to be notified/emergency contacts and details of proxy decision-makers. Service users are often interested in including other personal life management choices e.g. childcare, financial instructions.

Table 9 presents service user and consultant psychiatrist preferences in relation to AD content. Both stakeholder groups were presented with a list of content options from the literature. The majority of service users expressed a preference for the inclusion of treatment/medication preferences (80%, 88/110), counselling therapies (80%, 88/110); place of treatment (70%, 77/110) and ECT preferences (64.5%, 71/110). Service users were also given the opportunity to specify other content preferences. These included individuals to be present in a crisis and alternative therapies (23.6%, 26/110). Consultant psychiatrists (88.7%, 86/97) also expressed a preference for the inclusion of treatment/medication and place of treatment preferences (76.3%, 74/97). There were no significant differences between the groups in relation to content. Consultant psychiatrists were, however, more

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interested in the inclusion of life management choices (78.4%, 76/97) than service users (59.1%, 65/110). These differences were statistically significant [Fisher’s exact test $p = .004$, $phi = .21$]. Consultant psychiatrists were also given the opportunity to specify other content preferences. These included information on family carer involvement, limits of responsibility, relapse measures/point of involuntary intervention and proxy decision-makers.

Table 9: Preferences for AD Content: Service Users and Consultant Psychiatrists.

<table>
<thead>
<tr>
<th>Content</th>
<th>SU Freq</th>
<th>%</th>
<th>% of Cases</th>
<th>CPs Freq</th>
<th>%</th>
<th>% of Cases*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment/Medication</td>
<td>88</td>
<td>17.5%</td>
<td>80.0%</td>
<td>86</td>
<td>34.4%</td>
<td>88.7%</td>
</tr>
<tr>
<td>Place of Treatment</td>
<td>77</td>
<td>15.3%</td>
<td>70.0%</td>
<td>74</td>
<td>29.6%</td>
<td>76.3%</td>
</tr>
<tr>
<td>Life Management Choices</td>
<td>65</td>
<td>12.9%</td>
<td>59.1%</td>
<td>76</td>
<td>30.4%</td>
<td>78.4%</td>
</tr>
<tr>
<td>Other Information</td>
<td>26</td>
<td>5.2%</td>
<td>23.6%</td>
<td>14</td>
<td>5.6%</td>
<td>14.4%</td>
</tr>
<tr>
<td>Counselling Therapies</td>
<td>88</td>
<td>17.5%</td>
<td>80.0%</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECT Preferences</td>
<td>71</td>
<td>14.1%</td>
<td>64.5%</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>503</td>
<td>110</td>
<td>250</td>
<td>94</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Total figure exceeds 100% due to multiple responses. Per cent refers to percentage of responses. Per cent of cases refers to the percentage of respondents who selected the treatment preference.

5.6.2. ECT Preferences

Wide variations existed between the stakeholder groups in relation to the inclusion of ECT preferences. Figure 4 highlights the disparities between the groups in relation to ECT refusal. The majority of service users (82.4%, 89/108) expressed a preference for an AD that allows for the refusal of ECT, in comparison to a fifth (19.6%, 19/97) of consultant psychiatrists. The preference for a directive that allows for ECT refusal was four times higher amongst service users than consultant psychiatrists. These disparities were statistically significant [Chi-square test for independence, $\chi^2 (2, n = 205) = 82.4$, $p < 0.001$, Cramer’s $V = .63$].
Four out of the six participants in the survey who had been treated with ECT while they were involuntarily detained expressed a preference for an AD that would enable them to refuse ECT treatment in the future. More than half (53.6%, 52/97) of consultant psychiatrists were not supportive of ADs which provide for ECT refusal, while over a quarter were uncertain (26.8%, 26/97). Consultant psychiatrists referred to situations where the treatment could save the life of the person and the potential for abuse in the qualitative statements:

“The difficulty is the treatment would save their life.” Consultant Psychiatrist

“ECT may be only life-saving intervention for catatonia.” Consultant Psychiatrist

“I have had next of kin want an elderly person to be denied ECT in psychotic depression. The next of kin stood to inherit if the person died. The patient had successful treatment and went on to a long, happy life.” Consultant Psychiatrist

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**Fig 4: Advance Refusal of ECT: Service User and Consultant Psychiatrist Comparison**

Number of valid cases for service users = 104. Number of valid cases for psychiatrists = 97.
Figure 5 presents the differences between the groups in relation to advance consent to ECT. The preference to opt into ECT was significantly higher among consultant psychiatrists (56.7%, 55/97) than service users (26.2%, 28/107). The differences between the groups were statistically significant [Chi-square test for independence, $\chi^2 (2, n=204) = 22.9, p < 0.001$, Cramer’s $V = .34$].

![Bar chart showing advance consent to ECT](chart)

**Fig 5: Advance Consent to ECT: Service User and Psychiatrist Comparison**

Number of valid cases for service users = 107. Number of valid cases for psychiatrists = 97.

Both stakeholder groups displayed similar levels of uncertainty in relation to advance consent to ECT. A qualitative statement from a consultant psychiatrist referred to the value of agreement to ECT for avoiding involuntary detention:

“I’m an old age psychiatrist, seeing many patients with dementia. Currently very, very few make any plans regarding their future care. I do see patients who respond very well to treatment, especially ECT, who say they would want to have it again if unwell, lack insight then when unwell need detention.” Consultant Psychiatrist
5.6.3. Refusal of Treatment

The majority of consultant psychiatrists (82.7%, 81/98) were somewhat concerned (60.2%) or extremely concerned (22.4%) that service users will refuse all treatment, while 94% (93/99) were extremely concerned (75.8%), or somewhat concerned with leaving a person untreated (18.2%). The concern with refusal of all treatment had a significant negative impact on willingness to use ADs among consultant psychiatrists [Spearman’s rank-order correlation $r = -.23$, $n = 95$, $p < .03$]. A significant negative correlation was also found between leaving a person untreated and willingness to use ADs [Spearman’s rank-order correlation $r = -.24$, $n=96$, $p < .02$]. Figure 6 shows the majority of service users were more interested in using ADs to agree treatment with the treating psychiatrist (72%, 77/107); to refuse certain treatments/medications (63.6%, 68/107) and to opt into certain treatments (62.6%, 67/107). Less than a fifth were interested in refusing all treatment completely (17.8%, 19/107), while over a fifth were interested in accepting all treatment (21.5%, 23/107).

![Fig 6: Service User Treatment Preferences](image)

Case response percentage refers to per cent of respondents who responded to multiple response questions. Number of valid cases = 107. Number of valid responses = 273.
The involuntary admission group (60.7%, 17/28) were less interested in using ADs to agree treatments with the treating psychiatrist than other service user participants (78.1%, 57/73) or to opt into treatments/medications (53.6%, 15/28). They were also more interested in using ADs to refuse treatments (32.1%, 9/17) than other service users (13.7%, 10/57). The differences in relation to the refusal of treatment were statistically significant [Fisher’s exact test \( p = .047, \phi = -.21 \)]. The qualitative statements suggest that individuals would more willingly seek help if their treatment wishes were legally protected:

“I would be more likely to seek help in future times of distress in the framework of the medical model if I knew my wishes regarding treatment (especially regarding medication) could not be compromised and would be legally protected.” Service User

5.6.4. *Proxy Directives*

Preferences can be expressed through an instructional directive, which provides directions regarding treatment or a proxy directive where the authority to communicate preferences is given to a designated person, or a hybrid directive which includes both features.\(^{53}\) The majority of service users in the survey (86%, 92/107) were interested in appointing a person to communicate their treatment wishes when unwell, with almost three-quarters (72.8%, 67/92) specifying a particular person. Over half (62.7%, 42/67) specified a family member, while 10.4% per cent (7/82) chose a trusted friend. Half of consultant psychiatrists (50%, 48/96) stated that they would be more willing to follow the directive if a proxy decision-maker is appointed.

Service users with higher educational levels were more interested in appointing a proxy decision-maker. The majority of those (88.1%, 52/59) with third level education and all of those with higher secondary education (100%, 20/20) expressed a preference for a proxy, compared to 69.2 per cent (18/26) of those with a primary or lower secondary education. Service users who were very familiar with ADs (100%, 16/16) were also more interested in appointing a proxy decision-maker than

those who were not familiar at all (79.6%, 39/49). These differences were not statistically significant.

5.6.4.1. Lack of Trusted Person to Act as Proxy Decision-Maker
One third of service users (32.7%, 36/110) perceived that appointing a trusted person to communicate on their behalf would be a barrier to developing an AD. This barrier was significantly higher for participants who were involuntarily detained (57.1%, 16/28) than other service users (24%, 18/75) [Chi-square test for independence, $\chi^2 (2, n = 103) = 8.68, p = .003, phi = -.31$]. Those who lacked a trusted proxy to act were more interested in using the AD to refuse all treatment (28.6%, 10/35) than other participants (12.7%, 9/71). They were also less interested in agreeing treatment with the treating psychiatrist (54.3%, 19/35) than other service users (81.7%, 58/71). These differences were not found to be statistically significant.

5.6.5. Support to Complete the Advance Directive
The research suggests that individuals with mental health conditions are capable of completing ADs, but some may require assistance.\textsuperscript{54} The majority of services users were interested in support to complete the AD, with only 15.9 per cent stating that they wished to develop the directive without assistance. Support can be provided by a peer, mental health professional or other trusted person. Table 10 shows the AD support preferences of service users and consultant psychiatrists. Both stakeholder groups were given a list of possible support persons. Almost three-quarters of service users (73.8%, 79/107) expressed a preference for a family member or trusted friend, while the majority of consultant psychiatrists (79.8%, 79/99) identified the treating psychiatrist. Consultant psychiatrists (79.8%, 79/99) were more interested in using the treating psychiatrist for support than service users (44.9%, 48/107). These variations were statistically significant [Chi-square test for independence, $\chi^2 (1, n = 206) = 26.6, p < 0.001, phi = .36$]. No significant differences were found between the groups for the other seven support persons ($p > .05$). Less than a third (31.8%, 34/107) of service users and 42.4 per cent of consultant psychiatrists identified a peer advocate. Other support preferences for consultant psychiatrists included any other

person the individual might find helpful, while service users specified key workers or therapists from outside the mental health system.

Table 10: Preferences for Support to Complete ADs: Service Users and Consultant Psychiatrists

<table>
<thead>
<tr>
<th>Support</th>
<th>SU Freq</th>
<th>SU %</th>
<th>Case %*</th>
<th>CP Freq</th>
<th>CP %</th>
<th>Case %*</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treating Psychiatrist</td>
<td>48</td>
<td>13.8%</td>
<td>44.9%</td>
<td>79</td>
<td>22.7%</td>
<td>79.8%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Independent Psychiatrist</td>
<td>18</td>
<td>5.2%</td>
<td>16.8%</td>
<td>22</td>
<td>6.3%</td>
<td>22.2%</td>
<td></td>
</tr>
<tr>
<td>Other Mental Health Professional</td>
<td>61</td>
<td>17.5%</td>
<td>57.0%</td>
<td>65</td>
<td>18.7%</td>
<td>65.7%</td>
<td></td>
</tr>
<tr>
<td>Other Medical Professional</td>
<td>49</td>
<td>14.0%</td>
<td>45.8%</td>
<td>37</td>
<td>10.6%</td>
<td>37.4%</td>
<td></td>
</tr>
<tr>
<td>Legal Professional</td>
<td>28</td>
<td>8.0%</td>
<td>26.2%</td>
<td>25</td>
<td>7.2%</td>
<td>25.3%</td>
<td></td>
</tr>
<tr>
<td>Peer Advocate</td>
<td>34</td>
<td>9.7%</td>
<td>31.8%</td>
<td>42</td>
<td>12.1%</td>
<td>42.4%</td>
<td></td>
</tr>
<tr>
<td>Family Member/Trusted Friend</td>
<td>79</td>
<td>22.6%</td>
<td>73.8%</td>
<td>68</td>
<td>19.5%</td>
<td>68.7%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>4.3%</td>
<td>14.0%</td>
<td>10</td>
<td>2.9%</td>
<td>10.1%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>349</td>
<td>100.0%</td>
<td>107</td>
<td>348</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Case percentage refers to per cent of respondents who responded to multiple response questions. Number of valid cases for service users = 107 and consultant psychiatrists = 99.

Consultant psychiatrists (94.9%, 93/98) perceived consultation with the treating psychiatrist to be extremely important (73.5%) or somewhat important (21.4%) when preparing the AD, but time and resources were also barriers. Over a fifth (22.7%, 25/110) of service users perceived getting someone they trusted to help them to complete the directive as a potential barrier in the survey. The need for support to complete the directive was also identified in the qualitative research. Corresponding statements from consultant psychiatrists included:

“Need encouragement for patients to actually do them-people often very passive.”
Consultant Psychiatrist

Other consultant psychiatrists asserted that caution needed be exercised in relation to the choice of support:

“Need to use caution regarding who gives advice to patient-advocates/family can push very unhelpful views and may cause people to not want to agree to AD (would rather you made decisions for me doctor).” Consultant Psychiatrist
Service users who were involuntarily detained (35.7%, 10/28) were less interested in the support of the treating psychiatrist than other service users (47.9%, 49/107). They were also less interested in the support of family members or trusted friends (67.9%, 19/28) than other service users (76.7%, 56/73). Almost a third (32.1%, 9/28) of those who were detained envisaged difficulty getting somebody to support them to complete the AD, compared to 18.7 per cent (14/75) of other service users. These differences were not found to be statistically significant.

5.6.6. Capacity Determinations
Capacity has traditionally been used as a threshold for executing, invoking and revoking ADs. The CRPD shifts from capacity determinations and deficits to the identification of supports to exercise legal capacity. The 2013 Bill provides a new statutory framework for those who need assistance in making decisions in Ireland. Under the 2013 Bill, the capacity to enter into decision-making agreements will be determined by the Circuit Court, which will provide for review of the decision. The draft legislation for ADs extends the presumption of capacity in the 2013 Bill to the ability to execute a directive. The scheme uses capacity as a threshold for executing, invoking and revoking the directive, but does not specify who will determine capacity. The capacity to consent to treatment is currently determined by the responsible consultant psychiatrist without independent review under Irish mental health legislation and decisions are made in the person’s ‘best interests’ if he/she is deemed to lack capacity.

Table 11 presents the capacity determination preferences of service users and consultant psychiatrists. Both stakeholder groups were given a list of possible individuals to determine decision-making capacity for the purpose of ADs. Significant differences were found between the groups for five of the eight

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56 The Irish government committed to introducing capacity legislation that complies with the CRPD in the Programme for Government.
57 An application for review of the declaration can be made to the court. The decision will be automatically reviewed at intervals of 12 months or not more than 3 years if the person is unlikely to recover. Assisted Decision-Making Bill, s. 30(2).
58 Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 3 (2)(a).
59 Ibid.
60 Mental Health Act, 2001. The 2001 Act is currently under review, it is still unclear as to how it will interface with the 2013 Bill.
categories. Over half of service users expressed a preference for a family member or trusted friend (51.4%, 56/109), compared to 5.1 per cent (5/98) of consultant psychiatrists. These differences were statistically significant. [Fisher’s exact test \( p < 0.001 \), \( \phi = -0.51 \)]. Consultant psychiatrists were significantly more interested in determinations by the treating psychiatrist (59.2%, 58/98) [Fisher’s exact test \( p = 0.003 \), \( \phi = 0.21 \)] and the independent psychiatrist (50% 49/98) [Fisher’s exact test \( p < 0.001 \), \( \phi = 0.46 \)] than service users (38.5% and 8.3%). Over a third of service users were interested in a mental health professional (33.9%, 37/109) or other medical professional (36.7%, 40/109), compared to 7.1 per cent of consultant psychiatrists. These differences were statistically significant [Fisher’s exact test \( p < 0.001 \), \( \phi = -0.33 \)] [Fisher’s exact test \( p < 0.001 \), \( \phi = -0.35 \)]. No significant differences were found between other categories. One fifth (22%, 24/109) of service users specified a preference for a person familiar with their preferences and over half (11/25) wanted to decide their own capacity.

Table 11: Capacity Determination Preferences. Service Users and Consultant Psychiatrists

<table>
<thead>
<tr>
<th>Capacity Determinations</th>
<th>SU Freq</th>
<th>SU %</th>
<th>Case %*</th>
<th>CP Freq</th>
<th>CP %</th>
<th>Case %*</th>
<th>( p )-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treating Psychiatrist</td>
<td>42</td>
<td>17.4%</td>
<td>38.5%</td>
<td>58</td>
<td>35.6%</td>
<td>59.2%</td>
<td>.003</td>
</tr>
<tr>
<td>Independent Psychiatrist</td>
<td>9</td>
<td>3.7%</td>
<td>8.3%</td>
<td>49</td>
<td>30.1%</td>
<td>50.0%</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Mental Health Professional</td>
<td>37</td>
<td>15.4%</td>
<td>33.9%</td>
<td>7</td>
<td>4.3%</td>
<td>7.1%</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Medical Professional</td>
<td>40</td>
<td>16.6%</td>
<td>36.7%</td>
<td>7</td>
<td>4.3%</td>
<td>7.1%</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Multidisciplinary Team</td>
<td>19</td>
<td>7.9%</td>
<td>17.4%</td>
<td>24</td>
<td>14.7%</td>
<td>24.5%</td>
<td></td>
</tr>
<tr>
<td>Legal Professional</td>
<td>14</td>
<td>5.8%</td>
<td>12.8%</td>
<td>11</td>
<td>6.7%</td>
<td>11.2%</td>
<td></td>
</tr>
<tr>
<td>Family Member/Friend</td>
<td>56</td>
<td>23.2%</td>
<td>51.4%</td>
<td>5</td>
<td>3.1%</td>
<td>5.1%</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Other</td>
<td>24</td>
<td>10.0%</td>
<td>22.0%</td>
<td>2</td>
<td>1.2%</td>
<td>2.0%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>241</strong></td>
<td><strong>109</strong></td>
<td><strong>163</strong></td>
<td><strong>98</strong></td>
<td><strong>1</strong></td>
<td><strong>2.0%</strong></td>
<td></td>
</tr>
</tbody>
</table>

* Case percentage refers to per cent of respondents who responded to multiple response questions.
Number of valid cases for service users = 109 and number of valid cases for consultant psychiatrists = 98.
Variations also existed within the service user group in relation to capacity determinations. Service users who were involuntarily detained were less in favour of the treating psychiatrist (21.4%, 6/28) or family members (46.4%, 13/28), than those who were not detained (44%, 33/75) (53.3%, 40/75). The differences in the capacity determination preferences in the involuntary admission group were not statistically significant. The qualitative statements highlighted the impact of involuntary detention on the familial relationship:

“In the past my siblings were involved in sectioning me even though we are not very close. It has caused a lot of tension in our relationships ...” Service User

5.6.7. Family Relationships and Decision-Making Burden

The decision-making burden on family members during crisis periods can result in decisional conflict. ADs are proposed to improve service user, provider and family relationships and reduce conflict in relation to the person’s wishes. Qualitative statements by service users referred to the role of ADs in communicating information and promoting family understanding:

“Very beneficial as it could help in your recovery and also for other people i.e. family members - it could help them better understand and help you.” Service User

The perceived helpfulness of ADs to the family and treating team during crisis periods was conveyed in the statements:

“In the event I become unwell the document will provide important information to my family/friends and the treating team on what my wishes are for treatment.” Service User

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Other service users commented on how ADs could assist family understanding of mental health difficulties:

“Advance directives are a great idea and would benefit everyone in the long term. It would help families understand mental illness as that's where the main problem is. Families should be educated more on mental illness.” Service User

Consultant psychiatrist statements also referred to the role of ADs in involving families/carers. Over half (57.8%, 56/97) of consultant psychiatrists perceived that ADs would increase (35.1%) or significantly increase (22.7%) the decision-making burden of family members. In comparison, the majority of service users (84.4%, 92/109) perceived that ADs would assist families. Some consultant psychiatrists expressed concerns about undue influence and unhelpful treatment advice from family members in the qualitative statements.

5.6.8. Mental Health Tribunals
The inclusion of ADs in mental health tribunal decisions was considered in the survey. The tribunals were established to provide procedural safeguards for involuntary patients under the 2001 Act. Any person admitted to an approved centre as an involuntary patient, is entitled to an independent review hearing by a mental health tribunal. The function of the tribunal is to review the detention and to decide whether to confirm or revoke the involuntary admission order. In order to do this, the tribunal must be satisfied that the person is suffering from a mental disorder and there has been compliance with certain procedures. The role of the tribunal may be expanded to include treatment decisions in the future. The tribunal has to consider the content of the AD when making decisions in Scotland. Figure 7 shows the tribunal preferences of service users and consultant psychiatrists. Service users (79.1%, 87/110) were significantly more interested in the AD being considered in tribunal decisions than consultant psychiatrists (57%, 57/100). These differences were statistically significant [Chi-square test for independence, $\chi^2 (2, n = 210) = 13, p = .002$, Cramer’s $V = .25$]. The involuntary admission group were less supportive

62 Mental Health Act, 2001, s 17. Procedural safeguards are needed for substantive safeguards.
63 Ibid s 18(1)(a).
(67.9%, 19/28) of ADs in tribunal decisions than other service users (84%, 63/75). These differences were not found to be statistically significant.

Figure 7: ADs in Mental Health Tribunal Decisions. Service Users and Consultant Psychiatrist Comparison
Number of valid cases for service users = 110. Number of valid cases for consultant psychiatrists = 100.

5.6.9. Preferences for Varying Forms of Advance Directives
ADs vary in the extent to which they are legally binding or whether providers, families or other parties are involved in their development. Some directives are legally binding whereas others are non-legally binding. The directive can be either positive or negative in that it includes advance consent or refusal of treatment, or it may stand alone or be used in conjunction with a proxy decision-maker. Some jurisdictions specify that a person must have decision-making capacity to revoke a directive, while others allow the AD to be revoked at any time.64 Other

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64 Arizona, Washington allow the person to decide the revocability of the AD at execution. In Germany mental health ADs can be revoked informally at any time even with limited decision-making capacity.
jurisdictions allow the person to choose whether the document is revocable during crisis periods at execution.

Figure 8 reveals the AD preferences of service users. Over three-quarters of service users (76.2%, 80/105) expressed a preference for an AD that is followed when they are unwell and can be changed when they are well. Over half (51.4%, 54/105) of service user participants expressed a preference for a directive that can be followed as much as possible, but allows them to change their mind when unwell. The risk of change of mind was a barrier for over a quarter of service users (26.4%, 29/110). Over a third of service users (36.2%, 38/105) expressed a preference for AD wishes to be followed regardless of the wishes of their treating doctor or family. Those who were involuntarily detained (53.8%, 14/26) were more interested in this form of directive than other service users (30.6%, 22/72). This was not statistically significant $p = .06$. Over a fifth of service users were interested in non-legally binding directives.

Figure 8: Forms of ADs. Service User Preferences
Case percentage refers to per cent of respondents who responded to multiple response questions. Number of valid cases = 105. Number of responses = 208.

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65 Arizona, Washington, Virginia.
5.6.10. *Legal Status of Advance Directives*

Table 12 presents the AD preferences of consultant psychiatrists. The majority of consultant psychiatrists (87.8%, 86/98) expressed a preference for a co-operative arrangement with service users. Over half (55.1%, 54/98) were in favour of non-legally binding directives opting into or out of treatment or WRAP crisis plans (50%, 49/98). Only 11.2 per cent of consultant psychiatrists (11/98) expressed a preference for legally binding directives that allow individuals to opt out of certain treatments/medications. Figure 8 showed that just over a fifth (21%, 22/105) of service users were interested in non-legally binding directives.

**Table 12: AD Legal Status Preferences: Consultant Psychiatrists**

<table>
<thead>
<tr>
<th>Preference</th>
<th>Freq</th>
<th>%</th>
<th>Case %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-operative Arrangement</td>
<td>86</td>
<td>26.3%</td>
<td>87.8%</td>
</tr>
<tr>
<td>Patient Initiated AD</td>
<td>52</td>
<td>15.9%</td>
<td>53.1%</td>
</tr>
<tr>
<td>Legally Binding Opting In</td>
<td>17</td>
<td>5.2%</td>
<td>17.3%</td>
</tr>
<tr>
<td>Legally Binding Opting Out</td>
<td>11</td>
<td>3.4%</td>
<td>11.2%</td>
</tr>
<tr>
<td>Non-Legally Binding Opting In</td>
<td>54</td>
<td>16.5%</td>
<td>55.1%</td>
</tr>
<tr>
<td>Non-Legally Binding Opting Out</td>
<td>54</td>
<td>16.5%</td>
<td>55.1%</td>
</tr>
<tr>
<td>Non-Legally Binding WRAP</td>
<td>49</td>
<td>15.0%</td>
<td>50.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>327</td>
<td>100.0%</td>
<td>337.1%</td>
</tr>
</tbody>
</table>

* Case response percentage refers to per cent of respondents who responded to multiple response questions. Number of valid cases = 98.

Figure 9 shows the AD preferences of both stakeholder groups under the Irish legal framework. The majority of service users (85.8%, 91/106) expressed a preference for a legal right to have their AD decisions respected. Almost two-thirds (64.3%, 63/98) of consultant psychiatrists were in favour of making ADs available under the Irish legal framework, but over a quarter were not sure (25.5%, 25/98). Significant differences were found between the groups in relation to the inclusion of ADs under the Irish legal framework [Chi-square test for independence, \( \chi^2 (2, n = 204) = 12.8, p = .002, Cramer’s V = .25 \).]
Consultant psychiatrists were asked where they would like to see ADs provided for in the Irish legal framework. Almost half (43.4%, 43/99) expressed a preference for the inclusion of ADs under capacity legislation and less than quarter (23.2%, 23/99) would like to see them included under mental health legislation, while almost a fifth were uncertain (19.2%, 19/99). It is proposed to incorporate the draft scheme for ADs into the 2013 Bill at the Committee stage of the legislative process.\(^6\) The qualitative statements also suggested consultant psychiatrists supported the incorporation of ADs under capacity legislation.

The legal status of ADs also emerged in the qualitative statements with service users emphasising the importance of legally binding ADs and consultant psychiatrists expressing a preference for non-legally binding directives. Several service users

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asserted that the impact of ADs would be limited without legal enforceability:

“Without a legal right there is no advance directive. The rights of the patient must supersede any other rights within the mental health framework in order for therapeutic processes to exist. Coercion [forced treatment] destroys the therapeutic basis of the proposed treatments.” Service User

“But if it is not legal as it is at present, then it could be useless!” Service User

“It has to be legally binding.” Service User

In contrast, the majority of consultant psychiatrists supported non-legally binding forms of directives, which can be overridden. Examples of corresponding statements in relation to legal enforceability included:

“ADs would need to be very carefully constructed and not legally binding.” Consultant Psychiatrist

“Definitely need to be sure that patients may be unable to put themselves in a position where they really understand the nature of an episode of mental illness such as psychosis. Therefore advance directives must be taken into consideration but not be legally binding ...” Consultant Psychiatrist

5.6.11. Review of Advance Directives
AD preferences may change over time requiring provision for review. Concerns often arise in relation to changing the directive to incorporate new preferences before an individual goes into crisis. Both stakeholder groups agreed on the need to review the directive. Under half of service users (42.3%, 44/104) and consultant psychiatrists (42%, 42/100) expressed a preference for the AD to be reviewed after each mental health crisis. Over a third of consultant psychiatrists (38%, 38/100) believed they should be reviewed on patient request. Other preferences included reviewing the directive every 6 months (31.7%, 33/104, service users) or on an

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annual basis (19.2%, 20/104, service users) (27%, 27/100, consultant psychiatrists). No significant differences were found between the groups in relation to review preferences.

5.7. Perceived Impact of Advance Directives

5.7.1. Motivating Factors

The motivations for using ADs were considered in the survey. Both stakeholder groups were given a list of potential motivating factors from the literature. Table 13 shows the motivations for service users and consultant psychiatrists. The most frequently cited motivating factor for service users (87.6%, 92/105) was increased control over treatment. Other major motivations included planning for periods when decision-making capacity may be impacted (75.2%, 79/105) and the provision of a forum for listening (72.4%, 76/105). Nearly two-thirds (65.7%, 69/105) of service users stated that providing information on treatment history, improving future treatment experiences (62.9%, 66/105) and enhancing the therapeutic relationship (59%, 62/105) would encourage them to develop an AD. The reduced need for hospitalisation (59%, 62/105) and involuntary treatment (61%, 64/105) were also motivations for service users.

Table 13 also shows the motivating factors for consultant psychiatrists. The most frequently cited motivations for consultant psychiatrists included treatment planning (90.4%, 85/94), patient control over treatment (75.5%, 71/94) and the enhancement of the therapeutic relationship (74.5%, 70/94). The provision of a forum for communication and reflection was also a motivating factor (69.1%, 65/94). Over half of consultant psychiatrists (56.4%, 53/94) were motivated by increased adherence to treatment, while three-quarters of service users stated that they would be more willing to adhere to treatment if they had an AD. Almost three-quarters of service users who were involuntarily detained were motivated by increased adherence to medication. Only 34 per cent of consultant psychiatrists identified the provision of information on treatment history as a motivating factor, while 58.5 per cent were motivated by improving the quality of treatment decisions.
Table 13: Motivating Factors for Using ADs: Service Users and Consultant Psychiatrists.

<table>
<thead>
<tr>
<th>Service User Motivations</th>
<th>Freq</th>
<th>%</th>
<th>Case %*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased Control over Treatment</td>
<td>92</td>
<td>13.7%</td>
<td>87.6%</td>
</tr>
<tr>
<td>Plan for Future Periods</td>
<td>79</td>
<td>11.8%</td>
<td>75.2%</td>
</tr>
<tr>
<td>Forum for Listening</td>
<td>76</td>
<td>11.3%</td>
<td>72.4%</td>
</tr>
<tr>
<td>Information on Treatment History</td>
<td>69</td>
<td>10.3%</td>
<td>65.7%</td>
</tr>
<tr>
<td>Improve Future Treatment Experiences</td>
<td>66</td>
<td>9.8%</td>
<td>62.9%</td>
</tr>
<tr>
<td>Reduce Involuntary Treatment</td>
<td>64</td>
<td>9.5%</td>
<td>61.0%</td>
</tr>
<tr>
<td>Enhance Therapeutic Relationship</td>
<td>62</td>
<td>9.2%</td>
<td>59.0%</td>
</tr>
<tr>
<td>Reduce the need for Hospitalisation</td>
<td>62</td>
<td>9.2%</td>
<td>59.0%</td>
</tr>
<tr>
<td>Previous Negative Experiences</td>
<td>51</td>
<td>7.6%</td>
<td>48.6%</td>
</tr>
<tr>
<td>Reflect on Past Experiences</td>
<td>50</td>
<td>7.5%</td>
<td>47.6%</td>
</tr>
<tr>
<td>Total</td>
<td>671</td>
<td>100%</td>
<td>639.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consultant Psychiatrist Motivations</th>
<th>Freq</th>
<th>%</th>
<th>Case %*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan for Future Periods</td>
<td>85</td>
<td>13.9%</td>
<td>90.4%</td>
</tr>
<tr>
<td>Patient Control over Treatment</td>
<td>71</td>
<td>11.6%</td>
<td>75.5%</td>
</tr>
<tr>
<td>Enhance Therapeutic Relationship</td>
<td>70</td>
<td>11.4%</td>
<td>74.5%</td>
</tr>
<tr>
<td>Forum for Dialogue and Reflection</td>
<td>65</td>
<td>10.6%</td>
<td>69.1%</td>
</tr>
<tr>
<td>Improve Future Treatment</td>
<td>63</td>
<td>10.3%</td>
<td>67.0%</td>
</tr>
<tr>
<td>Quality of Treatment Decisions</td>
<td>55</td>
<td>9.0%</td>
<td>58.5%</td>
</tr>
<tr>
<td>Adherence to Treatment</td>
<td>53</td>
<td>8.7%</td>
<td>56.4%</td>
</tr>
<tr>
<td>Reduce the need for Hospitalisation</td>
<td>47</td>
<td>7.7%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Reduce Involuntary Treatment</td>
<td>46</td>
<td>7.5%</td>
<td>48.9%</td>
</tr>
<tr>
<td>Information on Treatment History</td>
<td>32</td>
<td>5.2%</td>
<td>34.0%</td>
</tr>
<tr>
<td>Reduce Costs</td>
<td>25</td>
<td>4.1%</td>
<td>26.6%</td>
</tr>
<tr>
<td>Total</td>
<td>612</td>
<td>100%</td>
<td>665.2%</td>
</tr>
</tbody>
</table>

* Case percentage refers to per cent of respondents who responded to the multiple response questions. Number of valid cases for service users = 105. Number of responses = 671. Number of valid cases for consultant psychiatrists = 94. Number of responses = 612.

The motivation for developing ADs varied within the service user group. Participants who were involuntarily detained (56%, 14/25) were less motivated by planning than other service users (80.8%, 59/73). These differences were statistically significant. [Fisher’s exact test, $p = .03$, phi = .25]. The involuntary admission group were also less interested in enhancing the relationship with their treating doctor (44%, 11/25) or providing information on treatment history (56%, 14/25) than other service user participants (65.8%, 48/73) (69.9%, 51/73). These differences were not statistically
significant. Service users who were involuntarily detained (64%, 16/25) were not significantly more interested in using ADs to reduce the need for involuntary treatment than other service users (61.6%, 45/73).

Variations were also found between the stakeholder groups. Service users were significantly more motivated (87.6%, 92/105) by control over treatment than consultant psychiatrists (75.5%, 71/94) [Fisher’s Exact Test, $p = .04$, $\phi = -.16$]. Consultant psychiatrists, in comparison, were significantly (90.4%, 85/94) more motivated by planning than service users (75.2%, 79/105) [Fisher’s exact test $p = .005$, $\phi = .20$]. Significant differences were found between the groups in relation to the provision of information on treatment history, with just over a third (34%, 32/94) of consultant psychiatrists identifying this as a motivating factor, compared to almost two-thirds (65.7%, 69/105) of service users [Fisher’s Exact Test $p < 0.001$, $\phi = -.32$]. Variations also existed in relation to the motivation to use ADs to reduce the need for involuntary treatment and hospitalisation. Consultant psychiatrists were less motivated by a reduced need for involuntary treatment (48.9%, 46/94) and hospitalisation (50%, 47/94) than service users (61%, 64/105; 59%, 62/105). Less than a third of consultant psychiatrists (28.8%, 28/97) perceived that ADs would somewhat decrease (24.7%) or significantly decrease (4.1%) the need for involuntary treatment, while over half (58.8%, 57/97) believed that they would neither increase nor decrease it, while 39.4 per cent identified decreased use of coercion as factor they would consider in deciding whether to follow the directive.

The consultant psychiatrist group were significantly more motivated by the enhancement of the therapeutic relationship (74.5%, 70/94) than service users (59%, 62/105) [Fisher’s Exact Test, $p = .03$, $\phi = .16$]. When asked if the process of developing an AD would improve or disimprove the therapeutic relationship, half of service users (50%, 53/106) and just over half of consultant psychiatrists (53.1%, 52/98) perceived that ADs would improve the therapeutic relationship. Uncertainty was found in both stakeholder groups with almost a third (30.6%, 30/98) of consultant psychiatrists perceiving that ADs would neither improve nor disimprove the relationship and over a quarter of service users (26.4%, 28/106) were unsure. Service users who were involuntarily detained also perceived ADs would improve the therapeutic relationship, while over three-quarters believed they would assist
family understanding. The value of ADs in enhancing the therapeutic relationship and promoting trust were supported by the qualitative statements from consultant psychiatrists:

“It should enhance the therapeutic relationship and cause one to reflect on best practice treatment options taking into consideration patient preferences. It should enable a holistic approach.” Consultant Psychiatrist

5.7.2. Recovery and Therapeutic Benefits

The recovery approach envisions a process by which service users take control of their lives and plan for crisis with the support of trusted persons. Individuals can ascribe different meanings to recovery including the freedom to make choices, working with providers, or being able to return to work. The development of an AD can assist in the recovery process by enabling individuals to express treatment preferences, develop capacity, acquire information and become empowered by the process.

Figure 10 shows the perceived benefits of ADs to recovery for both stakeholder groups. Service users (81.7%, 85/104) perceived ADs to be significantly more helpful to recovery than consultant psychiatrists (59.8%, 58/97). These variations were statistically significant [Chi-square test for independence, χ² (2, n = 201) = 12.9, p = .002, Cramer’s V = .25]. Almost a third of consultant psychiatrists (30.9%, 30/97) were uncertain about the benefits of ADs in the recovery process. However, in another question, over three-quarters (76.3%, 74/97) of consultant psychiatrists perceived that ADs may have a therapeutic value, while over three-quarters of service users (76.9%, 83/108) perceived they would improve their self-esteem.

The involuntary admission group perceived ADs to be more helpful to recovery (100%, 24/24), than other service user participants (76.7%, 56/73). The variation in terms of involuntary detention and the perceived impact on recovery was not statistically significant. Over half (58.9%, 56/95) of consultant psychiatrists perceived that particular diagnostic groups would benefit from developing an AD. Of these, almost half (47.3%, 26/55) identified individuals with bipolar disorder, while only 10.9 per cent (6/55) identified individuals with schizophrenia. Almost a third (32.7%, 32/98) of consultant psychiatrists believed that individuals between 16 and 18 year olds should be allowed develop an AD, while 45.9 per cent (45/98) disagreed and 21.4 per cent (21/98) were uncertain.
Recovery also emerged as a theme for service users in the qualitative statements. Service users perceived that ADs would give structure to their wellness, improve their well-being and lead to improved outcomes. Examples of corresponding statements from service users include:

“\textit{It could help with my future unwellness at the early stages and prove a better outcome.}” Service User

“\textit{It would help my mental health wellbeing. It would help me cope on a day to day basis ...}” Service User

“\textit{I think they would help people gain a greater power over their lives and recovery.}” Service User

Some service users perceived ADs had capacity building benefits enabling them to develop insight into treatment and recovery strategies. Other service users perceived ADs would help them to evaluate ‘what works and doesn’t work’ for them:

“\textit{It would give me an insight into my treatment and help me recover more quickly.}” Service User

“\textit{Clear well thought information and opinion put on paper by myself-understanding my own recovery.}” Service User

“\textit{A way of working out what's best for me before I become mentally unwell.}” Service User

5.8. Perceived Barriers to ADs
The implementation of ADs in mental health care poses a myriad of legal and practical challenges. The literature suggests that stakeholders are interested in ADs, but substantial barriers may prevent completion and utilisation.\footnote{Richard Van Dorn and others, ‘Psychiatric Advance Directives and Social Workers: An Integrative Review’ (2010) 55 (2) Social Work 157.} The perceived
barriers vary between the stakeholder groups in the literature. The multiple barriers often relate to clinician willingness to implement ADs and service user ability to complete the document. Several barriers have been identified in the literature: including lack of stakeholder support; lack of knowledge or training; legal liability and ethical issues or overriding the document; system capacity and continuity of care.

5.8.1. Service User Barriers

Service users were given a list of potential barriers to AD completion from the literature. Figure 11 shows the percentage of service users who selected the various completion barriers. The most frequently cited barriers for service users included the potential for wishes to be ignored or overridden by medical staff (50%, 55/110); limited understanding of the AD (35.5%, 39/110) and legal implications (36.4%, 40/110); uncertainty as to what to include in the directive (35.5%, 39/110); and the lack of a trusted person to communicate on their behalf (32.7%, 36/110). Over a quarter of service users (27.3%, 30/110) believed that obtaining information from the treating doctor would be a potential barrier. Other service user barriers included the risk of change of mind since the directive was created (26.4%, 29/110) and support to complete the document (22.7%, 25/110). The change of mind barrier was associated with lower levels of familiarity and education. A fifth of service users (20.9%, 23/110) felt that having to reflect on their mental health experiences would discourage them from developing an AD.

Fig 11: Service User Barriers to ADs
* Case response percentage refers to per cent of respondents who gave multiple responses to questions. Number of valid cases = 110.

The stated barriers were endorsed by less than 50 per cent of the service user group for all but one barrier i.e. the potential for wishes to be overridden or ignored by medical staff. This barrier was higher among participants who were involuntarily detained (60.7%, 17/28) than other service users (46.7%, 35/75). The difficulty obtaining information from the treating doctor barrier was also higher among those who were detained (35.7%, 10/28) than other user participants (22.7%, 17/75). These differences were not statistically significant. The potential for the AD to be overridden also emerged in the qualitative statements from service users:

“I may rely on it being implemented and respected which could turn out to be a delusion as there is no guarantee that people will accept it and follow it.”

“I feel service providers may however challenge and discourage it like they do presently ...” Service User
5.8.1.1. Education, Familiarity and Service User Barriers

Service users with lower educational levels perceived increased barriers to ADs. Higher barriers were found among those with lower educational levels in all but one barrier i.e. the potential for wishes to be overridden by medical staff. Table 14 reveals the association between educational levels and AD barriers. Significant associations were found in four out of ten barriers. The lack of understanding of the legal implications, limited understanding [Chi-square test for independence, $\chi^2 (2, n = 108) = 10.4, p = .006$, Cramer’s $V = .31$] and not knowing what to say or write in the document [Chi-square test for independence, $\chi^2 (2, n = 108) = 5.96, p = .05$, Cramer’s $V = .24$] barriers were significantly higher for those with lower education. Those with a primary or lower secondary education identified significantly higher levels of ‘the time and trouble’ barrier than those with a third level education. [Mann-Whitney U test $U = 539.5, z = -2.7, p = .006, r = .3$.]. The lack of a trusted person to support AD completion was also higher among those with lower education (33.3%, 9/27). This was not found to be statistically significant. The change of mind barrier was also significantly higher for service users with primary or lower secondary education (44.4%, 12/27). These differences were statistically significant [Chi-square test for independence, $\chi^2 (2, n = 108) = 6.50, p = .04$, Cramer’s $V = .25$]. No statistically significant associations were found in the other six barriers ($p > .0.05$). Those with lower educational levels were also significantly less familiar with ADs than other service users [Spearman’s rank order correlation $r = -.34, n = 106, p < 0.001$].
Lower levels of familiarity were also associated with increased barriers in the service user group. Table 15 reveals the association between familiarity and increased barriers. Significant associations were found in six out of ten barriers. Those with low levels of familiarity had significantly higher levels of limited understanding [Mann-Whitney U test, \( U = 1013, z = -2.92, p = .003, r = .3 \)], lack of understanding of the legal implications [Mann-Whitney U test, \( U = 984, z = -2.46, p = .01, r = .24 \)] and ‘not knowing what to say or write in the AD’ barriers [Mann-Whitney U test, \( U = 1009, z = -2.20, p = .03, r = .21 \)]. Service user participants with lower levels of familiarity also had significantly greater fear about changing their mind after the directive is executed. [Mann-Whitney U test, \( U = 769, z = -2.62, p = .009, r = .3 \)]. In comparison, service users who identified the potential for ADs to be ignored or overridden by medical staff barrier were significantly more familiar with ADs than other service users [Mann-Whitney U test, \( U = 1001, z = -2.98, p < 0.001, r = .3 \)]. No statistically significant associations were found in the other four barriers (\( p > 0.05 \)).
Table 15: Barriers and Familiarity with ADs. Service Users

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Freq</th>
<th>Familiar</th>
<th>Freq</th>
<th>Unfamiliar</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Understanding</td>
<td>8</td>
<td>18.6%</td>
<td>30</td>
<td>46.9%</td>
<td>= .003*</td>
</tr>
<tr>
<td>Not Knowing what to put in AD</td>
<td>11</td>
<td>25.6%</td>
<td>27</td>
<td>42.2%</td>
<td>= .03*</td>
</tr>
<tr>
<td>Trusted Person to Communicate</td>
<td>14</td>
<td>32.6%</td>
<td>21</td>
<td>32.8%</td>
<td></td>
</tr>
<tr>
<td>Support to Complete AD</td>
<td>9</td>
<td>20.9%</td>
<td>14</td>
<td>21.9%</td>
<td></td>
</tr>
<tr>
<td>Information from Treating Doctor</td>
<td>11</td>
<td>25.6%</td>
<td>18</td>
<td>28.1%</td>
<td></td>
</tr>
<tr>
<td>Legal Implications</td>
<td>9</td>
<td>20.9%</td>
<td>30</td>
<td>46.9%</td>
<td>= .01*</td>
</tr>
<tr>
<td>Wishes Ignored or Overridden by Medical Staff</td>
<td>25</td>
<td>58.1%</td>
<td>28</td>
<td>43.8%</td>
<td>= .003*</td>
</tr>
<tr>
<td>Reflecting on Past Experiences</td>
<td>9</td>
<td>20.9%</td>
<td>13</td>
<td>20.3%</td>
<td></td>
</tr>
<tr>
<td>Change of Mind</td>
<td>5</td>
<td>11.6%</td>
<td>23</td>
<td>35.9%</td>
<td>= .009*</td>
</tr>
<tr>
<td>Time and Trouble to Draft AD</td>
<td>4</td>
<td>9.3%</td>
<td>14</td>
<td>21.9%</td>
<td>= .05*</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>43</strong></td>
<td><strong>64</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Mann-Whitney U Test.

5.8.2. Consultant Psychiatrist Barriers

Consultant psychiatrists were provided with a list of potential barriers from the clinician literature. Figure 12 shows the percentage of consultant psychiatrists who agreed with statements describing potential barriers to AD completion. The most frequently cited barriers for consultant psychiatrists were the quality of the information in the document (88%, 88/100); change of mind in relation to content during a crisis (79%, 79/100) and inappropriate treatment requests (77%, 77/100). Figure 12 also presents the system barriers identified by consultant psychiatrists. These included lack of training (76%, 76/100); access to the document (71%, 71/100); lack of resources to support ADs (62%, 62/100) and lack of time to review the document (39%, 39/100). Other barriers related to the risk of violence (50%, 50/100).
Consultant psychiatrists were also given the opportunity to identify other barriers to ADs in the quantitative question. These included the relevance of the directive to the situation, predictability, hospital management, the legal profession, support, the duty of care to involuntary patients, undue influence, lack of respect for treatment preferences among staff, the power differential, lack of electronic records and access to the requested intervention. Seven out of ten consultant psychiatrists who were unfamiliar with ADs perceived the risk of violence to be a barrier, while all of those who were unfamiliar (10/10) perceived lack of training to be a barrier.

Legal liability was identified in the context of other AD barriers (18%, 18/100), 38.9%, 7/18). This barrier was also a factor in deciding to comply with the person’s preferred choice of treatment (45.5%, 45/99). The majority of consultant psychiatrists (84.4%, 38/45) who identified legal liability were extremely concerned with leaving a patient untreated, even though the majority of service users were not interested in using the AD to refuse all treatments (82.2%, 88/107). The legal
liability theme also emerged in the qualitative statements. Examples of barrier statements in relation to legal liability included:

“Failure to implement an advance directive opens the field to malpractice and vexatious complaints.” Consultant Psychiatrist

“My fear is that advance directives would be introduced but at the same time, paradoxically doctors would still be held responsible for the patient ‘not getting better.” Consultant Psychiatrist

Another consultant psychiatrist referred to the fear of litigation in Irish medicine:

“Irish medicine tends to be preoccupied by fears risk of litigation, at times which may potentially interfere with patients’ ‘best interests’.” Consultant Psychiatrist

System barriers also emerged in the qualitative statements with references to time, resources, access, information and training. One consultant psychiatrist referred to the need for electronic access so that the AD would be immediately accessible:

“We would need very good administrative framework for use of same including advance directives being available online in services-patients presenting in crisis especially need such directive to be immediately accessible.” Consultant Psychiatrist

Time and resources also emerged as a barrier theme in the qualitative statements with some consultant psychiatrists commenting on the time required to develop the document:

“Concern re burden of work that this may bring to some psychiatrists and their team.” Consultant Psychiatrist

“A lot more work with ever decreasing resources!” Consultant Psychiatrist

Just over a quarter (26.6%, 25/94) of consultant psychiatrists identified reduced costs as a motivation for using ADs. One consultant psychiatrist who had used ADs in
Scotland stated that they were “taking much less time than would have thought” while another psychiatrist commented on how they “they might save time.” Others commented on how they might allow the early treatment of psychosis.

5.8.3. Service User and Consultant Psychiatrist Barrier Comparison
The AD barrier levels were significantly higher for consultant psychiatrists than service users. Eight out the ten barriers were endorsed by more than half of the consultant psychiatrist group, compared to one barrier for service users. An independent-samples t-test was conducted to calculate the total number of barriers for each stakeholder group. Significant differences were found between the mean barrier scores for service users [$M = 3.05, SD = 2.32$] and consultant psychiatrists [$M = 6.10, SD = 2.30$; $t(208) = -9.58, p < .001$]. On average each service user identified 3.05 barriers, whereas consultant psychiatrists identified 6.05 barriers. The difference in the barrier levels was statistically significant [Independent t test, $t = -9.58$, dfg = 208, $p < 0.001$]. The magnitude of the difference between the groups was large [mean difference = -3.06, 95% CI: -3.68 to -2.43] [eta squared = .307].

The concern with the possibility of change of mind in relation to the content of the directive during crisis was significantly higher among consultant psychiatrists (79%, 79/100) than service users (26.4%, 29/110) [Fisher’s exact test $p < 0.001, phi = .53$]. This barrier was also identified in the context of concerns with service user insight and capacity in the qualitative research. Examples of qualitative statements from consultant psychiatrists included:

“Difficulty can be lack of insight during acute episode when patients feel their advance directives are not relevant … ” Consultant Psychiatrist

“It has been shown that patients change their minds at times of illness and what was agreed as AD is now to be disregarded.” Consultant Psychiatrist

5.8.4. Overriding the Advance Directive
The circumstance in which the AD may be overridden is a barrier for both stakeholder groups. Mental health legislation frequently provides grounds for overriding ADs but a single criterion is lacking. The introduction of mental health
ADs is often characterised by exceptions to enforceability and revocability. This fails to comply with the right to equal recognition before the law in the CRPD. The provisions vary, but generally an AD may be overridden in situations where the person is considered a danger to themselves or others, during defined emergencies, where the directive was executed in bad faith or is inconsistent with clinical standards.

Over half (56.7%, 55/97) of consultant psychiatrists believed they should be permitted to override the AD instructions if evidence of better treatment exists, while half of service users were concerned with their wishes being overridden. Over half of consultant psychiatrists (58.8%, 57/97) perceived ADs would not undermine their clinical judgment, but 28.9% (28/97) were uncertain. The desire to override the AD was reported in the qualitative statements:

“... should be possible to override in certain circumstances: perhaps with support of independent psychiatrist.” Consultant Psychiatrist

“Protections need to be put in place for clinicians to over-rule an advanced directive in an emergency-especially if not previously agreed by clinicians before crisis.” Consultant Psychiatrist

One consultant psychiatrist commented that it was rare for treatment to suddenly appear and would usually become practice over time. The ability to override the directive informed the preference for non-legally binding ADs in some of the qualitative statements from consultant psychiatrists:

“Advance directives must be taken into consideration but not be legally binding i.e. consultant psychiatrists can make a decision to override the advance directive when in the patient’s best interests to do so: perhaps supported by independent psychiatrist when ready to do this.” Consultant Psychiatrist

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79 Article 12 (1)(2).
Some consultant psychiatrists believed that they had a better understanding of clinical needs than the person on his/her treatment:

“Need open discussion and will need to ensure support for MH teams & psychiatrists—will be difficult at times to respect patient wishes re advance directive when we know best.” Consultant Psychiatrist

“I would worry about conflict between advance directive and my clinically informed experience.” Consultant Psychiatrist

Another consultant psychiatrist recognised that the AD would allow the person to be treated in accordance with personal experience:

“It allows a patient to be treated or not treated as the patient sees fit, not as the doctor sees fit. Sometimes we treat patients to make us feel better not the patient.” Consultant Psychiatrist

Some service users considered themselves ‘experts by experience’ in the qualitative statements and trusted themselves to know ‘what works, doesn’t work.’ Examples of corresponding statements included:

“I know what it is like to be unwell and I know what helps.” Service User

“I trust myself. I trust my experience and knowledge of the mental health services in Ireland. I know what works and what doesn't work in my care. I know what has helped me to recover and what has hindered my progress.” Service User

5.8.4.1 Compliance with Informal Treatment Preferences
Almost half of service users (44.8%, 47/105) reported expressing future treatment preferences informally to the treating psychiatrist or other member of the treatment team, while 70.8 per cent (68/96) of consultant psychiatrists reported patients communicating preferences. The differences between the groups were statistically significant [Chi-square test for independence, $\chi^2 (2, n = 201) = 16.2, p < 0.001$, Cramer’s $V = .28$]. Of the service users who expressed future treatment preferences
informally, 39.1 per cent (27/69) reported that their treatment preferences were not complied with when unwell and 24.6 per cent (17/69) were unsure. Almost a third (32.3%, 21/65) of consultant psychiatrists reported complying with treatment wishes; over half complied some of the time, while 12.3 per cent (8/65) did not comply. Over half (59.3%, 16/27) of service users who were involuntarily detained reported expressing future treatment preferences to their treating psychiatrist or other member of the treatment team, compared to 38 per cent of other service users (27/71).

However, only one of the participants who was involuntarily detained, reported being given the treatment they preferred when unwell, compared to 47.7% (21/44) of other service users. These differences were statistically significant [Chi-square test for independence, $\chi^2 (2, n = 64) = 12.67, p = .002$].

5.8.4.2. Factors in Deciding to Comply with the Advance Directive

The consultant psychiatrist group were given a list of factors they would consider in deciding whether to follow a person’s preferred choice of treatment in the directive. Figure 13 shows the factors chosen by consultant psychiatrists. The most frequently cited factors were insight$^{81}$ (86.9%, 86/99), patient autonomy (77.8%, 77/99), therapeutic collaboration (76.8%, 76/99), current cognitive functioning (69.7%, 69/99) and family support for treatment preferences (65.7%, 65/99). Almost two-thirds of consultant psychiatrists (62.6%, 62/99) identified risk of violence. Risk of violence was also perceived to be a barrier to ADs (50%, 50/100) in a previous finding. Non-adherence to treatment (59.6%, 59/99) and legal liability (45.5%, 45/99) were also identified as factors to consider when following the directive. The decreased need for coercion was identified by 39.4 per cent (39/99) of consultant psychiatrists, while less than a third (31.3%, 31/99) identified reduced stigmatisation. Consultant psychiatrists were given the opportunity to identify other factors. These included the person’s current mental state; ethical responsibility and duty of care; choice and empowerment (10.1%).

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$^{81}$ Insight has been defined as the person’s understanding of their condition and how it affects interactions. Ivana Markova, German E Berrios, ‘The Meaning of Insight in Clinical Psychiatry’ (1992) 160 British Journal of Psychiatry 850.
Insight also emerged as a theme in the qualitative statements. Some consultant psychiatrists were concerned about capacity when executing the AD, whereas others were concerned with lack of insight during a crisis resulting in a change of mind:

“If patient retains a degree of insight-advance directives should be helpful. Loss of insight is likely to result in usual involuntary treatments.” Consultant Psychiatrist

The issue of insight and non-adherence was referred to in the qualitative statements.

“Sixty per cent of those with mental illness have a history of or are non-compliant at any given time. This will apply to ADs also, unless legally binding ... Our most seriously ill often don’t want treatment and have little or no insight ... An AD is unlikely to change the outcome or improve adherence to treatment in this group.” Consultant Psychiatrist

Figure 13: Factors in Deciding to Comply with AD. Consultant Psychiatrists

* Case response percentage refers to per cent of cases that responded to multiple response question so total figure exceeds 100%. Number of valid cases = 99. Number of responses = 711.
6. Qualitative Analysis of Open-Ended Questions
The qualitative statements were categorised under four main question headings for service users and consultant psychiatrists under which themes were grouped i.e. support for introduction of ADs; preferences for implementation; perceived barriers and benefits. Seventy two per cent (80/111) of service users made a qualitative response to two open ended question on ADs in the service user survey. Ninety-six per cent (73/76) of these statements related to their perceived helpfulness. Forty one per cent (46/111) made open ended comments on the perceived impact of ADs, where all but four statements were positive.

Seventy two per cent of consultant psychiatrists made some form of response to the three qualitative questions in the psychiatrist survey. Of the 59 per cent (59/100) of consultant psychiatrists that responded to the question on the perceived helpfulness of ADs, 81 per cent (48/59) made statements in relation to helpful aspects, while 19 per cent (11/59) referred to unhelpful aspects. This compared to 7.2 per cent in the quantitative findings. In the open-ended question on willingness to use ADs, almost two-thirds of consultant psychiatrists (30/47) made statements indicating their willingness to use the measure, while over a third made statements conveying their possible unwillingness, compared to 10.5 per cent in the quantitative question. Similarly, in the open ended question in relation to the introduction of ADs, over half of the 28 consultant psychiatrists who responded made a negative statement (17/28), suggesting some ambivalence in this group.

The qualitative statements highlighted the divergent preferences in relation to the legal status of ADs, with service users making statements in relation to the need for legally binding directives and consultant psychiatrists referring to non-legally binding directives. The analysis of the qualitative statements confirmed service user support for the introduction of legally binding ADs with few barrier statements, while consultant psychiatrists were in favour of non-legally binding ADs, which can be overridden in certain circumstances.
6.1. Perceived Benefit Themes
The perceived benefits for service users in the qualitative analysis included autonomy, communication and recovery, while the benefits for consultant psychiatrists included the enhancement of the therapeutic relationship, planning and to a lesser extent autonomy. These themes are consistent with the quantitative findings, but recovery and communication were more prominent in the qualitative statements for service users. Many service users wanted to use ADs to enhance autonomy and recovery and to communicate wishes to their treating doctor and family. In comparison, consultant psychiatrists were more interested in using ADs to enhance the therapeutic relationship and treatment planning. The enhancement of the therapeutic relationship was a major perceived benefit for consultant psychiatrists. ADs were perceived to improve communication in the context of the therapeutic relationship and involving family and relatives. Consultant psychiatrists ascribed a different meaning to autonomy than service users. Autonomy was viewed within the confines of the therapeutic alliance framework where clinicians and consultant psychiatrists are involved in the agreement of treatment choices.

6.1.1. Respect
The theme of respect also emerged in the qualitative statements for service users. The qualitative statements suggested that service users believe their wishes are not respected in the current system. Service users viewed ADs as tools, which could potentially increase respect. The perception of respect may be more important than clinical outcomes for service users.

“Would like my wishes to be respected and change in old regime.” Service User

“We should be respected as creative individuals who are well able to determine our own lives if allowed. Everyone needs a bridge over troubled waters at times!” Service User

One service user referred to how their human rights could be respected through the use of ADs, while another referred to how the introduction of directives would obligate the psychiatric authorities to treat individuals with more respectful forms of care and take away the coercive aspect of hospital admission and treatment:
“I would have a right as a person as a human being.” Service User

“It would obligate the psychiatric authorities to focus on treating me with useful, respectful and dignified forms of genuine care, without recourse to violent, abusive and dangerous ‘remedies’ whether practiced or implied! It would alter the terms under which I exit, and leave the psychiatric hospital. It would take away the coercive imposition of the psychiatric authority, at least in individual cases!” Service User

The importance of respect for treatment wishes to recovery was also conveyed in a service user statement:

“The respect you are/aren't treated with impacts you, possibly even more so than when you are well. Also, when recovering if your wishes were followed when unwell, recovering is easier as you can see your own behaviour/unwellness more easily and without having to heal from hurt inflicted intentionally or unintentionally by ignoring one's wishes.” Service User

6.2. Perceived Barrier Themes
Consultant psychiatrists supported ADs in certain non-legally binding forms, but identified increased barriers. Several barriers emerged in the qualitative statements for consultant psychiatrists including legal liability, insight, clinical decision-making autonomy and the ability to override the directive. Legal liability and insight were major concerns for consultant psychiatrists. System barriers such as the need for information, training, resources, time and accessibility also emerged. Both groups were concerned with the potential to override the AD with consultant psychiatrists concerned with their ability to override the directive and service users concerned with their wishes being overridden. The ability to change the directive during crises was also a concern for both stakeholder groups. Disparities existed in relation to clinical decision-making. Both groups perceived themselves to be experts, with many service users claiming to be ‘experts by experience’ and consultant psychiatrists regarding themselves as clinical experts. The qualitative statements suggested a medical model approach among some consultant psychiatrists. Under the medical model, clinicians are considered to be the experts regarding the cause and
appropriate response to disability. The social model of disability recognises the unique perspective offered by individuals with ‘lived experience’ and promotes participation. Recovery oriented services recognise the different forms of expertise.

6.2.1. Trust
Trust emerged as a major theme in the qualitative statements and throughout the survey. The mental health experience led to distrust in the system for some service user participants. Lack of trust in the system and the therapeutic relationship were pervading themes for participants who were involuntarily detained. The need for increased control over treatment and protection were common. The fear that the AD will be ignored or overridden also points to a lack of trust in the service user group. Statements from consultant psychiatrists expressing a desire for the ability to override the AD suggest these concerns may be valid. Barrier statements communicated by service users can be linked to system trust:

“I believe the present system would cause me more harm than good.” Service User

“I cannot imagine the system changing to accommodate my wishes.” Service User

The detrimental impact of coercion and lack of choice in the current system was encapsulated in a service user statement. The importance of communication and engagement for rebuilding trust was also highlighted:

“When I became unwell ... an ambulance, two police and a swarm of psychiatric nurses and ambulance staff arrived at my house, even though I had not endangered my own life or those around me. I was carted off to the local hospital which never would have been my hospital of choice. When I got there I was made 'voluntary', the Mental Health Commission were not informed of my detention ... I was not allowed speak to my boss to try and salvage my job, so I lost my temporary job and (nearly 4 years down the road) I have lost my career ... My experience with psychiatry was a very negative one. It nearly destroyed me. I am trying hard to bounce back from the trauma of it all ... My mental health has been severely damaged by the experience. It was only by meeting or connecting with doctors I can trust that I saw a future.”
Service User
Negative experiences in the mental health system led one service user to believe doctors could use the AD choices against him when unwell leading to further disempowerment.

“Unhelpful if it is used against my choices e.g. ‘But you said in your directive ... I'm not sure whether it would empower or disempower me??? My personal experience is disempower. e.g. ‘Perhaps you weren't well when you made those choices’ Doctor.” Service User

A sense of security and control were particularly important for service users who were involuntarily detained, many of whom stated that an AD would give them protection and ‘peace of mind’.

“It would give me more peace of mind. I believe peace of mind is the key to happiness.” Service User

Other service users who were not involuntarily detained felt they had built control and trust through a long relationship with their treating psychiatrist pointing to the need for continuity of care.

“Sufficient control, I have total faith in my psychiatrist after a long relationship.” Service User

One consultant psychiatrist articulated how the level of trust varies and may develop slowly:

“It depends, it's always different, it's always individual and it changes from time to time and some patients want me to be ‘the expert’ and some don't trust me to be ‘the expert’ and some don't trust me at all, and some slowly trust ...” Consultant Psychiatrist

While service users reported distrust in the system and treating doctors, consultant psychiatrists recognised the value of ADs in engagement and building trust in the therapeutic relationship.
“Help develop therapeutic relationship in a more collaborative way, engage patient to gain information on illness and treatment options and be general discussion. Engage carer/family/advocate involvement and probably improve MDT working-helps engagement and build trust.” Consultant Psychiatrist

A number of consultant psychiatrists had already used ADs either informally or in another jurisdiction and articulated how they improved trust:

“The conversation between health professional and patient-improved relationship/trust.” Consultant Psychiatrist

“By consenting to patients wishes-patients were more co-operative and trusting and ‘warmer’ during treatment.” Consultant Psychiatrist

“Have used them before and found this improves relationships and understanding.” Consultant Psychiatrist

7. Discussion
The empirical research sought to determine the views of service users and consultant psychiatrists towards ADs and the extent to which they will be supported. This was achieved by comparing the views and preferences of both stakeholder groups and the perceived impact of ADs in Irish mental health practice. The findings for both stakeholder groups will be discussed under the main survey themes headings: support for the introduction of ADs; familiarity and opinions; personal experience; preferences for implementation and perceived benefits and barriers. The implications of the findings for the introduction of legislative provisions for ADs and implementation into mental health practice will be addressed in the discussion. The strengths and limitations of the study and recommendations for future research will also be considered.

7.1. Demographics
The national figures suggest the service user sample is generally representative of the population. The National Psychiatric Inpatient Reporting System (NPIRS) figures show an equal proportion of male and female admissions and higher admissions in
the 45-54 age groups. The national data also indicate that single persons account for over half (55%) of all admissions to mental health facilities. Single persons accounted for 60.4 per cent of the service user sample. Almost two-thirds (64.2%) of service user participants lived in urban areas, which is in line with the 2011 census figures. Over half of the service user sample had a third level education (54.6%, 59/108), three-quarters had higher secondary education or above and 8.7 per cent had primary education. The Central Statistics Office (CSO) figures in 2012 indicated that 33.9% of the Irish population aged between 15-64 years had a third level qualification, 70.6 per cent had higher secondary education or above and 10.7 per cent had primary education. The level of third level education may therefore be higher in the sample. European research suggests lower levels of educational attainment among individuals with mental health difficulties.

The representativeness of the consultant psychiatrist sample is more difficult to determine due to lack of national figures. The consultant psychiatrist sample consisted of a higher proportion of males (63.3%) than females (36.7%). The lower percentage of females in the sample may be explained by the greater proportion of males at consultant level in medicine, although female representation has been found to be higher in psychiatry. The majority of participants had over 10 years’ experience (94.9%) and were general adult consultant psychiatrists.

7.2. Use of Mental Health Services
Almost three-quarters of the service user participants were hospitalised more than once. This is consistent with the high readmission rate in the Irish mental health system. Readmissions accounted for 66 per cent of the 18,173 admissions to Irish

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83 Ibid.
psychiatric units in 2012.\textsuperscript{88} The findings suggest the readmission rate is significantly higher among participants who were involuntarily detained. This is consistent with Mental Health Commission data, which indicated that 7 per cent ($n = 569$) of all involuntary admissions orders between 2006 and 2010 were due to multiple readmissions.\textsuperscript{89} High readmission rates have also been found in this group internationally.\textsuperscript{90} Over a quarter (25.5\%) of service users in the survey had been subject to involuntary admission. Involuntary admissions accounted for 11 per cent of all admissions in Ireland in 2012.\textsuperscript{91} The involuntary admission rate decreased substantially after the mental health tribunals were established in 2007, but has been gradually increasing again since 2010.\textsuperscript{92} Figures from the Mental Health Commission show that coercive measures such as seclusion are still common in the Irish mental health services.\textsuperscript{93} The high readmission rate and the increasing use of coercion suggest the need for alternative responses in the Irish mental health services. ADs have been shown to reduce readmission rates and the need for involuntary admission in previous studies.\textsuperscript{94} The findings suggested that consultant psychiatrists were less motivated by the reduced need for involuntary treatment and hospitalisation than service users, suggesting a need to increase awareness of the potential role of ADs in this area.

\textsuperscript{89} The data showed that 121 individuals had multiple involuntary admissions constituting 7 per cent of all involuntary admission orders between 2006 and 2010. Multiple readmission was defined as having three or more involuntary episodes in one calendar year. Mental Health Commission, \textit{Annual Report 2010 including Report of the Inspector of Mental Health Services} (Mental Health Commission 2011) 36.
\textsuperscript{90} Stefan Priebe and others, ‘Patients’ Views and Readmissions One Year after Involuntary Hospitalisation’ (2009) 194 (1) British Journal of Psychiatry 49.
\textsuperscript{92} The number of involuntary admissions decreased from 2,830 in 2005 to 1,574 in 2011. Involuntary admission rates to approved centres increased by 5\% between 2010 and 2011 and 4\% from 2011 to 2012. Mental Health Commission, \textit{Annual Report 2012 including Report of the Inspector of Mental Health Services} (Mental Health Commission 2013) 32.
\textsuperscript{93} 1,683 seclusion episodes were reported in approved centres. Mental Health Commission, \textit{The Use of Seclusion, Mechanical Means of Bodily Restraint and Physical Restraint in Approved Centres: Activity Report 2011} (Mental Health Commission 2013).
7.3. *Familiarity*

The survey findings highlighted wide variations in AD familiarity between the stakeholder groups. Service users were significantly less familiar with ADs than consultant psychiatrists. Seventy per cent of consultant psychiatrists were familiar with ADs, compared to 27.5 per cent of service users. Low levels of familiarity and education were associated with increased AD barriers in the service user group, suggesting a need for information and education. This is consistent with previous research where service user information and awareness have been identified as implementation barriers.95 The findings indicated that service users with higher educational levels and those who were subject to involuntary admission were more familiar with ADs and identified less barriers. The increased familiarity in the involuntary admission group may be linked to an increased demand for ADs among those who feel coerced.96 The familiarity rate was higher than in a previous Irish study with involuntary patients, where only 8 per cent were aware of ADs.97

The findings revealed higher familiarity rates among consultant psychiatrists than in previous international research with mental health professionals.98 Nevertheless, only a quarter of consultant psychiatrists reported that they were very familiar with ADs and over three-quarters identified a need for staff training and knowledge. The need for information and training was also identified in the qualitative statements. The findings indicated a degree of uncertainty in relation to the perceived impact of ADs among consultant psychiatrists, suggesting some disparity between the perceived familiarity and practice knowledge. The perceived barriers were also significantly higher among consultant psychiatrist than service users. Previous research has found that lack of provider knowledge and training to be associated with increased barriers.

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96 Ibid.
to ADs. The high barrier levels for consultant psychiatrists and the increased barriers for service users with lower levels of familiarity suggest a need for AD awareness and education in Ireland.

7.4. Support for Advance Directives
The findings suggest that Irish service users and consultant psychiatrists are broadly supportive of the introduction of ADs, but have varying implementation preferences. Over 90 per cent of service users and 80 per cent of consultant psychiatrists perceived ADs to be helpful. Service users had higher levels of perceived helpfulness than consultant psychiatrists. Less than 10 per cent of participants in both stakeholder groups perceived ADs to be unhelpful or were unwilling to use them. However, only 15.3 per cent of consultant psychiatrists perceived ADs to be extremely helpful in clinical practice and identified significantly increased barriers in both the quantitative and qualitative findings. This is consistent with the literature, which shows varying levels of support for ADs and a high level of ambivalence among clinicians. The literature suggests psychiatrists are less supportive of ADs than other clinicians. The responses to questions on involvement in planning for mental health treatment, perceived helpfulness and willingness to use ADs were largely positive, but satisfaction with current involvement in mental health treatment, preferences for implementation and perceived benefits and barriers varied widely between the stakeholder groups and within the service user group. Consultant

psychiatrist support can represent a barrier to the implementation of ADs.\textsuperscript{102} In a previous study, psychiatrists’ knowledge was linked to increased support of the measure.\textsuperscript{103} Clinicians who were adequately informed about the legislation and the circumstances in which an AD may be overridden were found to be more supportive of the measure.\textsuperscript{104} The survey findings suggest a need to increase consultant psychiatrist knowledge to achieve higher levels of support and facilitate service user interest in the measure.

The survey findings suggest that the WRAP programme may be an important tool for garnering consultant psychiatrist support for ADs and facilitating service user completion of the document. WRAP is being used to support the development of ADs in other jurisdictions.\textsuperscript{105} The findings suggest that consultant psychiatrists using WRAP were more willing to use ADs, while service users with WRAP plans had higher perceptions of control over treatment. The integration of ADs with individual care planning may also help garner support for ADs. Consultant psychiatrists perceived that ADs would enhance the framework for participation in individual care plans. The majority of participants in a previous Irish study with involuntary patients were interested in including an AD in their care plan.\textsuperscript{106} The integration of ADs with WRAP and individual care plans can strengthen the framework for service user participation and increase satisfaction and control in Irish mental health treatment.

7.4. Personal Experience and Service User Perceptions
7.4.1. Listening
The survey findings highlight the need for listening. One third of service users perceived they were not listened to by their treating psychiatrist and almost a quarter were uncertain. The perception of ‘not being listened to’ was significantly higher among participants who were involuntarily detained. The provision of a forum for listening was a major motivation for AD development among all service user

\textsuperscript{104} Ibid.
\textsuperscript{105} See State of Virginia in chapter 5.
participants. The importance of listening, participation and the development of trust were highlighted in a previous Irish study on recovery.\textsuperscript{107} In a previous survey, 21 per cent of service users did not think the treatment team listened to them.\textsuperscript{108} One of the core messages being communicated to the Irish lobby group Mental Health Reform is the desire to be listened to by professionals. Previous research shows individuals with mental health conditions view ADs as communication tools, providing a forum for dialogue and the exchange of information.\textsuperscript{109} Some commentators argue that the major benefit of ADs is that they force psychiatrists to listen to their patients.\textsuperscript{110} ADs have an important role in promoting active listening and communication through open collaborative discussion thereby increasing trust.

7.4.2. Control

The findings indicate low perceptions of control over mental health treatment among Irish service users. Almost two-thirds of service users perceived they had no control over treatment when being treated by the mental health services. The vast majority of service users were interested in using ADs to increase control over treatment. The perception of control over treatment was grounded in individual mental health experiences such as involuntary admission, hospitalisation, gender and diagnoses. Service users who were hospitalised or involuntarily detained had significantly lower perceptions of control than other participants and were more interested in using ADs to increase control over treatment. Previous research suggests the perception of coercion impacts more on control more than admission status.\textsuperscript{111} Male service users also had significantly lower perceptions of control than female service users and were less satisfied with involvement in treatment. The development of an AD is reported to increase the perception of control over treatment.\textsuperscript{112} A number of clinical outcomes have been associated with increased control including enhanced self-

\textsuperscript{107} Yulia Kartalova-O’Doherty and Donna Tedstone Doherty, \textit{Reconnecting with Life: Personal Experiences of Recovering from Mental Health Problems in Ireland}, HRB Research Series 8 (Health Research Board 2010) 32.

\textsuperscript{108} Inspectorate of Mental Health Services, ‘National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010’ (Mental Health Commission 2011).


\textsuperscript{112} E Maitre and others, ‘Advanced Directives in Psychiatry: A Review of the Qualitative Literature, A State –of-the-Art and Viewpoints’ 39 (4) Encephale 244.
esteem and treatment satisfaction. The low level of control amongst service users suggests a need for ADs in Irish mental health care.

7.4.3. Satisfaction with Involvement in Treatment

Service users were significantly less satisfied with involvement in planning for future mental health treatment than consultant psychiatrists. Higher levels of satisfaction with involvement in treatment had a positive correlation on the perception of control in the service user group. This finding suggests that greater involvement can increase treatment satisfaction and control. Those who were less satisfied with treatment involvement were also more interested in refusing treatment. The low perception of control among service users suggests a need for participative measures that can increase satisfaction with involvement in treatment. Prior research indicated that individuals who perceived less coercion on admission and while receiving treatment in hospital were more satisfied with treatment. The development of an AD is reported to result in a higher level of satisfaction including increased control, respect and value as a person.

Several reports have identified low levels of participation in the Irish mental health services. Participation emerged as a key priority in the National Inpatient Survey, suggesting a need for measures that can increase involvement and satisfaction. ADs are proposed to increase participation, treatment satisfaction and decrease crises. The measure may be particularly beneficial to those who experience low levels of control such as male service users and those who have been involuntarily detained or hospitalised. The literature suggests ADs have an important role in

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increasing listening, control and satisfaction with mental health treatment. This can lead to increased participation and engagement in the Irish mental health services.

7.5. Preferences for Implementation

7.5.1. Legal Status of Advance Directives

Wide variations existed between the stakeholder groups in relation to the legal status of ADs. The findings suggest that consultant psychiatrists are in favour of non-legally binding ADs, whereas service users are interested in legally binding directives. Only 11.2 per cent of consultant psychiatrists supported legally binding directives allowing for refusal of treatment, while just over a fifth of service users were interested in non-legally binding directives. The findings suggest consultant psychiatrists are in favour of non-legally binding directives, which are a co-operative arrangement between the service user and the treating psychiatrist, whereas service users are more supportive of legally binding ADs, which allow them to opt into and out of certain treatments and have varying preferences in relation to the involvement of the treating psychiatrist. The relationship of trust with treating doctors and communication were common themes underlying AD preferences for service users. The divergent preferences in relation to legal status were affirmed in the qualitative statements. The findings are consistent with the preference for legally binding ADs among service users in the literature and lower levels of support among psychiatrists. Previous studies show clinician support for ADs to be associated with knowledge of their legal status, particularly the ability to override the document.

The service user concern with the potential for ADs to be overridden may inform the preference for legally binding directives, while the consultant psychiatrist concern for the ability to override ADs may inform the preference for non-legally binding directives in this group. The divergent preferences in relation to the legal status of ADs will have to be addressed in the legal framework. The high level of non-compliance with informal treatment preferences and the desire to override the directive, in combination with the service user concern with the AD being overridden, suggest a need for legally binding directives. The support of consultant psychiatrists is critical to the successful implementation of ADs so the underlying concerns in relation to legally binding ADs and the refusal of treatment should be addressed prior to the introduction of the legislation. Previous research suggests clinicians are more willing to support ADs if they are educated about the parameters of the legislation. The provision of education programmes and consensus building can help address the consultant psychiatrists’ concerns in relation to legally binding ADs.

7.5.2. Content of Advance Directives

The findings suggest broad agreement between the stakeholder groups in relation to AD content. This is consistent with the literature, which shows consensus among the stakeholder groups in relation to the value of the information. Both stakeholder groups were interested in including treatment/medication preferences and place of treatment. Service users were also interested in specifying other interventions such as counselling. This preference raises questions about the extent to which the mental health system relies on medication relative to other psychosocial interventions. A recent report by the Inspector of mental health services found treatment is often based on the medical model. The survey findings indicated that consultant

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psychiatrists were significantly more interested in including life management choices. Personal life management choices can include decisions in relation to issues such as childcare, household finances and are generally not legally binding. This finding varies from the literature, which shows service users are more interested in including life choices. Consultant psychiatrists may be more cognisant of the benefits of including life choices and find these less threatening than treatment refusals. The inclusion of non-treatment choices in the directive is considered particularly beneficial to autonomy.

7.5.3. ECT Preferences

Significant disparities existed between the consultant psychiatrist and service user groups in relation to ECT preferences. The majority of service users expressed a preference (82.4%) for the option to refuse ECT, compared to only a fifth of consultant psychiatrists (19.6%). This is consistent with preferences articulated in previous research, where almost three-quarters of service users indicated they would refuse ECT. The qualitative statements showed that some consultant psychiatrists had concerns in relation to the refusal of life-saving treatment. Some clinicians argue that ECT may be the only rapid and effective life-saving treatment for those with severe and treatment resistant conditions. ECT is most commonly used in cases of severe depression, which is resistant to antidepressant drugs or psychotherapies. According to the College of Psychiatry in Ireland, ECT can be a life-saving treatment for individuals with catatonia or those who are actively suicidal or physically debilitated by depression. An assessment report by National Institute for Health Care and Excellence (NICE) in the U.K. found that ECT may be of benefit for the rapid control of catatonia or mania. However, the report concluded


129 It is estimated that 15% of people with severe depression will die by suicide. ECT is reported to be life-saving in the case of sudden onset of viral encephalitis.

130 College of Psychiatrists in Ireland, Electroconvulsive Therapy (ECT) Position Statement EAP01/2011 (College of Psychiatrists in Ireland 2011) 2.

that the evidence in relation to the effectiveness of ECT in determining a therapeutic strategy is weak. The findings suggest the need for safeguards in the legislation to alleviate consultant psychiatrists’ concerns in relation to the use of life-saving, but this does not justify the exclusion of ECT refusal in the AD. In a previous study, service users were more willing to agree to ECT treatment where their life was in danger. The circumstances in which treatment will be refused or accepted should be set out in the terms of the directive and include the person’s wishes in relation to life-saving mental health treatment. The legislation should include exceptions for life-threatening emergencies to help address concerns, unless the person has expressly stated they do not want to receive it in these circumstances.

The findings indicated that consultant psychiatrists were more in favour of including advance consent to ECT in the AD, with over half endorsing this option compared to just over a quarter of service users. Similar levels of uncertainty were found in both stakeholder groups in relation to advance consent to ECT. Some consultant psychiatrists believed that advance consent to ECT may be beneficial for individuals who have previously found the treatment to be effective and avoid the need for involuntary admission. The Irish Mental Health Commission reported 332 programmes of ECT in 2011 representing a rate of 7.2 programmes per 100,000 of population and a 4.3 per cent decrease since 2010. While the rates of involuntary ECT treatment are relatively low in Ireland, the findings suggest that service users have a strong preference for ADs, which allow them to refuse ECT.

7.5.4. Proxy Directives
AD preferences can be expressed through an instructional directive, which provides directions regarding future treatment or a proxy directive where the authority to communicate preferences is given to a designated person. The findings suggested the majority of service users (86%) were interested in appointing a proxy decision-maker. This is consistent with previous research, which found 74 per cent of service

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users were interested in appointing a proxy. Participants with higher levels of familiarity and education were more interested in appointing a proxy in the survey. This is consistent with a study by Ambrosini which found those with greater levels of familiarity and insight were interested in proxy directives. The findings also suggested that consultant psychiatrists would be more willing to follow the AD if a proxy was appointed. The literature suggests clinicians are more comfortable when AD decisions are communicated by a proxy decision-maker and are more likely to support them. The option to appoint one or more proxy decision-makers in the directive should be included in the Irish legal framework.

Although, the majority of service users were interested in executing a proxy directive, one third lacked a trusted person to communicate on their behalf. This is somewhat consistent with previous research, which found 20 per cent of service users did not have a trusted proxy. The proxy decision-maker barrier was also identified in the State of Virginia. The survey findings indicated that the lack of a trusted proxy and support to complete the directive was significantly higher among service users who were involuntarily detained. This may be indicative of the negative impact of involuntary admission on familial relationships found in previous Irish research. Participants who lacked a trusted proxy were also more interested in refusing treatment. Figures from the Mental Health Commission indicate that 61 per cent of the applications for involuntary admission were made by a spouse or family member in 2010, while only 7 per cent were made by an authorised officer of

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139 See chapter 5. Virginia.
the HSE.\textsuperscript{141} The negative impact of involuntary admission on family relationships suggests a need to change this approach. ADs can facilitate communication and help rebuild family relationships.\textsuperscript{142} The lack of a trusted proxy to communicate suggests the need to build support networks and for the inclusion of instructional and proxy directives in the legal framework. The draft legislation for ADs provides the option of appointing a patient-designated healthcare representative, but this is not obligatory.\textsuperscript{143}

7.5.5. \textit{Revocability and Review of the Advance Directive}

The findings indicated that over three-quarters of service users were interested in an AD that can be followed when they are unwell and revoked when they are well. However, over half of service user participants were interested in a directive that allowed them to change their mind when unwell. The ‘risk of change of mind’ since the directive was executed was a barrier for over a quarter of service users. These preferences are consistent with those articulated in previous research, which shows a substantial proportion of service users prefer the directive to be revocable at any time, even though few are fully revoked in practice.\textsuperscript{144} In a previous Irish report, respondents had a clear sense of their preferences despite being unwell.\textsuperscript{145} Some individuals fear they may experience a limitation in treatment not intended in their previously expressed will or may wish to change aspects of the instructions. The change of mind barrier was associated with lower levels of familiarity and education in the service user group. The provision of information and education may therefore help alleviate concerns in relation to change of mind. The service user preferences and concerns in relation to change of mind suggest a need for ADs that are revocable during crisis periods in the legal framework. The draft scheme provides for ADs that

\begin{itemize}
\item An authorised officer is an officer of the HSE who is authorised to exercise the powers conferred on authorised officers by section 9 of the Mental Health Act, 2001. Mental Health Commission, \textit{Annual Report 2010 including Report of the Inspector of Mental Health Services} (Mental Health Commission 2011) 36.
\item Daniel Ambrosini and others, ‘Perceptions of Psychiatric Advance Directives among Legal and Mental Health Professionals in Ontario and Quebec (2008) 3 Journal of Ethics in Mental Health 1.
\item Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 7(1).
\item In one study of 106 service users with ADs and 487 crisis events, the directive was never revoked as a whole, although in 105 (22 per cent) of the crises, service users changed their minds about some specific instructions: Debra Srebnik and Scott Kim, ‘Competency for Creation Use and Revocation of Psychiatric Advance Directives’ (2006) 34 (4) Journal of the American Academy of Psychiatry and the Law 501.
\item Liz Brosnan and others, \textit{Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective} (Western Health Board 2002).
\end{itemize}
The risk of change of mind in relation to the content of the directive during crisis was a barrier for over three-quarters of consultant psychiatrists. These findings are consistent with the literature, which suggests service user and clinician opinions differ significantly in relation to the revocability of the directive. Clinicians generally express a preference for legislation that requires capacity to revoke the directive, while service users prefer it to be revocable at any time. The change of mind concern also emerged in the qualitative statements for consultant psychiatrists. The revocability barrier can be alleviated through the inclusion of an optional Ulysses clause in the legislation. This allows aspects of the ADs preferences to be changed at any time unless the person clearly specifies that they wish their AD choices to be irrevocable during crisis periods. The Ulysses clause is being used in the State of Virginia and other jurisdictions, and is reported to be popular with service users and psychiatrists.

Other strategies which can ensure changes are incorporated in the directive include the appointment of a trusted proxy decision-maker and regular review. The AD should be reviewed periodically to incorporate changes and facilitate communication. The findings suggest reviewing the directive after each mental health episode or on a six monthly or annual basis if a crisis has not occurred. The review allows the AD to act as a vehicle for learning for future mental health experiences. An inbuilt statutory review may impact on the validity of the directive so should form part of a Code of Practice in the legislative framework. The draft

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146 Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 4(6).
148 See chapter 5, State of Virginia.
scheme for ADs does not stipulate a statutory review period, but this question has been posed as part of the public consultation.\footnote{151 Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013’ (Department of Health 2014).}

7.5.6. Support for Completion of the Advance Directive

The provision of support for completion is a key variable in AD development.\footnote{152 Pablo Nicaise, Vincent Lorant, Vincent Dubois, ‘Psychiatric Advance Directives as a Complex and Multistage Intervention: A Realist Systematic Review’ (2012) 21 (1) Health and Social Care in the Community 1.} The survey findings indicated that the majority of service users were interested in support to complete the directive, with only 15.9 per cent stating that they wished to complete the AD without assistance. The findings are consistent with previous research, which found service users preferred support to develop ADs and the majority needed some form of assistance.\footnote{153 Tracy Peto and others, ‘Support Needed to Create Psychiatric Advance Directives’ (2004) 31 (5) Administration and Policy in Mental Health 409; Jeffrey Swanson and others, ‘Psychiatric Advance Directive: A Survey of Persons with Schizophrenia, Family Members and Treatment Providers’ (2003) 2 International Journal of Forensic Mental Health 73.} AD completion can be supported by a peer, mental health professional, family member or other person. The findings found variations in support preferences between the stakeholder groups. The majority of service users chose a family member or trusted friend, while consultant psychiatrists were in favour of the treating psychiatrist. Consultant psychiatrists viewed consultation with the treating psychiatrist to be extremely important when preparing an AD, but time and resources were also perceived barriers. Almost three-quarters of service users were interested in agreeing treatments/medications with the treating psychiatrist, but less than half expressed a preference for the support of the treating psychiatrist when drawing up the directive. The literature suggests that the degree to which individuals want their treating psychiatrist involved in the AD will partly depend on the level of trust in the relationship.\footnote{154 Richard Laugharne and Stefan Priebe, ‘Trust, Choice and Power in Mental Health: A Literature Review’ (2006) 41 (11) Social Psychiatry and Psychiatric Epidemiology 843.} The service user finding in relation to the involvement of the treating psychiatrist may be indicative of lack of trust in the therapeutic relationship. The findings are consistent with suggestions that family, friends or other trusted individuals should support AD completion.\footnote{155 Joseph Rogers and Jay Centifanti, ‘Beyond ‘Self-Paternalism: Response to Rosenson and Kasten’ (1991) 17 (1) Schizophrenia Bulletin 9.}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|}
\hline
Variable & Description & Value \hline
Service user & Interested in support & 75.0\% \hline
Consultant psychiatrist & In favour of support & 100.0\% \hline
Peer & Preferred & 25.0\% \hline
Mental health professional & Preferred & 25.0\% \hline
Family member & Preferred & 50.0\% \hline
Trusted friend & Preferred & 50.0\% \hline
\end{tabular}
\caption{Support preferences between stakeholder groups.}
\end{table}
Variations also existed within the service user group in relation to preferences for support. Participants who were involuntarily detained were less interested in the support of the treating psychiatrist or family members. This may be indicative of the lack of trust in this group. The preference for the support of family members may also vary based on trust.156 Over a third of service users did not want families or carers involved in their treatment in a previous Irish survey.157 Involuntary admission was found to have a negative impact on therapeutic and familial relationships.158 AD preferences have been found to be grounded in personal mental health experiences in the literature.159

While consultant psychiatrists recognised the value of ADs in involving families and carers, some expressed reservations in relation to undue influence. This is consistent with previous research where clinicians expressed fears in regard to pressure from family members on treatment decisions.160 The survey findings indicated that over half of consultant psychiatrists perceived ADs would increase the decision-making burden of family members, while the majority of service users perceived that ADs would assist family understanding of their wishes. Physicians often raise concerns about family members being burdened with complex treatment decisions, due to emotional involvement.161 Irish GPs reported that an end-of-life planning tool enhanced their relationship with patients and reduced the potential for family conflict.162 The involvement of an independent facilitator in the development of the directive may help alleviate fears in relation to undue influence from family members or clinicians. A peer facilitator can act as a mediator and advocate for the

162 Sarah Murphy, Brendan O’Shea, ‘Think Ahead: An Irish Care Planning Tool’ 3 (2) British Medical Journal Supportive and Palliative Care 270.
person ensuring their choices are respected. The CRPD requires that health professionals directly engage with the individual and ensure that support persons do not have undue influence over decisions.163

The findings also highlight the difficulty some service users may experience in securing support to complete the directive. Over a fifth of service users had difficulty getting a trusted support person to assist them. The lack of support persons has been articulated in a number of previous studies.164 This barrier was higher for participants who were involuntarily detained and those with lower levels of education in the survey. The increased barriers to understanding among participants with lower educational levels suggest a greater need for support in this group. Those with lower educational levels required a significant amount of assistance in the State of Virginia.165 The literature for general ADs shows higher use among college graduates.166 The lack of support suggests a need for facilitators to assist AD completion. The research suggests peers may provide appropriate support because of their independence from the treatment relationship, unique knowledge and shared experience.167 Peers are being used to support AD completion in Virginia and other jurisdictions.168 Previous research found service users were more comfortable with facilitators from outside the mental health system.169 This was evident among some service users in the survey who expressed a preference for the support of therapists from outside the system. The balance of power in the clinician facilitated directive raises concerns in relation to undue influence. However, the involvement of the psychiatrist may increase compliance with the AD and increase service user

165 See State of Virginia, chapter 5.
interest. Even if the AD is designed to enhance autonomy, clinician support is crucial for effectiveness. Consultation with the treating psychiatrist may therefore be necessary after the AD is developed with another support person to facilitate communication and to ensure the treatment preferences are respected.

7.5.7. Perceived Benefits of Advance Directives

The findings suggested that the majority of service users were interested in using ADs to increase control over treatment; to plan for future crisis periods; to provide a forum for listening and communication; and to assist recovery. The desire to use ADs as a forum for listening and to increase control over treatment are consistent with the low perception of control and listening found among service users in the survey. ADs are posited to increase listening and control in mental health treatment. Trust and respect also emerged as a perceived benefit in the qualitative findings. These findings are consistent with preferences articulated in the literature where service users perceived ADs as tools for promoting autonomy, communicating treatment wishes and avoiding conflict in treatment decisions.

Consultant psychiatrists were interested in using ADs to plan for future crisis periods; to increase patient control over treatment; to enhance the therapeutic relationship and to provide a forum for communication. The enhancement of the therapeutic relationship was a major perceived benefit of ADs for consultant psychiatrists. The literature suggests the process of preparing an AD can enhance service user trust and collaboration with clinicians, improving the therapeutic

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relationship and treatment engagement. The survey findings suggest that consultant psychiatrists were more interested in using ADs to improve the therapeutic relationship or to use them as a reminder of the care plan. Consultant psychiatrists defined autonomy in the context of the therapeutic alliance framework and agreement of choices with treating doctors. This is consistent with the literature on psychiatrist use of ADs. While service users were interested in improving the therapeutic relationship, they were significantly less motivated by this factor. The findings of a previous Irish study recommended improving personal engagement and realising the potential of the therapeutic relationship with mental health professionals. Participation and consultation on treatment were found to decrease fear and increase trust. The low level of listening, control and trust in the survey suggests an urgent need for measures that can promote communication, participation and increase trust in the therapeutic relationship.

A number of significant differences were found between the groups in relation to the perceived benefits of ADs. Consultant psychiatrists were interested in planning and the therapeutic relationship and service users more motivated by increased control, communication and recovery. Interestingly, service users were more interested in using ADs to communicate information on treatment history, while consultant psychiatrists were interested in improving the quality of decisions. The finding suggests the expertise of the person may not be recognised in mental health decision-making. This may be indicative of the medical model of treatment where medical practitioners are considered to be the experts. The issue of repeating treatment history to different doctors was identified by service users in a previous Irish survey. The qualitative statements indicated that some service users wanted to use ADs to communicate concerns on the harmful side effects of treatment. This is consistent with a previous study which shows service users perceive ADs to be

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175 Ibid.
177 Ibid.
useful for avoiding side effects and preventing involuntary treatment.\textsuperscript{179} The findings indicated consultant psychiatrists perceived ADs to be significantly less beneficial in the recovery process than service users, suggesting the need to promote the measure as a recovery tool in this group. This is consistent with a previous study in the U.S. where only a small proportion of clinicians perceived ADs would be beneficial to recovery.\textsuperscript{180} The findings show similarities between the groups in using ADs to enhance communication.

7.5.8. Perceived Barriers to Advance Directives

The AD barriers present the greatest challenges to the implementation of the legislation in Ireland. The survey findings indicated that the barriers varied between the stakeholder groups, with consultant psychiatrists identifying significantly more barriers than service users. The most frequently cited barriers for service users included the potential for wishes to be ignored or overridden by medical staff, limited understanding of ADs and the lack of a trusted person to communicate on their behalf. These are consistent with barriers articulated in the literature.\textsuperscript{181} The survey findings also identified other barriers including change of mind, getting information from the treating doctor and support to complete the directive. Low levels of familiarity and education were associated with increased barriers amongst service users.

Service users were primarily concerned with the potential for the AD to be ignored or overridden by medical staff. This barrier was greater for service users who were more familiar with ADs and had higher levels of education, suggesting increased understanding. The high rate of non-compliance with informal treatment preferences and the desire for the ability to override the directive among consultant psychiatrists suggest these concerns may be well-founded. Service users who were involuntarily detained were more concerned with the potential for the AD to be overridden than other participants. The low level of compliance with informal treatment preferences


\textsuperscript{181} Ibid.
in this group substantiates this concern. The belief that the AD will be ignored or overridden can cause further distrust in the therapeutic relationship.

The consultant psychiatrist desire for the ability to override the directive and the service user concern in relation to it being overridden are potential barriers to AD implementation. The lack of clear guidelines as to when an AD can be overridden can lead to clinician ambivalence and low completion rates among service users. The legislative framework should therefore include clear guidelines and accountability mechanisms to alleviate the concerns of both stakeholder groups. The circumstances in which an AD can be overridden should be limited to defined life-saving emergencies and treatment preferences should be respected during involuntary detention. Previous research suggests that the majority of service users support the use of emergency life-saving treatment.

Trust also emerged as a barrier for service users in the qualitative findings, with many reporting a lack of trust in the mental health system and the therapeutic relationship. Those who were involuntarily detained had lower levels of trust than other service users. Consultant psychiatrists referred to the role of ADs in promoting trust and engagement in the qualitative statements. One consultant psychiatrist participant suggested that both parties needed to develop trust in each other. The findings suggest that service users need to build trust in consultant psychiatrists to respect their AD preferences and consultant psychiatrists need to trust service users to make reasonable treatment choices. A trusting therapeutic relationship is associated with more treatment requests than refusals. Consultant psychiatrists who had already used some form of AD referred to their potential to increase engagement and build trust in the therapeutic relationship. The need for respectful, empathetic relationships between service users and providers was also found in the

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National Inpatient Survey.\textsuperscript{186} The survey findings showed the importance of developing trust and treating individuals with dignity and respect.

The findings suggest a need for accountability and monitoring mechanisms in the legislative framework to alleviate service user concerns and promote trust. This is particularly pertinent given that service users who believe their wishes will be followed are more likely to engage with treatment.\textsuperscript{187} Treatment engagement was increased and coercive interventions were reduced by half for individuals who completed facilitated ADs in a previous study.\textsuperscript{188} In the survey, service user participants stated that they would be more willing to seek help in future crises if they knew their treatment wishes were legally protected, while over three-quarters stated that they would be more willing to adhere to treatment if they had an AD. The desire to refuse treatment was significantly higher among service users who were dissatisfied with involvement in treatment. The literature shows ADs can increase adherence to treatment\textsuperscript{189} and promote self-directed recovery in practice.\textsuperscript{190} Over half of consultant psychiatrists in the survey were motivated by the potential for ADs to increase adherence to treatment. The potential for increased treatment engagement and reduced readmission may therefore be used to increase psychiatrist support for ADs.

The AD barriers were significantly higher for consultant psychiatrists than service users. The most frequently cited barriers for consultant psychiatrists included the quality of the information in the directive; change of mind during a crisis; inappropriate treatment requests and refusal of treatment. Legal liability and insight concerns were also identified in the qualitative findings. System barriers such as lack of training, access, resources and lack of time to review the document were also viewed as problematic. These barriers are consistent with those articulated in the

\textsuperscript{186} Mental Health Commission, \textit{Your Views of Mental Health Inpatient Services: Inpatient Survey 2011} (Mental Health Commission 2012).
\textsuperscript{187} Robert Calsyn, Joel Winter and Gary Morse, ‘Do Consumers who have a Choice of Treatment have Better Outcomes?’ (2000) 36 Community Mental Health Journal 149.
\textsuperscript{188} Jeffrey Swanson and others, ‘Psychiatric Advance Directives and Reduction of Coercive Crisis Interventions’ (2008) 17 Journal of Mental Health 255.
\textsuperscript{189} Christine Wilder and others, ‘Medication Preferences and Adherence among Individuals with Severe Mental Illness and Psychiatric Advance Directives’ (2010) 61 (4) Psychiatric Services 380.
\textsuperscript{190} Patricia Backlar, ‘Anticipatory Planning for Psychiatric Treatment is not quite the same as Planning for End-of-Life Care’ (1997) 33 Community Mental Health Journal 261.
The literature suggests that clinician resistance may be due to lack of awareness, practice pressures, legal liability concerns or discomfort with self-directed care or shared decision-making. However, ADs may actually reduce legal liability by increasing patient satisfaction and communication. Prior research suggests patient dissatisfaction is one of the major factors in malpractice claims. Practitioners with poor communication skills and who failed to consider patient/family concerns were more likely to be the subject of litigation, than those with positive communication approaches. The international research also shows that psychiatry has the lowest malpractice rate. ADs provide a forum for communication, which can enhance satisfaction and potentially reduce legal liability rather than increase it. System barriers such as access can be addressed through the establishment of a registry. Some consultant psychiatrists already using ADs reported that they took less time than envisaged. The research suggests ADs may actually save time and resources in the longer term.

The findings indicated that the refusal of all treatment and the potential for a person to be left untreated were major barriers for consultant psychiatrists. These concerns were correlated with a decreased willingness to use ADs. The refusal of treatment concern is frequently articulated in the literature by clinicians leading to reluctance to use ADs. However, the survey findings suggest that these concerns are

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unfounded. The majority of service users were not interested in using ADs to refuse all treatment and were more interested in choosing particular treatments or to communicate concerns. Almost two-thirds of service users wanted to opt into certain treatments and refuse others, while almost three-quarters wanted to agree treatments with their treating psychiatrist. Three-quarters of service users stated that they would actually be more willing to adhere to treatment if they had a directive, suggesting that directives may lead to increased treatment engagement rather than refusals. The findings indicated that a higher level of dissatisfaction with participation in treatment was associated with an increased preference to refuse certain treatment/medication. While these preferences do not confirm behaviour in practice, the international research shows ADs are rarely used to refuse all treatment. Hypothetical scenarios have shown to be a feasible method of identifying treatment preferences in previous studies of ADs. The literature shows that individuals with mental health conditions are generally interested in helping clinicians to make decisions or to inform providers of concerns. The concern with refusal of all treatment may inform the preference for non- legally binding directives among consultant psychiatrists. The findings and the research evidence can help alleviate concerns in relation to the refusal of all treatment and increase support for legally binding ADs.

The quality of the information in the directive and inappropriate treatment requests were also barriers for consultant psychiatrists. However, the literature suggests that the majority of ADs contain clear and valuable information, are consistent with

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clinical practice and can improve the quality of treatment decisions.\textsuperscript{202} Prior research suggests service users exercise reasonable treatment preferences and are informed on effective medications.\textsuperscript{203} The qualitative statements in the survey highlighted service user knowledge of effective treatment. The findings suggest service user insight and capacity were also perceived barriers for consultant psychiatrists. Concerns with low insight and inappropriate treatment requests have also been identified in the literature.\textsuperscript{204} However, studies suggest individuals with mental health conditions are capable of completing ADs\textsuperscript{205} and exercise reasonable choices.\textsuperscript{206} Previous research suggests individuals with higher levels of insight were more likely to develop ADs.\textsuperscript{207} The survey findings suggested service users perceived ADs to have capacity building benefits enabling them to develop insight into treatment and recovery. This is consistent with previous research, which suggests ADs can actually help individuals gain insight into their condition and develop recovery strategies.\textsuperscript{208} Consultant psychiatrists also cited insight and recovery as factors in deciding whether to comply with an AD in the findings. The literature shows insight is often used to override ADs.\textsuperscript{209} Some psychiatrists have overridden valid directives on the


\textsuperscript{203} Daniel Ambrosini, Anne Crocker and Eric Latimer, ‘Preferences for Instructional or Proxy Advance Directives in Mental Health: An Exploratory Mixed Methods Study’ (2012) 6 Journal of Ethics in Mental Health 1.


\textsuperscript{206} Daniel Ambrosini, Anne Crocker and Eric Latimer, ‘Preferences for Instructional or Proxy Advance Directives in Mental Health: An Exploratory Mixed Methods Study’ (2012) 6 Journal of Ethics in Mental Health 1.


premise that they have better clinical understanding of treatment than the person.\textsuperscript{210} There was some evidence of this view in the qualitative statements, suggesting treatment is still based on the medical model in Irish mental health care.

Significant disparities were also found between the groups in relation to determinations of decision-making capacity with service users expressing a preference for a family member or trusted friend, while consultant psychiatrists were in favour of the treating psychiatrist or an independent psychiatrist. Only 5.1 per cent of consultant psychiatrists were in favour of a family member. This may be indicative of a fear of loss of control in clinical decision-making, even though over half of consultant psychiatrists perceived ADs would not undermine their clinical judgement. The severity of the condition, lack of insight and risk are frequently used to deny choice in mental health.\textsuperscript{211} However, the research suggests that in the absence of substance abuse, the increased risk of harm is relatively low and violence occurs very rarely.\textsuperscript{212}

The survey findings suggest consultant psychiatrists may be more willing to comply with the directive if a proxy decision-maker is appointed, if there is family support of treatment preferences or it promotes therapeutic collaboration. These findings are consistent with previous research, which shows psychiatrists place higher value on family opinions, therapeutic alliance and insight when following an AD.\textsuperscript{213} Other studies suggest clinician compliance increases when: ADs are not legally binding; they have longer professional experience; they have increased awareness of the legislation; a proxy decision-maker has been appointed\textsuperscript{214} or when mental health professionals have been involved in development.\textsuperscript{215} The inclusion of reasons for

\textsuperscript{210} Debra Srebnik and Joan Russo, ‘Consistency of Psychiatric Crisis Care with Advance Directive Instructions’ (2007) 58 Psychiatric Services 1157.
\textsuperscript{211} Amita Dhanda, ‘Universal Legal Capacity as a Universal Human Right’ in Michael Dudley, Derrick Silove and Fran Gale (eds), Mental and Human Rights: Vision, Praxis and Courage (Oxford University Press 2012) 181.
\textsuperscript{212} John Monahan and others, Rethinking Risk Assessment: The MacArthur Study of Mental Disorder and Violence (Oxford University Press 2001).
\textsuperscript{214} Ibid.
treatment choices increased compliance in other studies. The increased likelihood of compliance may influence the service user choice of directive and encourage inclusion of reasons for choices.

7.5.9. Involuntary Admission Group

The findings revealed significant variations among service users who were subject to involuntary admission. Service users who were involuntarily detained were less satisfied with involvement in future treatment, had lower perceptions of control, listening and choice in treatment and had higher levels of multiple readmissions. These findings are consistent with the National Inpatient Survey, which found dissatisfaction with mental health services to be higher among those who were involuntarily detained. Priebe found that service users who expressed dissatisfaction with treatment showed greater chance of subsequent involuntary admission. The importance of treatment satisfaction is reiterated by Fitzpatrick, who states that if satisfaction with treatment is not present, than cooperation with after care may also be impeded. The findings highlight the importance of participation and satisfaction to prevent future involuntary admissions.

Service users who were detained were more concerned with the potential for their wishes to be overridden by medical staff. The impact of involuntary admission on respect for informal treatment preferences in the survey shows that these concerns are valid. Over half of the participants who were involuntarily detained expressed future treatment preferences informally to their treating psychiatrist or other member of the treatment team, but only one had their wishes respected. The findings suggest an urgent need for measures that promote trust and respect for treatment choice in this group. ADs are proposed to increase trust, but additional discussions, time and support may be needed for those who have been coerced. The development of a care or WRAP plan prior to AD completion may assist the initiation of discussions.

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around past experiences and future plans. Interestingly, participants who were subject to involuntary admission had lower levels of WRAP completion even though the need for effective recovery strategies and engagement was greater due to the high level of readmission. The finding suggests that this group should be specifically targeted to complete WRAP plans and ADs. The difficulties experienced by those subject to involuntary admission were illustrated in a qualitative study by McGuinness, which suggested that the mental health services need to be more caring and to acknowledge the person’s experience. This can be achieved in some way through the provision of information, providing a sense of being cared for and being listened to, and seeing the person beyond the condition. The forum for listening and communication provided by ADs can help achieve these objectives.

Involuntary admission also had a negative impact on therapeutic and family relationships. Service users who were involuntarily detained were less interested in involving their treating psychiatrist in the development of the AD or in capacity decisions and were more concerned with obtaining information from treating doctors. They also had an increased preference for the refusal of treatment and for the directive to be followed regardless of the wishes of their treating doctor or family. This may be explained by the decreased trust in therapeutic and family relationships due to involuntary admission. Prior research suggests that perceived coercion is associated with negative perceptions of medication and the desire to retain control over treatment. The findings also showed participants who were detained were less motivated by the enhancement of the therapeutic relationship or planning. However, they perceived ADs to be more helpful and beneficial to recovery. The decreased interest in planning may be explained by the reluctance to plan for readmission and to recall distressing experiences. The ‘lack of a trusted person to communicate’ and to support the completion of the directive barriers were higher in the involuntary admission group, suggesting a lack of external support

221 Daniel Ambrosini, Anne Crocker and Eric Latimer, ‘Preferences for Instructional or Proxy Advance Directives in Mental Health: An Exploratory Mixed Methods Study’ (2012) 6 Journal of Ethics in Mental Health 1.
networks. This may be indicative of the negative impact of involuntary admission on family and interpersonal relationships.

Service users who were involuntarily detained were less interested in ADs being taken into consideration by a mental health tribunal than other participants. This may be due to their experience of the tribunal process. Tribunal hearings were found to be alienating experiences for service users in a previous U.K. study. The Irish tribunals are heavily weighted in favour of the medical model with the involvement of three psychiatrists. The Mental Health Commission assigns a free legal representative to represent each service user. A study is currently being undertaken on the experience of Irish service users in the tribunals.

The survey findings suggest involuntary admission has a significant impact on AD preferences. Lack of trust in the therapeutic relationship and the mental health system were pervading themes throughout the survey for those who were detained. The findings raise concerns about the level of trust and autonomy in the therapeutic relationship and the impact of coercion. A previous Irish study found individuals in more secure wards had the least interpersonal trust in clinicians. ADs are proposed to improve therapeutic and other relationships and provide an alternative response to coercive treatment. In the survey, half of the service users who were involuntarily detained were less interested in ADs being taken into consideration by a mental health tribunal than other participants. This may be due to their experience of the tribunal process. Tribunal hearings were found to be alienating experiences for service users in a previous U.K. study. The Irish tribunals are heavily weighted in favour of the medical model with the involvement of three psychiatrists. The Mental Health Commission assigns a free legal representative to represent each service user. A study is currently being undertaken on the experience of Irish service users in the tribunals.

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224 The mental health tribunals involve the Responsible Consultant Psychiatrist (RCP); a second opinion psychiatrist and the psychiatrist member of the tribunal. The tribunal also includes a tribunal chairperson, a lay member and the patient’s legal representative. A peer advocate can accompany the person to the tribunal in certain circumstances, but this is not a statutory right.
225 Mental Health Act 2001, s 17.
involuntarily detained perceived ADs would improve the therapeutic relationship, while over three-quarters believed they would assist family members to understand their wishes.

ADs can promote trust and increase engagement. The survey findings indicated that three-quarters of service users who were detained would be more willing to adhere to treatment if they had an AD. This is pertinent given that service users who were involuntarily detained were longer users of mental health services and had significantly higher levels of multiple readmissions. The use of ADs may be particularly beneficial for increasing engagement, trust and reducing the need for involuntary readmission. The literature suggests individuals who believe their choices will be respected are more likely to engage and benefit from treatment than those who feel coerced and disrespected. The results of a previous survey found that the fear of coercion was a deterrent for 28 per cent of individuals seeking mental health treatment. The higher level of familiarity and perceived helpfulness among participants who were detained suggest an increased recognition of the value of ADs in this group. The findings are consistent with a previous Irish study, which found that 84 per cent of individuals who were involuntarily detained were interested in developing an AD. ADs can help avert the need for coercion and promote dignity and respect in mental health treatment.

7.5.10. Education and Training
The survey findings highlight the need for AD education in both stakeholder groups. Low levels of familiarity and education were associated with increased barriers to ADs among service users. While consultant psychiatrists were more familiar with ADs, the high barrier levels indicate the need for education to alleviate concerns and provide information on the role of ADs in practice. The findings also suggest they

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may not be aware of the impact of ADs on coercion and recovery. The lack of information across the stakeholder groups has been identified as a barrier to implementation in the literature. The provision of education for clinicians is important to promote a culture of respect for treatment preferences. The Gundersen Lutheran ‘Respecting Choices’ programme for end-of-life directives achieved over 90 per cent participation and compliance through 40 hours of provider education on advance planning. Education and awareness should also be provided for mental health professionals, management, peer advocates, proxy decision-makers and family members to ensure the person’s wishes are reflected in decisions.

The survey findings also provide guidance on areas that need to be addressed in the educational programmes. Both stakeholder groups need to be educated on each others preferences to alleviate concerns on refusal of treatment, legal liability and the circumstances in which an AD can be overridden. This approach was suggested in the stakeholder survey in Virginia. The developmental benefits of ADs should be addressed to promote their role in the recovery process, enhancing communication and trust, building capacity and reducing the need for readmission and coercion. The traumatic impact of coercion and the need for alternative responses that provide respect for the person should be highlighted. Logistical concerns such as insight and capacity; change of mind; support for completion; review; access; the appointment of a proxy decision-maker should also be addressed. The literature suggests providers should also be educated on the parameters of the legislation. The need for training among clinicians in areas such as human rights; recovery; individual care planning; and the operation mental health legislation was highlighted in previous


Irish reports.\textsuperscript{237} The low level of familiarity with the CRPD suggests the need for education on international human rights standards and new approaches to decision-making in the 2013 Bill. All the stakeholder groups should be given the opportunity to complete an AD as part of the education process.

Stakeholders may be more receptive if training is delivered by a range of representatives in a multidisciplinary setting.\textsuperscript{238} Prior research suggests the need for targeted on-going training for providers to decrease fears around ADs.\textsuperscript{239} The inclusion of service users in the delivery of educational programmes is crucial for promoting the adoption of ADs across stakeholder groups and to reduce stigma.\textsuperscript{240} Wider community education and awareness will also be needed. The Office of the Public Guardian will have an education and awareness under the 2013 Bill,\textsuperscript{241} but the Mental Health Commission may provide training in the mental health services. The draft scheme for ADs does not refer to education, but this may be addressed in a Code of Practice.\textsuperscript{242} Without adequate discussion and attention to the legal and practice concerns identified in the survey findings, the introduction of ADs for mental health decisions may be significantly threatened in Ireland.

7.5.11. Legal Framework
The enforceability of mental health ADs often depends on the strength of the legal framework in which they are introduced. The legislative provisions are often characterised by differential standards and exceptions to enforcement. These legislative approaches can reinforce stigma and limit the use of ADs. The draft scheme for ADs for incorporation into the 2013 Bill proposes to limit the use of ADs during involuntary detention and make them non-legally binding.\textsuperscript{243} The survey findings suggest an urgent need for legally binding ADs for individuals who are

\begin{thebibliography}{99}
\bibitem{238} Agnes Higgins and others, \textit{Evaluation of the Mental Health Recovery and WRAP Education Programme, Report to the Irish Mental Health and Recovery Consortium} (Trinity College Dublin 2010).
\bibitem{239} Christine Wilder and others, ‘A Survey of Stakeholder Knowledge, Experience, and Opinions of Advance Directives for Mental Health in Virginia’ (2013) 40 (3) Administration and Policy in Mental Health 232.
\bibitem{240} Heather Zelle, VOCAL Statewide Consumer Conference 2013, Virginia.
\bibitem{241} Assisted Decision-Making Bill, s 56(1)(a), s 56(2).
\bibitem{242} Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.
\bibitem{243} Ibid Head 5(7).
\end{thebibliography}
involuntarily detained to increase the perception of control, respect and to promote trust and engagement. Respect for the AD is a fundamental outcome of development and not just an operational issue that may limit effectiveness.\textsuperscript{244} The 2001 Act should therefore be amended to allow legally binding ADs for treatment during involuntary detention.

The low level of compliance with informal treatment preferences for those who are involuntarily detained, combined with the service user concern with the AD being overridden and the consultant psychiatrist desire for the ability to override the directive suggests a need for legally binding directives with accountability mechanisms in the Irish legal framework. While non-legally binding AHDs with accountability mechanisms are valuable, the use of differential standards reinforces the notion that the treatment choices of individuals who are involuntarily detained are not respected on an equal basis with others. Non-legally binding directives are more susceptible to being overridden and are more difficult to enforce. This is particularly pertinent in a system with low levels of respect for informal treatment preferences and participation in mental health treatment. The findings suggest that the mental health system is still dominated by the medical model, legal liability and risk concerns. Weller suggests the need for a strong legal model with less flexibility where there is negativity and the attitudes of mental health professionals are influenced by legal uncertainty.\textsuperscript{245} The low perceptions of control, listening, trust and satisfaction with involvement in treatment and the high level of readmissions suggest a need for more participative responses in Irish mental health care. The legal status of ADs is also important in a system where continuity of care is lacking. The findings suggest that the introduction of legally binding ADs is critical for increasing the perception of trust and respect during voluntary and involuntary admission. The belief that the AD will not be respected due to their inferior legal status may lead to low completion rates and further distrust and disengagement in the mental health system.

\textsuperscript{244} Claire Henderson and others, ‘A Typology of Advance Statements in Mental Health Care’ (2008) 59 (1) Psychiatric Services 63.

\textsuperscript{245} Penelope Weller, New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose (Routledge 2013) 161.
The ‘change of mind’ concerns in the findings also suggest the need for flexibility in relation to the revocability of the directive during crisis periods. The inclusion of a Ulysses clause in the legislation allows individuals to change aspects of their instructions at any time unless they clearly specify that they wish their AD choices to be irrevocable during crisis periods. The Ulysses clause can also alleviate consultant psychiatrist concerns in relation to change of mind during a crisis. The concerns of consultant psychiatrists in relation to life-saving treatment suggest the need to define emergencies so treatment can be given in limited situations. The lack of trusted decision-makers and support to complete the directive suggest the need for a choice of instructional and proxy directives in the legislation and the provision of support for completion. The draft legislation provides for a choice of proxy and instructional directives, but does not address support to complete the directive. The varying support preferences show the need for choice in relation to the involvement of third parties in development. The increased barriers for service users with lower levels of education reinforce the need for support and to minimise formalities to execution. This suggests the need to remove witness limitations or requirements to obtain professional advice at execution. The provision of education, support, flexibility and accountability mechanisms can alleviate many of the barriers to ADs in the survey. The findings suggest a need for legally binding ADs with strong accountability and oversight mechanisms until a culture of trust and respect for treatment preferences is established in Irish mental health practice. The appointment of a statutory oversight body and the publication of figures showing the low level of AD overrides can help instil confidence.

While the structure of the legislative framework is crucial in promoting respect, the developmental benefits of ADs may be the most important aspect of the measure in the Irish mental health system. ADs are reported to increase autonomy and empowerment and to enhance recovery outcomes, even if they are never legally invoked. The document may not only be useful as a communicative platform, but

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in helping individuals to re-examine their values, develop capacity and build trust. The survey findings highlight the need for increased communication and trust between the stakeholder groups. ADs can facilitate on-going engagement and promote trust and respect in therapeutic and family relationships and reduce the need for coercion. The introduction of ADs can contribute to a broader attitudinal shift in the conceptualisation of individuals with mental health conditions and how they are treated in Ireland. The perception of respect and promotion of trust may be the most important aspect of ADs in the Irish mental system, regardless of clinical outcomes.

8. Limitations
Similar to other surveys, the current study presents some limitations. The size of the sample limits the reliability of the findings. The low response rates and difficulty accessing the service user population necessitated the use of snowball and convenience sampling, which may have increased selection bias among the participants. Limited access to the service user group resulted in an overrepresentation from the HSE West region and may have resulted in responses from more active participants. The high percentage of service user participants with third level education may also have resulted in increased levels of understanding. The difficulty accessing a comprehensive up-to-date list of consultant psychiatrists in Ireland may have resulted in the exclusion of some psychiatrists from the study and a higher proportion of male psychiatrists. The degree to which the results represent the population as a whole is therefore unclear.

Due to the time constraints of the study, the qualitative research was limited to the responses in open-ended questions. Individual follow up interviews with service users and consultant psychiatrists may have achieved more in-depth insights. The survey distribution methods for the service user group may also have also resulted in bias. The combination of self-completed postal questionnaires and face-to-face completion with the researcher and the service user representative may have increased bias. Furthermore, the survey examined perceptions and beliefs rather than actual behaviour in practice due to the fact that this is a completely new area of research in Ireland.

9. Strengths

The current empirical study offers a unique contribution to the disability and mental health field in that it provides the first comprehensive Irish stakeholder perspective on ADs in mental health care and under the CRPD. The study is also timely given that ADs are to be incorporated into the Assisted Decision-Making (Capacity) Bill 2013 for the first time in Ireland in 2014. The draft legislation for ADs was published and opened for public consultation at the time of writing. The study will help inform the Irish state at a critical juncture in the legislative process and will provide valuable information for successful implementation. The research has been used to inform legislative submissions for the public consultation on the draft legislation. It is also valuable internationally in that it is first study to consider the introduction of ADs under the CRPD, which is a key driver of international and Irish law reform. The study findings were communicated at a meeting of civil society groups on legislative proposals for ADs in the 2013 Bill and informed the development of CRPD principles on ADs and a legislative submission by the Centre for Disability Law and Policy at NUI Galway. The findings were also used to inform a legislative response on behalf of the Irish Mental Health Commission and a personal submission on the draft scheme in March 2014. The researcher independently communicated with officials and legislators in the Department of Justice and the Bioethics Unit in the Department of Health in relation to legislative proposals and sent published materials from the research.

10. Implications

The empirical study has several implications for the introduction of ADs in the Irish mental health context. The study provides the views of key stakeholder groups in

250 Mental Health Commission, Centre for Disability Law and Policy, NUI Galway.
Ireland and suggests that service users and consultant psychiatrists are broadly supportive of ADs, but have varying implementation preferences. Moreover, the study suggests the need for consensus building and education with key stakeholder groups prior to the implementation of the legislation and the need to pilot ADs on a mental health site(s) to determine behaviour in practice. Several consultant psychiatrists referred to the need for open discussion with stakeholders in the qualitative statements.

The study suggests that the introduction of the new law requires a systematic and coordinated approach to build trust, reduce barriers and promote a cultural shift towards respect for individual preferences. System and law reform should therefore be undertaken in tandem with each other. The findings show the need for information and education to increase familiarity and address barriers to stakeholder support. The study emphasises the importance of providing support for the completion of ADs and minimising the barriers to execution. The findings suggest a need for a choice of directives in the legislation to meet varying needs and preferences. The study also suggests the need for flexibility and choice in relation to the revocability of the directive. System barriers such as access to the AD also need to be addressed through the establishment of a registry. The integration of ADs with individual care planning and WRAP can provide a comprehensive framework for meaningful service user participation in mental health treatment in Ireland.

11. Directions for Future Research
Further research is needed on the implementation of ADs in Irish mental health care prior to the introduction of the legislation in the wider mental health services. The survey examined perceptions and beliefs, rather than actual behaviour in practice. ADs therefore need to be piloted on a mental health site to determine whether these beliefs translate into behaviour. A pilot study can help decrease barriers and alleviate the concerns of both stakeholder groups by providing evidence that service users make reasonable and informed decisions and that consultant psychiatrists are willing to respect treatment choices in practice. The survey limitations and comments from consultant psychiatrists suggest the need for further qualitative research to acquire more in-depth insight into the views of stakeholders. This research could be conducted through the pilot study. The pilot study will also facilitate the
development of appropriate resources for AD implementation including forms, access, facilitator training and support and the development of education programmes for stakeholders. The consultant psychiatrists already using some form of ADs in the survey could participate in the pilot study. Information champions and site preparation will be critical in achieving a cultural shift towards respect for choice. Research with other key informants such as mental health professionals, family members and peer advocates also needs to be conducted to ensure the concerns of all stakeholders are addressed. The implementation of the legislative framework for ADs is dependent on key stakeholder support so it is crucial that consensus building and education are undertaken for the legislation to succeed in practice.

12. Summary of Findings

12.1. Familiarity with Advance Directives:
- Familiarity with ADs varied between the stakeholder groups with consultant psychiatrists significantly more familiar with ADs than service users.
- Service users with higher educational levels were significantly more familiar with ADs than those with lower educational levels.
- Service users with lower levels of familiarity and education perceived significantly increased barriers to ADs.

12.2. Support for the Use of Advance Directives:
- Both stakeholder groups perceived ADs to be helpful, with service users perceiving higher levels of perceived helpfulness than consultant psychiatrists.
- The survey findings show a high level of support for ADs among service users and consultant psychiatrists, with service users more willing to use them.

12.3. Personal Experience:

_Satisfaction with Involvement in Future Mental Health Treatment_
- Service users had significantly lower levels of satisfaction with involvement in planning for future mental health treatment than consultant psychiatrists.
• Service users who were involuntarily detained had significantly higher levels of dissatisfaction with involvement in planning for future mental health treatment than other service user participants.

• Male service users were more dissatisfied with involvement in future mental health treatment than female service users and had significantly lower levels of perceived control.

• Service users who were dissatisfied with involvement in treatment were significantly more interested in using ADs to refuse certain medications/treatments than those who were satisfied.

• Satisfaction with involvement in planning for future mental health treatment had a significant positive correlation with perceptions of control.

Perceptions of Control

• Overall 60.4 per cent of service users perceived they were somewhat lacking in control (21.7%) or not in control (38.7%) of treatment at all when being treated by the mental health services.

• The majority of service users (87.6%) identified increased control over treatment as a motivating factor for using ADs.

• Perceptions of control were grounded in specific individual mental health experience such as involuntary admission, hospitalisation, gender, diagnoses.

• Service users who were involuntarily detained had significantly lower levels of control with over half perceiving a total lack of control over treatment, compared to less than third of other service users.

• Service users who were hospitalised had significantly lower levels of control than those who were never hospitalised.

• Individuals with schizophrenia and bipolar disorder had lower levels of control than other service users. A significant association was found between involuntary detention and schizophrenia and bipolar disorder.

• Male service users had significantly lower levels of control (56.8%) than female service users (23.3%).

• Service users who were involuntarily detained (57.1%) had lower perceived choice in future treatment than other service users (25.7%).
• Those who were involuntarily detained had lower levels of WRAP plan completion rates than other service users.

Listening
• One third of service users perceived the treating psychiatrist did not listen to their treatment wishes, while almost a quarter were not sure
• Individuals who were involuntarily detained had a significantly higher perception of not being listened to by the treating psychiatrist than other service users.

12.4. Preferences for Implementation:
Legal Status of Advance Directives
• Divergent preferences existed between the groups in relation to the legal status of ADs, with service users in favour of legally binding directives and consultant psychiatrists more supportive of non-legally binding directives. Just over a fifth of service users (21%) were interested in non-legally binding directives, while only 11.2 per cent of consultant psychiatrists expressed a preference for legally binding directives allowing for refusal of treatment.
• The majority of consultant psychiatrists (87.8%) expressed a preference for a co-operative arrangement between the service user and the treating psychiatrist.
• Almost three-quarters of service users were interested in agreeing treatments/medications with the treating psychiatrist, but less than half (44.9%) expressed a preference for the support of the treating psychiatrist to complete the directive.

Proxy Directives
• The majority of service users (86%) expressed a desire to appoint somebody to communicate their AD wishes when they are unwell, with most identifying a family member or spouse/partner (62.7%).
• Half of (50%) of consultant psychiatrists stated they would be more willing to follow an AD if a proxy decision-maker was appointed.
Almost a third (32.7%) of service users perceived that getting somebody they trusted to act as proxy decision-maker would be a barrier to AD completion. The lack of a trusted proxy was significantly higher for service users who were involuntarily detained with over half (57.1%), perceiving that getting a trusted person to act would be a barrier, compared to 24 per cent of other service users.

**Preferences for Support and Determination of Decision-Making Capacity**
- The majority of service users expressed a preference for support to complete the directive, with just 15.9% wishing to complete the AD without assistance.
- The majority of service users expressed a preference for support from a family member or trusted friend, while consultant psychiatrists were in favour of the treating psychiatrist. Consultant psychiatrists were significantly more in favour of the treating psychiatrist than service users.
- The majority of consultant psychiatrists (94.9%, 93/98) perceived consultation with the treating psychiatrist (73.5%) to be extremely important or somewhat important (21.4%) when developing the AD.
- Almost two-thirds of service users (69.2%, 74/107) felt confident enough to manage their mental health.
- Service users were more interested in using a family member or trusted friend to determine decision-making capacity. Over a half of service users (51.4%) expressed a preference for a family member or trusted friend, compared to 5.1 per cent of consultant psychiatrists.
- Over half of consultant psychiatrists (59.2%) expressed a preference for the treating psychiatrist to determine capacity, compared to 38.5 per cent of service users.

**Revocability of the Advance Directive**
- Over three-quarters of service users (76.2%) stated they would like their AD to be followed when they are unwell and allow them to change their mind when they are well.
• Over half (51.4%) of service users expressed a preference for an AD which could be followed as much as possible but allows them to change their mind when unwell.

• The risk of change of mind or desire to change the contents of the directive was a barrier for over a quarter of service users, and over three-quarters of consultant psychiatrists. Consultant psychiatrists had significantly higher levels (79%, 79/100) of the change of mind barrier than service users (26.4%, 29/110).

ECT Preferences

• The preference for a directive that allows advance refusal of ECT was four times higher among service users (82.4%) than consultant psychiatrists (19.6%). The differences between the groups were statistically significant.

• The preference for a directive that includes advance consent to ECT was significantly higher among consultant psychiatrists (56.7%) than service users (26.2%).

Mental Health Tribunal Decisions

• Service users were significantly more interested in the AD being taken into account by a Mental Health Tribunal than consultant psychiatrists.

• Service users who were involuntarily detained were less supportive (67.9%) of an AD being taken into account by a Mental Health Tribunal, than other service users (84%).

12.5. Perceived Benefits of Advance Directives

• The most frequently cited motivating factor for AD development among service users included increased control over treatment (87.6%); planning for future periods when decision-making ability may be impacted (75.2%) and the provision of a forum for listening (72.4%).

• The most common motivating factors for consultant psychiatrists included treatment planning (90.4%); patient control over treatment (75.5%) and the enhancement of the therapeutic relationship (74.5%).
• Service users were significantly more motivated by control over treatment than consultant psychiatrists.
• Service users (81.7%) perceived ADs to be significantly more helpful to recovery than consultant psychiatrists (59.8%).
• Over three-quarters (76.3%, 74/97) of consultant psychiatrists perceived that ADs may have a therapeutic value.
• Consultant psychiatrists (90.4%, 85/94) were significantly more motivated by planning for future periods when decision-making autonomy may be impacted than service users (75.2%, 79/105).
• Over half (56%) of service users who were subject to involuntary admission identified planning as a motivating factor, compared to over three-quarters of other service user participants (80.8%).
• Service users (65.7%, 69/105) were significantly more motivated by providing information on treatment history than consultant psychiatrists (34%, 32/94).
• The majority of service users (84.4%) perceived ADs would assist family understanding of their wishes.
• Over half of consultant psychiatrists perceived that ADs would increase (35.1%) or significantly increase (22.7%) the decision-making burden of family members.
• Consultant psychiatrists were significantly more motivated by the enhancement of the therapeutic relationship (74.5%, 70/94) than service users (59%, 62/105).
• Less than half (44%) of service users who were involuntarily detained identified enhancing the relationship with their treating doctor as a motivating factor, compared to two-thirds (65.8%) of other service users.
• Over half of consultant psychiatrists (56.4%, 53/94) were interested in using ADs to increase adherence to treatment, while three-quarters of service users stated that they would be more willing to adhere to treatment if they had a directive. Consultant psychiatrists also identified non-adherence to treatment (59.6%) as a factor to consider when deciding whether to comply with the directive.
• Some variation also existed in the desire to use ADs to reduce the need for
involuntary treatment, with just under half (48.9%) of consultant psychiatrists identifying this as a motivating factor, compared to 61 per cent of service users.

- When asked whether ADs would increase or decrease the need for involuntary treatment, 28.8 per cent of consultant psychiatrists perceived they would decrease the need for involuntary treatment, while 58.8 per cent were uncertain.

### 12.6. Barriers to Advance Directives

**Service User Barriers**

- The most frequently cited barriers for service users included the potential for AD wishes to be ignored or overridden by medical staff (50%); limited understanding (35.5%) and the lack of a trusted person to communicate on their behalf (32.7%).

- Almost half of service users (44.8%) reported expressing future treatment preferences informally to the treating psychiatrist or other member of the treatment team. Nearly three-quarters (70.8%) of consultant psychiatrists reported that patients communicated treatment preferences to them informally.

- Of the service users who expressed future treatment preferences informally, 39.1 per cent (27/69) reported their treatment preferences were not complied with when unwell, while almost a quarter (24.6%, 17/69) were uncertain. Over a third (36.2%, 25/69) reported compliance with their preferences.

- Over half of service users (59.3%) who were involuntarily detained reported expressing future treatment preferences to their treating psychiatrist or other member of the treatment team, but only one was given the treatment they preferred when unwell compared to 47.7% (21/44) of other service users.

**Familiarity, Education and Barriers**

- Service users with lower levels of familiarity and education perceived higher barriers to ADs in all but one barrier.
• The association between low levels of familiarity and increased barriers was significant in five out of ten barriers. Service users with higher levels of education were more familiar with ADs.

• The association between lower levels of education and increased barriers was significant in four out of ten barriers.

• Service users with third level education and increased familiarity with ADs had higher levels of the potential for ADs to be overridden barrier.

• The difficulty getting a trusted person to support completion of the directive was higher for service users who were involuntarily detained and those with lower educational levels.

Consultant Psychiatrist Barriers

• Barrier levels were significantly higher for consultant psychiatrists than service users. On average each service user identified 3.05 barriers, whereas consultant psychiatrists identified an average of 6.05 barriers.

• The most frequently cited barriers for consultant psychiatrists included the quality of the information in the directive (88%), the desire to change the content of the directive during a crisis (79%) and inappropriate treatment requests (77%).

• The system barriers identified by consultant psychiatrists included lack of training and staff knowledge (76%); access to the document (71%); lack of resources to support the use of ADs (62%) and lack of time to review the document (39%). Other barriers related to the risk of violence (50%) and limited communication between staff (50%).

Refusal of Treatment Barriers

• The majority (82.7%, 81/98) of consultant psychiatrists were concerned that the AD would be used to refuse all treatment, while almost all of the group (94%, 93/99) were concerned with leaving a person untreated. The majority of service users (82.2%) were not interested in using ADs for this purpose. Three-quarters of service users stated that they would be more willing to adhere to treatment if they had a directive.
• Service users were more interested in using the AD to choose particular treatments and to agree treatment with the treating psychiatrist. Almost two-thirds (62.6%) of service users wanted to opt into certain treatments/medications and refuse others (63.6%), while 72 per cent wanted to agree treatments with the treating psychiatrist.

• The high level of concern with refusal of all treatment and leaving a person untreated had a significant negative correlation with support for ADs among consultant psychiatrists.

**Overriding the AD**

• Over half (56.7%) of consultant psychiatrists believed that they should be permitted to override the AD instructions if evidence of better treatment exists.

• The majority (86.9%) of consultant psychiatrists identified insight into the condition, respect for autonomy (77.8%) and therapeutic collaboration (76.8%) would be factors they would consider in deciding whether to follow a person’s choice of treatment, while 69.7 per cent identified current cognitive functioning and family support of treatment preferences (65.7%).

• The risk of violence (62.6%) and legal liability (45.5%) were also identified as factors by consultant psychiatrists, while 39.4% identified decreased use of coercion.

The findings from this chapter and the preceding chapters will be used to inform the conclusions and recommendations in the final chapter (chapter 7).
CHAPTER 7
Conclusions and Recommendations
1. Overview
This chapter provides an overview of the thesis chapters and the relevant research questions they sought to address. The findings from the preceding chapters will be used to outline recommendations for the introduction of a legal framework for ADs in Irish mental health care and to make a specific response to the draft legislation published by the Department of Health. The aim of the concluding chapter is to help address the main aim of the research, which is to inform the introduction of a legal framework for ADs in Irish mental health care.

Individuals with mental health conditions have had their right to autonomy systematically abolished by others for centuries and have been excluded from decisions relating to their own treatment and care. According to Dorothea Buck-Zerchin, one of the founders of the German Federal Association of (ex) users and survivors of psychiatry, “A person cannot be more devalued than to be considered unworthy or incapable of conversation.” ADs aim to restore the ‘voice’ of a vulnerable, stigmatised group of people who are often subject to dehumanising treatment. The measure has the potential to promote respect and avert the need for coercive treatment in mental health care. ADs offer a practical and timely way for the individual to build capacity, to communicate wishes and to engage in self-directed care. The broader social and cultural context must be considered when adopting ADs. Individuals with mental health conditions are among the most socially excluded groups in society. Stigma and discrimination have been identified as the greatest barriers to recovery. The inclusion of ADs in the legislative framework requires a shift in the conceptualisation of individuals with mental health conditions and how they are treated. The successful implementation of ADs requires a cultural shift in the response to individuals with mental health conditions and promotes respect. The measure provides an opportunity to redefine the current model of care and is important symbolically in reducing discrimination.

The international, comparative and empirical research show individuals with mental health conditions have a strong desire to develop ADs that allow them to communicate information to others when they are vulnerable. The Irish mental health system is characterised by high readmission rates and involuntary detention has been increasing again since 2010. The figures suggest a need for alternative responses in the Irish mental health services. ADs are associated with a reduced need for readmission and involuntary detention conferring economic and other benefits. While ADs have been widely discussed for decades, their ethical basis and associated barriers still remain a matter of debate. These barriers need to be addressed if the measure is to be justified as a compelling support and recovery measure by stakeholders. The introduction of provisions for ADs is a process that involves more than simply completing a document to assert one’s legal rights. ADs need to be viewed as documents or statements that confer a wide range of developmental benefits and facilitate an ongoing process of communication, engagement and support.

This thesis used an international, comparative and Irish stakeholder perspective to gain a more in-depth understanding of the legal, ethical and implementation issues surrounding the introduction of a legal framework for ADs in mental health care. The research sought to inform the introduction of a legal framework in Ireland and make a unique contribution to knowledge by integrating national issues with the requirements of international human rights frameworks. The research has significantly advanced understanding and knowledge in relation to the introduction of ADs in Ireland and other jurisdictions. In Ireland, this research represents the first comprehensive analysis relating to the introduction and implementation of a legal framework for ADs in mental health care from the perspective of key Irish stakeholders. The views and preferences of service users and consultant psychiatrists in the empirical study are critical in determining the format of the legal provisions at national level. ADs represent a new era of respect for the ‘will and preferences’ of the person in Irish law and ethical treatment in mental health care. This research can

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3 Readmissions accounted for 66 per cent of the 18,173 admissions to Irish psychiatric units and hospitals in 2012. Involuntary admission rates increased by 5 per cent between 2010 and 2011 and 4 per cent from 2011 to 2012: Mental Health Commission, Annual Report 2012 including Report of the Inspector of Mental Health Services (Mental Health Commission 2013) 32.
help inform the enactment of a legal framework and the future implementation of ADs in the Irish and international context.

This thesis also examined ADs under theoretical, international, comparative and Irish legal frameworks. Chapter 1 introduced the concept of ADs, provided a study overview and contextualised the issues that gave rise to the research in Ireland and at international and European level. The introductory chapter also set out the aims and objectives of the thesis, the research questions and the proposed contribution to knowledge.

Chapter 2 of the thesis sought to answer the following research question: What are the theoretical frameworks underpinning ADs and the legal, ethical and implementation issues associated with their use?

Chapter 2 set out the historical development of ADs, various theoretical frameworks underlying their use, different forms of the measure and issues arising in the literature. This chapter examined the use of ADs under human rights, autonomy, therapeutic jurisprudence and recovery frameworks. The analysis suggests that ADs are appropriate under a variety of frameworks and are particularly beneficial for promoting autonomy. The human rights and recovery frameworks provide the opportunity to reconceptualise ADs as supported decision-making measures and recovery tools, while therapeutic jurisprudence promotes the broader therapeutic impact of the measure. ADs are a key tool among a suite of recovery and support-decision making measures that can strengthen the framework for participation and respect for legal capacity.

This chapter also identified the varying forms of ADs and the range of formalistic and flexible legal approaches from a comparative perspective. Many of the legal, practical and implementation issues transcend jurisdiction. Variations were identified in relation to the requirements for executing, invoking and revoking ADs, proxy decision-makers, witnesses, support for completion, the involvement of clinicians, the circumstances in when the directive can be overridden, enforceability during involuntary detention and accountability mechanisms. The literature revealed varying preferences and levels of support among stakeholders. The empirical
literature shows high levels of support for ADs among service users, but low completion rates and clinician ambivalence towards the measure. A range of strategies are being employed to increase usage in mental health settings including education, support and promoting the developmental benefits under the recovery approach. The analysis provided the foundation for exploring the use of ADs under international, Irish and comparative frameworks and exploring the views of stakeholders in subsequent chapters. Although ADs have not achieved high completion rates, the measure has still been successful in shifting the healthcare decision-making process to the person. The gaps in the literature were also considered for future research. While ADs have received extensive legislative support internationally, little is known about how they can be effectively implemented into practice. Further research is needed on effective implementation strategies in different legal and system contexts. There is also a need for more informal and contextualised information about the practical elements of ADs not reported in the formal scientific literature. Future studies should focus on a variety of outcomes including the development benefits of the measure and their role in supporting the exercise of legal capacity under the CRPD.

Chapter 3 of the thesis sought to answer the following research question. What is the status of ADs under international and European human rights frameworks? Which model is suited to implementation under the CRPD and European frameworks?

Chapter 3 examined the use of ADs under international and European human rights frameworks. The first part of the chapter focused on international human rights instruments and new approaches to decision-making under the CRPD. The CRPD challenges the traditional justification for mental health laws and raises profound questions for legislators and social policy makers, which Ireland and other countries are trying to tackle. The CRPD seeks to reverse attitudes and behaviour that have led to stigma and discrimination for centuries. It requires the abolition of policies and legislative provisions that allow or perpetuate forced treatment and substitute

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decision-making and the development of a broad range of formal and informal measures to support the exercise of legal capacity. The chapter considered various provisions of the CRPD, but specifically examined the requirements of Article 12 and the implications for the use of support measures such as ADs.

The CRPD provides a new set of human rights standards, which challenge the traditional notions of capacity and incapacity on which ADs are predicated. It requires State Parties to separate ADs from existing legal frameworks, which use capacity as a threshold for activation and deactivation. It also requires respect for the legal capacity of all persons implying that ADs should be equally available to everyone, including those detained under mental health legislation. The CRPD requires State Parties to reform substitute decision-making laws and to replace them with supported decision-making alternatives. The implementation of ADs can act as a key driver of CRPD reform and embed a culture of autonomy and participation in mental health decision-making. This is the first time that the requirements for ADs have been considered in detail under the CRPD.

The second part of chapter 3 considered ADs under European legal frameworks. The legal status of ADs is disparate and their validity remains unclear in many European jurisdictions. Some countries have legal provisions for ADs and healthcare power of attorneys, while others have no provisions. The Council of Europe considers it essential that rapid progress is made on ADs and other measures to ensure the human rights and dignity of individuals across the whole continent. The CRPD has been ratified by 25 of the 28 EU member states and the EU acceded in 2010. The Council of Europe has issued a number of recommendations and resolutions, which have recognised ADs as a principal form of self-determination.

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6 UN Doc A/Res/61/106. Article 12 provides for equal recognition before the law. Article 14 provides for right to liberty and Article 17 provides a right to physical and mental integrity.
8 Council of Europe, European Committee on Legal Co-operation, Recommendation CM/Rec (2009) 11, 1073, adopted on 9 December, 2009; Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012).
ADs are also recognised in the Oviedo Convention. The case law of the European Court has explicitly referred to ADs and stated they should be legally binding as far as possible. A recent Council of Europe resolution provides more specific guidance and states that it is essential for member states to enact and fully implement AD legislation. The resolution recommends making ADs accessible to all, allow them to be revoked informally at any time and encouraging the person to review them at regular intervals. The analysis suggests an increasing trend toward the recognition of ADs at both European and international level. The UN, EU and Council of Europe are now moving in a common direction. The ratification of the CRPD will impose further obligations on the EU and State Parties. The Council of Europe recommendations and resolutions, the European Court judgments and national mental health and capacity laws will need to be harmonised with the CRPD to ensure a consensus on ADs at European and international level.

The following research question was addressed in chapter 4:
What are the potential issues for the implementation of ADs in the Irish context?

Chapter 4 considered the introduction and implementation of ADs in the Irish context. This was achieved by examining the history of mental health treatment in Ireland, the legislative and policy framework and the relevant system and cultural context in which they will operate. Ireland lags behind other common law jurisdictions in providing legislative provisions for ADs in general or mental health care. The Irish legal and policy framework supports the introduction of ADs and recent case law suggests that advance decisions for mental health treatment may be respected by the Irish courts, but a statutory framework is needed to provide certainty. The case law highlights paternalism in the Irish courts and society in relation to individuals with mental health conditions. The 2001 Act will also have to be amended to provide respect for ADs during detention. The national consent policy and the Irish Medical Council provide guidelines on the use of ADs for medical and

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9 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Article 9 (Council of Europe 1997).
10 Jehovah’s Witnesses of Moscow v Russia, Application No 302/02, 10 June 2010.
11 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012) paras 3, 4, 6.
health services staff. The limited empirical research undertaken prior to the current research suggests strong service user support for the introduction of ADs.

The research suggests that the implementation of ADs will largely depend on the prevailing culture in the mental health services and the attitudes of practitioners charged with implementing the law. The Irish mental health system has been traditionally characterised by a culture of control and lack of respect for choice and has been steeped in institutional approaches to care for centuries. Significant progress has been achieved in recent decades, but further legislative and cultural changes are still needed. Many individuals still have difficulty getting their ‘voice’ heard in the mental health system and are not given the opportunity to participate in treatment decisions. The empirical literature suggests many service users feel they have no choice in their treatment and are not listened to by professionals. Several reports have identified low levels of service user participation and compliance with individual care planning. The use of coercion and seclusion is still common. The high readmission rate and increasing use of involuntary detention suggest a need for alternative responses. The Irish literature suggests that involuntary admission and coercion has a detrimental impact on the person and on therapeutic and family relationships. The loss of dignity and trust in the admission process was apparent. The analysis suggests that the medical model still underpins many parts of the Irish mental health services and cultural change is slow. The threat of coercion impacts on voluntary and involuntary patients. The system further hinders autonomy and independence through the lack of participative responses and support measures. Several reports have pointed to serious deficiencies in the development of recovery-oriented services. The implementation of supported decision-making measures and the recovery approach will require cultural and structural change in Irish mental health care. This will require the implementation of a dedicated programme of

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cultural change to embed the values of respect, equality, empathy and human rights.\textsuperscript{14}

ADs are a key driver in the transition to person-centred services. The implementation of ADs can assist the ‘paradigm shift’ towards the supported decision-making model and the recovery approach in the Irish mental health system. The introduction of progressive human rights legislation is important in achieving attitudinal change. The integration of ADs for mental health decisions into the legislative framework on an equal basis with other treatment decisions is important symbolically in reducing stigma and discrimination. The 2013 Bill provides an appropriate location for ADs, but differential standards for treatment decisions during involuntary detention in the recently published draft scheme perpetuate stigma and limit their use in mental health settings.\textsuperscript{15} The provisions specifically state that ADs will not be legally binding where treatment is regulated under the 2001 Act or the Criminal Law (Insanity) Act (2006).\textsuperscript{16} This is justified on the basis that the State needs to uphold the common good and to protect and maintain the rights and ‘best interests’ of its citizens and may override a valid and applicable AD to protect the individual and/or the general population.\textsuperscript{17} The AD will therefore be taken into consideration, but will not be legally-binding during involuntary detention.\textsuperscript{18} This fails to comply with the right to equal recognition before the law in the CRPD.\textsuperscript{19} In order to achieve equal recognition before the law, legal capacity must not be denied discriminatorily.\textsuperscript{20} The CRPD requires equal recognition before the law and respect for the legal capacity of all persons, implying that legally binding ADs should be available to everyone, including those detained under mental health legislation. In the absence of agreement, the circumstances in which the 2001 Act can override a validly executed

\textsuperscript{14} Shari McDaid, \textit{Recovery ... What you should Expect from a Good Quality Mental Health Service (Mental Health Reform 2013)} 15.

\textsuperscript{15} Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.

\textsuperscript{16} Ibid Head 5(7).

\textsuperscript{17} Ibid Explanatory Memorandum, Head 5(7).

\textsuperscript{18} It is planned to incorporate a Code of Practice to accompany the legislative provisions so that ADs will be taken into consideration, but they will be non-legally binding, Head 5(7).

\textsuperscript{19} Article 12, Article 5.

AD should be limited to involuntary admission and defined emergencies, but treatment decisions should be binding during involuntary detention.

The justification for limiting the use of ADs during involuntary detention is based on the perception that individuals with mental health conditions may pose a risk to themselves or society. However, the research suggests the increased risk of harm is low and violence occurs very rarely.\(^\text{21}\) In the absence of substance abuse, the risk of violence is no greater than the general population.\(^\text{22}\) Blinder points out that relatively few patients die by suicide in the care of the mental health services.\(^\text{23}\) The international and empirical research also suggests that ADs are rarely used to refuse all treatment and are used to express a preference for particular treatments or to inform providers of concerns.\(^\text{24}\) The literature and the empirical research suggest that ADs can increase engagement with treatment. The introduction of mental health ADs is often characterised by exceptions to enforceability and differential standards. These legislative approaches reinforce stigma and limit the use of ADs. Mental health advocacy organisations recommend that ADs for mental health treatment decisions operate in the same way as physical health directives during involuntary admission subject to legitimate emergency situations.\(^\text{25}\) Even if all ADs are non-legally binding, the measure is still ethically valuable because it gives a voice to the person at a time when they are vulnerable to loss of autonomy. However, the integration of ADs for mental health treatment decisions into the legislative framework on an equal basis with other directives is important symbolically in reducing stigma and promoting inclusion.


\(^{22}\) Ibid.


Chapter 5 addressed the following research question:
To what extent are comparative legal frameworks suited to Ireland?

Chapter 5 sought to examine the introduction and implementation of a legal framework for ADs in the State of Virginia with a view to informing the Irish State at a critical juncture in the legislative process. This was achieved by describing the features of the Virginia legislation and the barriers and opportunities to implementation in practice. The Virginia Health Care Decisions Act is a progressive and comprehensive piece of legislation, which provides for ethical and person-centred approaches to ADs. The innovative and flexible features of the Virginia directive are based on the recovery approach, but encapsulate many of the CRPD principles. The enabling legislation provides a strong legal foundation for system reform in jurisdictions promoting these approaches. The Virginia directive promotes the principles of equality and non-discrimination through the integration of a broad range of healthcare decisions into a single AD. The legislation provides for a presumption of capacity and minimises exclusion by providing legally binding ADs that are easily executable and revocable by all persons, including those subject to involuntary detention. The grounds on which mental health treatment decisions can be overridden are limited to defined emergencies and involuntary admission, providing respect for treatment preferences during detention.

The State of Virginia is at the forefront of international efforts to successfully introduce and implement a legal framework for ADs into mental health care. The implementation points to the importance of accompanying ADs with a co-ordinated strategy, which includes appropriate resources, support and education. The Virginia model provides a participative response to mental health crises, reducing the need for coercion and promoting engagement. The provision of peer support for AD completion is a critical feature of the model, which should be considered for adoption in Ireland. The prospects for successful implementation remain promising with high levels of enthusiasm. The Virginia model provides valuable lessons for Ireland and other jurisdictions considering the introduction of ADs and is appropriate for use under the recovery approach and the CRPD. The primary research with stakeholders in Virginia also provides a novel contribution to knowledge in the field of mental health ADs.
Chapter 6 addressed the following research questions:
What are the views and preferences of service users and consultant psychiatrists towards the proposed use of ADs in Irish mental health care?
How familiar are they with the measure?
To what extent are they willing to support them?
What are the perceived barriers and benefits to the use of ADs in Ireland?
Which legal framework, if any, is most appropriate for implementation in Ireland based on the views and preferences of stakeholders?

Chapter 6 sought to determine the views and preferences of Irish service users and consultant psychiatrists towards the introduction of ADs in mental health care. The empirical study provides a unique contribution to knowledge by considering ADs from the perspective of Irish stakeholders. The empirical research determined the views of Irish service users and consultant psychiatrists towards the proposed use of ADs and the extent to which they will be supported. The study provides a comprehensive understanding and analysis of the national issues relating to the introduction of ADs in Irish mental health care. The findings have significant implications for the drafting of legislation on ADs and successful implementation into practice. The study is timely given that ADs are to be incorporated into the 2013 Bill and draft legislation has just been published.\(^{26}\) The study will help inform the Irish state at a critical juncture in the legislative process and provides crucial information for implementation. Information on how ADs can be effectively implemented into practice is lacking in Ireland and other jurisdictions.

The empirical study revealed broad stakeholder support for the introduction of ADs, but varying preferences and perceived benefits and barriers to implementation. The findings suggested high levels of support among service users, but some ambivalence among consultant psychiatrists. Divergent preferences emerged between the groups with service users expressing a preference for legally binding ADs and consultant psychiatrists more supportive of non-legally binding directives. A consistent theme throughout the empirical research for service users was the need to be listened to, and for increased control and choice in treatment. The findings

\(^{26}\) Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.
indicated a need for increased communication and participation. The concern that the AD will not be respected by medical staff was the greatest barrier for service users. The low level of respect for informal treatment preferences combined with the consultant psychiatrist desire for the ability to override the directive suggests a need for legally binding directives with accountability mechanisms to instil service user confidence and trust.

Service users who were detained were more concerned with the potential for their wishes to be overridden. This was substantiated in the empirical findings which found almost total non-compliance with informal treatment preferences in this group, suggesting a need for legally enforceable measures during detention. The draft scheme for ADs in the 2013 Bill proposes to limit the use of legally binding ADs during involuntary detention.\(^{27}\) This reinforces the notion that the treatment preferences of individuals with mental health conditions are not respected on an equal basis with others. Non-legally binding ADs are more susceptible to being overridden and are more difficult to enforce. Many service users in the empirical study asserted that the utility of ADs would be limited unless they are legally binding. ADs were viewed as a protection against the harmful side effects of unwanted treatment. The case law suggests that the threat of coercion is pervasive for voluntary and involuntary patients. The findings suggest the need for legally binding ADs during voluntary and involuntary admission to promote trust and respect for treatment choice. The need for legally binding ADs during involuntary detention is encapsulated in a service user statement from the empirical study:

“I would finally feel safe if my advance directive was legally binding—it is an awful feeling to know your liberty and rights can be taken away from you at any time and that you have no say whatsoever in your treatment.” Service User

The empirical study also highlights the traumatic impact of involuntary admission and the need to make it a more participative experience. Service users who were involuntarily detained were less satisfied with involvement in treatment, had lower perceptions of control, listening and choice in treatment and had significantly higher

\(^{27}\) Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013’ Head 5(7).
levels of readmission. Lack of trust was a pervading theme throughout the empirical research for those who were detained. The findings suggest an urgent need for legally binding ADs in this group to instil trust and confidence. The use of ADs can promote engagement, increase trust in therapeutic and family relationships and reduce the need for readmission and involuntary treatment. The findings indicated that three-quarters of those who were detained would be more willing to adhere to treatment if they had an AD, even though consultant psychiatrists were concerned they would be used to refuse all treatment. The empirical findings suggest that the Irish mental health system is still dominated by the medical model and lack of respect for choice. The findings suggest a need for education on service user preferences and the impact of ADs to alleviate consultant psychiatrist concerns. The research also suggests a need to increase awareness of the negative impact of coercion and to promote the importance of using participative measures, which facilitate care and treatment based on the choice of the person.

The findings indicated that the refusal of all treatment and the potential for a person to be left untreated were major barriers for consultant psychiatrists. These concerns were associated with a decreased willingness to use ADs and may inform the consultant psychiatrist preference for non-legally binding ADs so that treatment refusals can be overridden. However, the majority of service users were more interested in using ADs to choose particular treatments and to communicate concerns than to refuse all treatment completely. The survey findings are reflective of the international evidence, which show ADs are rarely used to refuse all treatment.²⁸ The research suggests that giving individuals with mental health conditions greater choice does not result in a torrent of treatment refusals. Instead, it promotes trust and communication in therapeutic and family relationships and enhances treatment engagement and satisfaction reducing the need for readmission and coercion. The increased satisfaction through treatment involvement can help reduce legal liability

rather than increase it. This can help alleviate concerns and increase support for legally binding ADs among consultant psychiatrists. The evidence and the potential benefits for engagement should be used address concerns in the education programmes.

The empirical research indicated that a substantial proportion of service users lacked a trusted person to communicate on their behalf or to support them to complete the directive. This barrier was higher among service users who were involuntarily detained and may be indicative of the negative impact of involuntary admission on interpersonal and family relationships. The development of an AD allows individuals to reflect on who they can trust to act as a proxy decision-maker and to develop greater awareness of effective recovery strategies. Individuals require substantial trust and confidence that others will be supportive and respect preferences during periods of vulnerability. The lack of trusted decision-makers suggests the need for a choice of stand-alone instructional and proxy directives in the legislative framework and to develop support networks. The preference for an AD which allows for change of mind when unwell, suggests the need for a directive, which is revocable at any time and the inclusion of a Ulysses clause for those who want their prior choices respected. The Ulysses clause can alleviate the concerns of both stakeholder groups in relation to the revocability of the directive during crisis periods. The completion of an AD requires mutual trust between service users, healthcare professionals and family members. ADs can help build trust in these relationships. The majority of service users expressed a preference for support to complete the AD, suggesting the need for peer facilitators. The varying support preferences suggest the need for choice in relation to the involvement of third parties in development. The findings point to the need for increased communication and trust between service users and consultant psychiatrists. The discussion of the AD after development with a third party can facilitate communication and trust. ADs are measures that have the potential to increase trust through open communication, build capacity and confidence and promote the development of support networks.

The provision of education, support and easily executable and revocable ADs with legal enforcement mechanisms can address many of the barriers in the empirical study. The findings suggest a need for legally binding ADs with strong
accountability and oversight mechanisms until a culture of trust and respect for treatment preferences is established in Irish mental health practice. While the structure of the legislation is critical in reducing stigma and promoting the perception of respect, the developmental benefits of ADs may be the most important aspect of the measure in the Irish context. The document may not only be useful for communication, but in helping individuals to re-examine their values, develop capacity and build trust. ADs can facilitate on-going communication and promote trust and respect in therapeutic and family relationships and reduce the need for coercion.

The introduction of legislation on ADs requires a co-ordinated strategy, which includes consensus building and education with stakeholder groups, leadership and appropriate resources and support. The implementation strategy requires the involvement of all stakeholders, the support of management and oversight mechanisms. A study on end-of-life directives in the U.S. found that the implementation of ADs required a structured communication process, information tailored to the needs of the person, improved documentation of wishes, inter-institutional access and educational programmes.29 The most successful programmes in general health settings are initiated by a healthcare professional and development is supported by a skilled independent facilitator. A community-based implementation approach is also considered to be critically important.30

Ultimately, the successful implementation of ADs will largely depend on a cultural shift in the mental health system and the support of stakeholders. ADs can help cultivate a culture of respect for individual preference and help drive system and societal transformation. The premise that individuals with mental health conditions have a right to participate in treatment decisions needs to be widely accepted. A healthcare culture in which knowledge, value and respect for treatment preferences is necessary for the effective implementation of ADs. The introduction of ADs can contribute to a broader attitudinal shift in the conceptualisation of individuals with

mental health conditions. The perception of respect and promotion of trust may be
the most important aspect of ADs in the Irish mental health system.

2. Recommendations for the Introduction and Implementation of a Legal
Framework for ADs in Ireland

This thesis sought to investigate the introduction of a legal framework for ADs in
Ireland and propose a suitable implementation model under international human
rights frameworks. The international, comparative, Irish and empirical research
informed the recommendations for the introduction and implementation of a legal
framework in Ireland. The empirical research identified high levels of support for
ADs among key Irish stakeholders, but varying preferences and implementation
barriers, which need to be addressed.

The draft legislation for advance healthcare directives\(^{31}\) was published by the
Department of Health in February 2014 after the core chapters of the thesis were
completed.\(^{32}\) This unexpected occurrence allowed the findings to be applied in a
practical way and to potentially impact on the legislative framework. It was decided
that it would be a lost opportunity if this scholarship did not address the issues raised
by the Irish government in the public consultation on the draft legislation. The
response to the draft scheme addresses one of the primary aims of the thesis, which
is to inform the introduction of a legal framework for ADs in Irish mental health
care. The key issues in legislating and effectively implementing ADs and ensuring
compliance with the CRPD are therefore addressed in the recommendations and
compared with the draft legislative proposals.

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\(^{31}\) Advance directives (ADs) are referred to as advance healthcare directives in the draft scheme.
\(^{32}\) Department of Health, Public consultation on Draft General Scheme for Advance Healthcare
Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.
2.1. The findings from the international, comparative, national and empirical research suggests that the following steps should be taken prior to the enactment of the AD legislation:

- The introduction of ADs should include a planned consensus-building approach to gain stakeholder support before the law is enacted. The establishment of representative groups (including service users and practitioners) is necessary to address practice concerns and garner support for the legislation. The effective implementation of a legal framework for ADs is dependent on the support of key stakeholder groups involved in development and enforcement. The failure to consider the views of clinicians and undertake adequate staff and organisational preparation is considered to be a critical limitation to implementation. The public consultation may help address concerns, but increased engagement is needed through a series of meetings and taskforces before the law is enacted.

- The introduction of ADs requires a systematic, co-ordinated approach. System and law reform should therefore be undertaken in tandem with each other. The research suggests that the law reform process is disconnected from the mental health system in Ireland. This is highlighted through the low level of compliance with individual care planning, informal treatment preferences and other aspects of mental health legislation. The successful implementation of the law in practice will require the stakeholder and system barriers identified in the research to be addressed. This will require awareness raising, education and structural change in the mental health services. The implementation of ADs requires more than just education it requires fundamental system transformation and cultural change towards a human rights based approach.

33 Graham Thornicraft and others, ‘Clinical Outcomes of Joint Crisis Plans to Reduce Compulsory Treatment for People with Psychosis: A Randomised Controlled Trial’ (2013) 381 The Lancet Published online March 26 2013.
2.2. The international, comparative and empirical research findings suggest that the legal framework in Ireland should consist of the following features:

- ADs should be legally binding for all healthcare decisions, including mental health decisions and applicable during periods of involuntary detention. The draft scheme suggests that an AD will be legally binding for the refusal of mental health treatment. However, the provisions propose that an AD will not be legally binding or have to be followed i.e. where an individual’s treatment is regulated under Part 4 of the Mental Health Act (2001).\(^{34}\) The scheme proposes to develop a Code of Practice, which will state that an AD should be taken into consideration during involuntary detention, but this will not be legally binding. This provision violates the right to equal recognition before the law and the principle of equality and non-discrimination in the CRPD. The proposed scheme also limits the use of ADs during pregnancy.\(^{35}\)

- The legislative provisions should integrate all types of healthcare decisions, including mental health decisions into a single AD. The law should be explicit in the inclusion of all types of healthcare decisions, including mental health decisions, and include life management choices. The draft scheme proposes a single legislative framework for ADs, which encompasses both general and mental health care decisions. The definition of treatment specifically encompasses both general health and mental health decisions.\(^{36}\) The integration of all health decisions is positive. However, ADs for mental health treatment decisions should operate in the same way as other directives during involuntary admission.

- Legislators should minimise the circumstances under which the Mental Health Act, 2001 can override ADs to clearly defined life-saving emergencies to address stakeholder concerns in relation to risk to the life of the person. This will require amendments to the treatment provisions under

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\(^{34}\) Department of Health, Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 5.

\(^{35}\) Ibid Head 5(6)(a).

\(^{36}\) Ibid Explanatory Memorandum, Head 2.
Part 4 of the 2001 Act to provide for enforceability for treatment during involuntary detention. Involuntary admission may be used where there is risk to the life of other persons, but ADs will provide an alternative response to coercion. The empirical research with service users suggests a need and demand for legally binding ADs during involuntary detention. To achieve equal recognition before the law under the CRPD, legal capacity must not be denied discriminatorily. The right to equal recognition before the law and freedom from discrimination require that when the State is permitted to remove legal capacity it must be on the same basis for all persons. ADs should therefore be legally binding for treatment decisions during periods of involuntary detention.

- The legislation should include a presumption of capacity to execute an AD in order to comply with the CRPD. The draft legislation provides a presumption of capacity for all adults to execute an AD. The principles uphold the right to refuse treatment, including life-sustaining treatment, for any reason including unwise or religious reasons even where this refusal may result in death. While these provisions are positive, the draft scheme is predicated on the capacity to execute, invoke and revoke the AD. Head 5 requires the individual to have capacity at the time the directive was executed for it to be valid, while Head 4 states that in order for the directive to be followed, the person must lack the capacity to make decisions. Head 4 proposes that the individual may only revoke the directive, while he/she has the capacity to do so. The draft scheme does not specify who will make determinations of capacity for the purpose of invoking and revoking the AD. This is a major issue that needs to be addressed. The CRPD requires ADs to be separated from legal frameworks that are predicated on capacity. Article 12 requires the removal of capacity and incapacity distinctions that are used to deny legal

38 Ibid Head 3(2)(a).
39 Ibid Head 3(2)(c)(d).
40 Ibid Head 5(1)(a).
41 Ibid Head 4(2)(c).
42 Ibid Head 4(6).
capacity.\textsuperscript{43} The person should set out the circumstances they want the AD activated or deactivated at execution e.g. on hospitalisation, during crisis. This does not imply the person lacks capacity during these periods, but may need an AD to support the communication of preferences.

- The burden of proof should be on the party challenging the directive. The draft scheme does not specify that the burden of proof will be on the party challenging the directive, but any interested party may make an application to the High Court where there is any doubt in relation to the existence, validity or applicability of the directive.\textsuperscript{44} The High Court has the ultimate authority to resolve cases where there is doubt or disagreement in relation to an AD. This does not stop a healthcare provider providing life-sustaining treatment or doing any act, which he/she believes to be necessary to prevent a serious deterioration in health or a deleterious impact on pregnancy while the decision is being sought.\textsuperscript{45} These provisions suggest that non-life sustaining treatment can be provided where the person does not consent to it in the intervening period. This implies that a person could be treated with ECT to prevent a serious deterioration in health while a decision is being sought. This exception should be limited to life-sustaining treatment. The scheme also clarifies that an attorney appointed under an enduring power of attorney, can make decisions regarding all forms of treatment including life-sustaining treatment and clarifies the mechanism by which disagreement between an EPA and an AD will be resolved.\textsuperscript{46}

- The research highlights the importance of adopting a relational understanding of ADs in the broader context of advance care planning, rather than a narrow legalistic approach. The empirical research showed the need for listening, participation and the development of trust. ADs need to be conceptualised as documents that confer a wide range of communication and developmental

\textsuperscript{43} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention-Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 12.
\textsuperscript{44} Department of Health, ‘Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 9(1).
\textsuperscript{45} Ibid Head 9(3).
\textsuperscript{46} Ibid Head 8(1)(2).
benefits beyond the legal aspects. The measure is more than a reference to a person’s choices. The development of an AD has capacity building, empowerment and recovery benefits, even if it is never legally invoked. ADs can act as a communication platform between the person, professionals and family at the development and implementation stage of the process and involve engagement over a longer period. The empirical research highlights the need for communication between service users and consultant psychiatrists and the development of respectful and trusting relationships. Increased satisfaction that can be achieved if advance care planning is a relational person centred communication process rather than a document-driven decision-focused event. The incorporation of ADs into the wider framework for advance planning with individual care planning and WRAP can strengthen the framework for ongoing communication and participation in Irish mental health care.

- The legislation should provide for the appointment of a trusted proxy decision-maker. The empirical research indicates that the majority of Irish service users are interested in appointing a proxy and consultant psychiatrists are more likely to follow the directive where a representative has been appointed. The literature suggests that the appointment of a trusted proxy is vital for communicating instructions, responding to changes in treatment and ensuring the person’s wishes are respected. Some commentators suggest that a trusted proxy is more valuable than instructions, but only if the proxy is adequately informed and educated. The person should be able to set out the authority of the proxy and when he/she should be consulted on execution of the directive. The empirical study suggests a significant proportion of Irish service users lack a trusted person to act on their behalf. This barrier suggests that the legislation should provide for stand-alone instructional directives, proxy directives and hybrid directives, which allow both instructions and a

49 Charles Sabatino, ‘Eight Advance Care Planning Lessons that took me Thirty Years to Learn’ 34 (6) Bifocal 115.
proxy. The lack of trusted decision-makers also suggests the need to build support networks for those who lack a trusted proxy. The CRPD requires State Parties to facilitate the creation of supports, particularly for individuals who are isolated and may not have access to naturally-occurring supports in the community.\textsuperscript{50}

The draft scheme for ADs provides for the appointment of a patient-designated healthcare representative to be involved in the healthcare decision-making process.\textsuperscript{51} It outlines the criteria and safeguards for those who may be nominated as a representative and their decision-making authority. The scheme states that the person must be over 18 years old and not a provider of paid personal care or healthcare services or an employee or owner of a residential care home where the person resides, unless the individual is a close relative of the person.\textsuperscript{52} The decision-making authority of the representative only takes effect when the person lacks capacity.\textsuperscript{53} The person may limit the powers of the representative to ensure the terms of the AD are carried out or confer a general power to consent to or refuse treatment, including life-sustaining treatment. It also allows the person to nominate an alternative representative if the original representative dies or is unable to act.

The decision-making representative provisions are generally positive, but they are predicated on the loss of capacity for the decision-making representative to act. The CRPD requires the use of more widely defined directives that enable the person to set out the circumstances in which he/she wishes the AD to be activated and when trusted proxy decision-makers should be consulted. The legislation should place an obligation on decision-makers to act in accordance with the instructions or the will and preferences of the person and to identify these where they are unknown. The Virginia

\textsuperscript{50} Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 25 (d).

\textsuperscript{51} Department of Health, Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 7.

\textsuperscript{52} Ibid Head 7 (2)(a)(b).

\textsuperscript{53} Ibid Head 7(4)(a).
legislation draws a distinction between proxy decision-making and ‘best interests’ to safeguard against substituted decision-making. In situations where these are unknown, a duty should be placed on the representative to try to identify them. The legislation should also allow more than one proxy decision-maker to be appointed for different decisions e.g. mental health and other decisions.

The AD legislation should include minimal formalities to ensure directives are easy to execute and available to everyone. This suggests the need to minimise limitations on adult witnesses, the requirement for legal certification or capacity assessments. ADs should be easily executable, invocable and revocable to prevent barriers to usage. The empirical research suggests that service users with lower education and familiarity had increased barriers to AD execution, highlighting the need for information, support and simplification of the process.

The draft scheme proposes that ADs are documented in writing and witnessed by two persons over the age of 18 years old, one of whom cannot be a member of the person’s family and entitled to any part of his/her estate. The limitations on witnesses from a person’s family may act as a barrier to AD execution. The empirical research identified difficulty appointing proxy decision-makers, which may also extend to witnesses. The Scottish review recommended extending the range of witnesses to increase AD participation. The Virginia legislation does not place limitations on adult witnesses, but stated it was best practice for heirs and proxy decision-makers not to act. The limitations on witnesses should form part of the Code of Practice rather than a legal requirement. The requirement to obtain professional advice or legal certification to prepare an AD may act as a

54 Va Code s 54.1-2986.1(b).
55 Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 4(5).
barrier to execution and reduce completion rates. Limited provision should be provided for oral ADs with independent witness safeguards and/or recorded evidence in circumstances, where the person is unable to communicate in writing. The CRPD requires an exploration of ways of providing information adapted to the needs of the individual. 58

- The empirical study suggested over half of service users were interested in an AD, which allowed them to change their mind when unwell. The risk of change of mind since the directive was executed was a barrier for over a quarter of service users and over three-quarters of consultant psychiatrists. However, the literature suggests that while some service users prefer directives to be revocable at any time, few are actually fully revoked in practice. 59 The presumption of capacity in the CRPD requires ADs to be revocable at any time so the person can change his/her wishes.

The provisions of the proposed scheme provide that an individual may revoke the AD either verbally or in writing at any time, provided he/she has the capacity to do so. 60 The AD should also be revocable by physically destroying it. While the informality is positive, the draft scheme states that capacity is a prerequisite to revoke a directive. 61 This fails to comply with the presumption of capacity in the CRPD and acts as a barrier to completion for individuals with change of mind concerns. The explanatory memorandum in the scheme states:

“Given that such directives are intended to be utilised at a time in the future when the person who made the directive lacks capacity, enabling a person

59 In one study of 106 service users with ADs and 487 crisis events, the directive was never revoked as a whole, although in 105 (22 per cent) of the crises, service users changed their minds about some specific instructions: Debra Srebnik and Scott Kim, ‘Competency for Creation Use and Revocation of Psychiatric Advance Directives’ (2006) 34(4) Journal of the American Academy of Psychiatry and the Law 501.
60 Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, Head 4(6).
61 Ibid Head 4(6).
who lacks capacity to revoke or alter his or her directive would defeat the purpose of preparing the directive.”

Given that relatively few ADs are fully revoked in practice, concerns in relation to revocability or defeating the purpose of a directive may be unfounded. Moreover, the literature suggests that preparation of an AD confers a myriad of developmental benefits even if it is never legally invoked. Several jurisdictions already allow the person to choose whether the document is revocable during crisis periods at execution. The revocability concerns can be resolved by allowing individuals to state whether they wish the AD to be revocable or not during crisis periods at execution. The inclusion of a Ulysses clause in the legislation can address situations where the individual clearly wants the AD wishes to stand over his/her own objection or change of mind during crisis periods. The execution of the Ulysses clause should be subject to safeguards at execution to ensure the person understands the implications i.e. an independent support person should ensure the person understands the clause and attest to this when signing the directive.

- The legislation should provide for the development of a statutory form(s), but this should not be a requirement for the AD to be valid. The form should be integrated to include physical health, mental health and other decisions. A separate form should be made available for those who wish to document mental health decisions separate to physical healthcare decisions in general health settings. The AD form can include details of any designated healthcare representative, treatment refusals or requests, hospitalisation preferences, emergency contacts, personal life management choices, participation in research, organ donation etc. The draft scheme provides that the AD does not have to be in prescribed form, but should contain some basic minimum information. A standard simplified form should be developed to provide a template for users and recognition of ADs by providers.

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• The legislation should require providers to ask if the person has an AD upon admission to hospital or for treatment in a healthcare facility and to document it in the medical record.

The draft scheme provides for ‘good faith’ immunity for healthcare professionals. This implies that health professionals who, acting in good faith, either comply with or fail to comply with the terms of a valid AD will not incur any civil or criminal liability, including where they were unaware of the existence or content of the directive at the time the treatment was carried out. While these provisions may alleviate legal liability concerns, the empirical research indicates that service users need to feel confident that the AD will be respected. The legislation should place a legal duty on providers to inquire whether a person has an AD and to make reasonable attempts to locate it. The provision of a registry and crisis cards can assist.

• The empirical research shows the need to provide user confidence that the AD will be respected. The legislation should provide accountability and oversight mechanisms where treatment is provided in conflict with a valid directive. The reasons for overriding the AD should be submitted in writing to an independent authority and documented in the person’s medical record. The override decision should be subject to review by the monitoring body. The Mental Health Commission should provide oversight for ADs in mental health care, while the Office of the Public Guardian may provide oversight for general ADs. The implementation of the legislation on ADs should be coordinated by these bodies. The use of ADs should be incentivised and measured within the system.

• The Office of the Public Guardian and the Mental Health Commission should monitor the implementation of ADs, promote public awareness and provide education to professionals and service users. Stakeholder education is critical for the effective implementation of ADs. Legal compliance training should

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64 Ibid Head 6(4).
be provided for health professionals after the law is enacted to garner support and to alleviate concerns. Education should also be provided for proxy decision-makers to safeguard against substitute decision-making.

- The legislation should provide support for AD completion. The international, comparative and empirical research shows the need for facilitated support for AD completion. The empirical research suggests the majority of Irish service users were interested in support to complete the directive, with many expressing a preference for a family member or trusted friend. A substantial proportion of service users lacked a trusted person to support them to complete the directive. Trained facilitators should be provided in a range of settings to support individuals to develop ADs. The research suggests that peers will be a critical source of support for AD completion. The role of peers in supporting the completion of ADs should be recognised in the Code of Practice. The CRPD requires State Parties to provide access to supports to exercise legal capacity.

- The research points to the importance of accompanying the introduction of ADs with appropriate resources. The resources required to implement ADs are often underestimated. However, ADs are associated with a reduced need for hospital readmission and involuntary detention conferring economic and other benefits in the longer term. The provision of appropriate education and training; support to complete the directive; information champions; compliance mechanisms and leadership will be critical for effectively implementing ADs into practice.

- In the absence of electronic medical records, the legislation should provide for the establishment of an electronic registry so that the AD can be accessed. ADs need to be accessible to providers in emergencies and crisis situations so they can be followed. The U.S. Living Will Registry has adopted an

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innovative approach. The secure registry maintains a database of ADs, organ donor information and emergency contacts and is accessible to healthcare providers with the consent of the person or proxy decision-maker. A copy of the document can be forwarded electronically to healthcare providers during an emergency with the prior consent of the individual or proxy decision-maker. Confidentiality issues arise in relation to mental health information. Some individuals do not want providers in general health settings to have access to mental health information due to stigma. The provision of consent for certain types of information, or a separate registry can be created to protect confidentiality. The registry provides confidence that the AD will be accessible, saves time and can be used in conjunction with crisis cards and medical records to ensure provider awareness. Crisis cards can be used to alert providers in relation to the existence and location of the directive. The 2013 Bill proposes to establish a register of decision-making agreements through the Office of the Public Guardian, but does not specify whether this will be accessible by healthcare providers. These issues may form part of the Code of Practice. The draft general scheme for ADs does not currently provide for a registry. The specific questions raised in the public consultation on ADs by the Department of Health will be addressed in the next section.

68 Assisted Decision-Making (Capacity) Bill 2013, s 56(2)(b).
3. Specific Response to the Public Consultation on Draft General Scheme for Advance Healthcare Directives

The Minister for Health announced the commencement of a public consultation on the draft general scheme of legislative provisions for advance healthcare directives for incorporation into the Assisted Decision-Making (Capacity) Bill 2013 in February 2014. The 2013 Bill is considered to be the most appropriate vehicle for providing a legislative framework for ADs given the intersection between the capacity legislation and the role of directives in supporting decisions. The department believes that the establishment of a statutory framework will provide greater clarity in relation to the will and preferences of individuals regarding future treatment. The draft general scheme for advance healthcare directives and the public consultation were published after the core chapters of the thesis were completed. The thesis research began in February 2010 and was completed in February 2014. It was decided to address specific questions relating to the consultation as a significant contribution to scholarship and to inform the introduction of a legal framework for ADs in Ireland. The author prepared a number of submissions on the legislation including the response of the Mental Health Commission and made a significant contribution to the principles and submission developed by the Centre for Disability Law and Policy at NUI Galway. A personal submission was also made by the Department of Health based on the findings of the thesis. The response to the public consultation questions was informed by the findings of the international, comparative, national and empirical research in the thesis. This was included as an additional piece to further inform the main aim of the research, which was to explore

1 Department of Health, ‘Minister announces Public Consultation on Legislating for Living Wills’ [http://www.dohc.ie/press/releases/2014/20140204.html] [accessed 5 February 2014]. The closing date for submissions was the 7th of March 2014.
2 Ibid.
the introduction of a legal framework for ADs in Ireland. The following specific questions were posed in a public consultation on the draft general scheme for ADs.

1. **What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?**

The requirement to obtain clinical or legal advice before preparing an AD may act as a barrier to completion. However, users should be encouraged to discuss their AD preferences with treating clinicians after the document is developed with an independent support person to facilitate communication and to ensure the AD is respected. This may form part of the Code of Practice. The involvement of a health professional in the development of the directive can raise concerns in relation to undue influence, particularly in mental health care. The discussion of the AD with the clinician after development can have significant benefits for the therapeutic relationship and promoting trust. Health professionals may also be involved in introducing ADs to the person and referring them to an independent support person for facilitation. The majority of service users in the empirical study were interested in agreeing their AD preferences with their treating psychiatrist, but were not necessarily interested in involving professionals in development. Some service users do not want their psychiatrist involved in the development of the directive. The service user should be given the opportunity to complete the directive with the support of an independent person e.g. trained peer facilitator.

2. **Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed?**

The requirement for a specific, mandatory time period for review in the legislative provisions may impact on the validity and enforceability of the directive. The AD should be reviewed periodically so changes in treatment preferences or personal circumstances are incorporated, but this should form part of the Code of Practice rather than a legislative requirement. The review of an AD should occur on an annual basis or after each episode of illness or crisis.
3. Should a standard format be developed for advance healthcare directives?

A standard simplified form (s) should be developed for ADs. However, a form should not be a legislative requirement for the AD to be valid and should be part of the Code of Practice. The form facilitates provider recognition of the directive and provides a template for instructions. This decreases the likelihood of ambiguous instructions and minimises provider error.

4. If a standard format for advance healthcare directives was developed what information should it contain?

The form should integrate all forms of healthcare decisions i.e. physical, mental health decisions. A separate form should also be developed for individuals, who wish to provide for mental health decisions separately to protect confidentiality in general health settings. The form should include details of the person, any designated decision-making representative (s), the authority of the decision-maker, emergency contacts, details of treating doctors, treatment refusals/requests, reasons, ECT preferences, Ulysses clause, preferences for life-sustaining treatment, life management choices, hospitalisation preferences, relapse symptoms, organ donation and participation in research. The person should only be legally required to provide minimal details such as name, address, date of birth, witness signatures and the details of any designated representative (s) if appointed for the AD to be valid. If the person appoints a representative, but does not provide specific instructions or limit his/her power, the representative will be bound to make decisions based on the persons will and preferences or to make every effort to identify them where unknown. Where specific instructions are provided, the representative will be bound to make decisions based on these where they are applicable.

5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?

In the absence of electronic medical records, ADs should be kept in an online registry with confidentiality safeguards. The registry should be accessible by healthcare providers with the consent of the person or the designated decision-
making representative. The Office of the Public Guardian proposes to provide a register for decision-making agreements, so ADs may also be included. In order to protect confidentiality, the Mental Health Commission may assume responsibility for access, where the AD includes mental health decisions. The person may specify in the AD, whether they wish mental health decisions, to be accessible by health professionals outside of mental health settings. The legislation should not require submission of the AD to the registry for it to be legally valid, but registration should be recommended in the Code of Practice. The registry should be easily accessible to enable individuals to submit their directive with support if needed. ADs should also form part of the recently published ehealth strategy and Health Identifiers Bill 2013, which will provide unique codes for patients and providers.

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?

The existence of an AD should be documented in the person’s medical record and in the online registry. Crisis cards (similar to organ donation cards) should also be made available to alert healthcare professionals of the existence of an AD. Individuals should be encouraged to discuss their AD preferences with treating healthcare professionals and distribute copies to treating professionals and services at execution. This should form part of the Code of Practice in the legislation. There should be an obligation on clinicians to inquire whether a person has an AD on admission to hospital or as part of the clinical assessment.

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?

An obligation should be placed on healthcare professionals to provide treatment requested in the directive where it is available and clinically appropriate. Treatment
requests should also be discussed with healthcare professionals when executing the AD to ensure requests are available and respected. A duty should be placed on the healthcare professional to inform the person or the designated decision-making representative and the monitoring body of the reasons why the requested treatment could not be provided (e.g. the Mental Health Commission) and to document it on the medical record. If the treatment is available through another professional or provider, reasonable efforts should be made to transfer the person to another provider or professional who is able or willing to comply with the request.

8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?

The provisions should include a choice of integrated and separate formats for mental health and general healthcare. An integrated form should be made available for both physical and mental health decisions. Many individuals with mental health conditions also have physical illnesses, which they may want to document on an integrated form. Other individuals may want to document mental health decisions separately to protect confidentiality in general health settings. A form may be also developed for individuals who only want to specifically state end-of-life preferences. The form for mental health decisions should include relapse symptoms, crisis responses, recovery strategies, treatment refusals/requests, reasons, hospitalisation preferences, ECT preferences and a Ulysses clause for individuals who want their AD wishes to stand over objection during crisis periods. It may also include life management choices when an individual is in crisis e.g. Childcare, household finances etc. The form should be reviewed after each crisis or on an annual basis as part of the Code of Practice.
9. What do you think the role of the patient-designated healthcare representative should be? Should the representative’s role be limited to that of interpreting the individual's advance healthcare directive? Should the representative have a broader role to advise as to what the individual's will and preferences regarding treatment are likely to be?

The legislation should place a duty on the healthcare representative to follow the person’s instructions or to make every effort to identify his/her will and preferences where instructions are not provided. The individual should specify the role of the designated healthcare representative in the terms of the directive i.e. when they want the representative to be consulted and whether they wish them to have broad or limited decision-making authority, or respond to changes in treatment. The AD form should allow the person to specify the role of the representative. In certain circumstances, the person may allow the representative to consent to admission to hospital for a limited period, subject to independent review safeguards. The legislation should allow individuals to have a choice of executing a stand-alone instructional directive; a proxy directive where a representative is appointed to communicate the person’s will and preferences or a hybrid directive where the person includes instructions and a healthcare representative. The empirical research suggests that a significant proportion of service users do not have a trusted person they can appoint as a decision-making representative so the option to execute a standalone instructional directive and to develop trusted support should be provided for in the legislation. Due to the conflict of interest, a healthcare professional should not act as a decision-making representative. The draft scheme states that a provider of paid personal or healthcare services should not act as a representative. The limitations on decision-making representatives could be provided for in the Code of Practice.
10. What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

In cases, where the person provides specific instructions, the representative should have a duty to follow these in treatment and other decisions. There should be some form of accountability where the proxy does not follow the person’s instruction. The support of a facilitator when developing the directive can help the person provide more specific instructions. In the absence of instructions, the representative should have duty to make decisions in accordance with the person’s will and preferences and make every effort to identify these where they are unknown. The Code of Practice should emphasise the importance of appointing a trusted decision-making representative, who is familiar with the person’s values where instructions are not provided. An obligation should be placed on providers to help build trusted support networks for individuals who lack a trusted person to communicate on their behalf. Educational programmes should also be provided for individuals who are appointed decision-making representatives to safeguard against substitute decision-making and to ensure the person’s wishes are reflected in decisions.

11. Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?

ADs should be legally binding for all healthcare decisions, including mental health decisions and equally applicable during periods of involuntary detention. The legislative provisions should also include a Ulysses clause for individuals who clearly want their AD wishes to be followed over their own future refusals during crisis periods. The previously executed wishes take priority over the person’s current preferences once the AD enters into force. The Ulysses clause caters for individuals who have prior experience of crisis and clearly want their AD wishes to be respected when unwell. Some individuals want to use the Ulysses clause to avoid deterioration and the need for involuntary admission to hospital. This clause should be optional and only executed by individuals who clearly do not want their AD wishes to be changed by themselves when unwell due to the impact on recovery and interpersonal
relationships. The clause should be subject to additional executional safeguards by an independent witness or healthcare professional to ensure that the person understands the implications of signing it at execution.

The word patient should be omitted from designated healthcare representative. The burden of proof should be placed on the party challenging the directive. Consideration should be given to allowing individuals between 16 and 18 years old to develop ADs. The LRC report on children and the law recommended that 16 and 17 year olds should be presumed to have capacity to consent to and refuse medical treatment, including in the area of mental health and to make an AD.\(^6\)

The Code of Practice should specify the need for trained peer or other facilitators to support AD completion. The empirical and international literature suggests that individuals with mental health conditions want and need support to develop ADs. Facilitated directives were found to achieve significantly higher completion rates, were more responsive to user needs and contained more valuable information in previous research.\(^7\) A key component of the successful Gundersen Lutheran programme for end-of-life directives in Wisconsin includes the provision of trained facilitators in a range of settings.\(^8\) The support person should be independent of the treating healthcare professional. The importance of peer support to complete the AD should be recognised in the Code of Practice. The provision of support has implications for healthcare resources. Some support may be provided through training for existing staff, peer advocates and volunteer facilitators.

The legislation should place an obligation on healthcare professionals to offer every individual the opportunity to develop an AD as part of the recovery and care planning process. This can be provided for in the legislation or the Code of Practice. Individuals should also be offered the opportunity to develop ADs in health settings

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where the person may be vulnerable to loss of autonomy or hospitalisation. Designated members of healthcare staff should be assigned responsibility for offering individuals the opportunity to develop an AD and/or referring them to a trained facilitator for support. The legislation should include some form of compliance mechanisms to ensure healthcare providers offer individuals the opportunity to develop an AD e.g. requiring professionals to document when individuals were offered the opportunity to develop an AD and the reasons for not developing one in the medical record and the care plan. Healthcare providers should be required to return annual figures on how many ADs were created in the service and they should form part of service performance measures. These figures should be returned to the monitoring body. The Inspector of Mental Health Services should report on AD compliance figures in the annual report published by the Mental Health Commission in a similar manner to individual care planning. There should be some form of accountability for not offering individuals the opportunity to execute an AD or complying with them. The overview of the draft legislation refers to the fact that ADs predominantly relate to the refusal of treatment. However, many ADs include both treatment requests and refusals. A trusting therapeutic relationship is associated with an AD containing more treatment requests than refusals. ADs should be promoted as measures that include treatment requests and refusals and have important recovery and capacity building benefits.

4. Concluding Remarks

The incorporation of legislative provisions for ADs in the 2013 Bill, the ratification of the CRPD, the new Council of Europe recommendations and review of the Mental Health Act 2001, provide the perfect opportunity to adopt non-discriminatory CRPD compliant ADs in Ireland. ADs are a means by which the principles espoused in the national and international human rights framework can be realised and help drive the cultural shift towards dignity and respect for all persons. This thesis argued that individuals have a right to exercise their legal capacity and have those choices respected on an equal basis with others. The use of differential standards for mental and general healthcare directives reinforces the notion that the rights of individuals with mental health conditions are not accorded equal respect. The enactment of a

legislative framework for ADs, whereby the preferences of individuals with mental health conditions are respected on an equal basis with others, can reduce stigma and discrimination and place Ireland at the forefront of new approaches to decision-making in mental health care.

Ultimately, the implementation of ADs under the Irish legal framework requires respect for the ‘voice’ of all persons. The establishment of a strong philosophical ethos of respect may be the most important aspect of the measure. This is encapsulated in the statement by the President of Ireland, Michael D Higgins, at a 2012 summer school:

“By depriving citizens of the right to represent themselves, and to make important decisions regarding their lifestyle and their medical care, we fail to promote their inclusion in society and we contradict the principles to which we should aspire; principles which espouse the upholding of a social rather than a medical model of disability and which required the integration of the fields of mental health law, non-discrimination and legal capacity.”

Individuals with mental health conditions have waited too long for a society that respects their dignity and rights. The minimum they deserve is the opportunity to develop and to reach their full potential as citizens.

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10 Michael D Higgins, President of Ireland, Centre for Disability Law and Policy, Summer School, 18 June 2012.
Bibliography


Ambrosini D and others, ‘Preferences for Instructional or Proxy Advance Directives in Mental Health: An Exploratory Mixed Methods Study (2012) 6 Journal of Ethics in Mental Health 1.


Amnesty International, Decision-making Capacity in Mental Health: Exploratory Research into the Views of People with Personal Experience (Amnesty International Ireland 2009).


Atkinson J, Advance Directives in Mental Health: Theory, Practice and Ethics (Jessica Kingsley 2007).


Bartlett P and others, Mental Disability and the European Convention on Human Rights (Brill 2007).


Barry O, ‘Mental Health Services need Long-Overdue Cultural and Structural Revamp in Opinion: Progress in Implementing 2006 Reform Plan has been Painfully Slow’ Irish Times (Dublin, 17 May 2013).

Bazelon Centre for Mental Health Law, Power in Planning: Self Determination through Psychiatric Advance Directives (Bazelon Centre for Mental Health Law 2003).


Bell A and Lindley P (eds) Beyond the Water Towers: The Unfinished Revolution in Mental Health Services 1985-2005 (Sainsbury Centre for Mental Health 2005).


Brosnan L and others, Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective (Western Health Board 2002).


Burns N and Grove S, Understanding Nursing Research: Building an Evidence-Based Practice (Elsevier 2011).


Calsyn R and others, ‘Do Consumers who have a Choice of Treatment have Better Outcomes?’ (2000) 36 Community Mental Health Journal 149.


Campbell P, ‘It does not Ring my Bell’


Centre for Disability Law and Policy, Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence and Equality (Centre for Disability Law and Policy 2011).


Centre for Reviews and Dissemination, Systematic Reviews: CRD’s Guidance for Undertaking Reviews in Health Care (Centre for Reviews and Dissemination 2009).


College of Psychiatrists of Ireland, ‘On the Road to Recovery’ (College of Psychiatrists of Ireland 2013).


Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, *Report to the Irish Government on the Visit carried out by the European Committee on the Prevention of Torture, Inhuman and Degrading Treatment and Punishment (CPT) from 31 August to 9 September 1998* (Council of Europe 2000).
Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, *Report to the Government of Ireland on the Visit to Ireland carried out by the European Committee on the Prevention of Torture, Inhuman and Degrading Treatment and Punishment (CPT) from 25 January to 5 February 2010* (Council of Europe 2011).


De Haan L and others, ‘Preferences for Treatment during a First Psychotic Episode’ (2001) 16 European Psychiatry 83.


Department of Health, White Paper: A New Mental Health Act (Stationery Office 1995).


Department of Health, ‘Public Consultation on Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013.'


Department of Health Australia, *A New Mental Health Act for Victoria: Summary of Proposed Reforms* (Department of Health 2012).


Ditto P and others, ‘Stability of Older Adults’ Preferences for Life-Sustaining Medical Treatment’ (2003) 22 (6) Health Psychology 605.


Donnelly M, Mental Health and Human Rights Seminar, Centre for Criminal Justice and Human Rights, Law Faculty, University College Cork (25th October 2007).


Draper M, ‘Involving Consumers in Improving Hospital Care: Lessons from Australian Hospitals’ (Department of Health and Family Services 1997).


Duffin C and others, ‘Forced Caesarean was 'Manifestly' in Alessandra Pacchieri’s Interest, says Judge’ The Telegraph (London, 4 December 2013).


European Commission, Public Framework for Mental Health in the EU (European Commission 2001).

European Commission, ‘Mental Health in the EU-Key Facts, Figures and Activities: A Background Paper provided by the Support Project’ (Luxembourg 2008).

European Science Foundation, ‘Advance Directives: Towards a Coordinated European Perspective?’ ESF Exploratory Workshop, Institute of Biomedical Ethics, University of Zurich 19-21 June 2008.


Fernando S, *Recovery Approach Limited to White Middle Classes* (European Centre for Migration and Social Care 2008).


Friedson E, Professional Dominance: The Social Structure of Medical Care (Aldin 1970).


Gruskin S and others, Perspectives on Health and Human Rights (Routledge 2005).

Gundersen Lutheran System, *Transforming Healthcare: Advance Care Planning*  

Gundersen Lutheran System, *Respecting Choices: Advance Care Planning*  


Hammerberg T, Commissioner for Human Rights of the Council of Europe, following his visit to Ireland from 1 to 2 June 201: Issue Reviewed-Human Rights of Vulnerable Groups in Times of Austerity Budgets, CommDH(2011) 27  


Health Research Board, Community Treatment Orders and Readmissions (Health Research Board Ireland 2004-2009).


Health Research Board, Selected Findings and Policy Implications from 10 Years of HRB Mental Health Research (Health Research Board 2013).

Health Research Board, Irish Psychiatric Units and Hospitals Census 2013 (Health Research Board 2013).

Health Service Executive (HSE) *National Service Plan* 2010 (Department of Health 2010).

Health Service Executive (HSE) *National Service Plan* (Department of Health 2012).

Health Services Executive South Regional Director of Operations, *Moving West Cork Mental Health Service in a Recovery Direction: Developing an Integrated Mental Health Service in Line with A Vision for Change* (Health Service Executive 2011).


Homer, The Odyssey Book XII (Penguin 2006).


Hyde A and others, Sociology for Health Professionals in Ireland (Institute of Public Administration 2004).


Inspectorate of Mental Health Services, National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2010 (Mental Health Commission 2011).

Inspectorate of Mental Health Services, Rehabilitation and Recovery Mental Health Services (Mental Health Commission 2011).

Inspectorate of Mental Health Services, National Overview of Service User Representatives, Carers/Family Representatives and Advocacy Groups 2011 (Mental Health Commission 2012).

Inspectorate of Mental Health Services, National Overview of Service User, Family/Carer, Advocacy Groups and Consumer Panels in Mental Health Services 2012 (Mental Health Commission 2013).

International Disability Alliance, ‘IDA on Functional Capacity’ Correspondence from the International Disability Alliance to Professor Ronald McCallum, UN Committee on the Rights of Persons with Disabilities (July 2010) <www.chrusp.org/home/resources> [accessed 2 February 2014].

Irish College of Psychiatrists, How to Set Up Rehabilitation and Recovery Services in Ireland: Guide for Consultants in Rehabilitation Psychiatry produced by the Faculty of Rehabilitation and Social Psychiatry, Occasional Paper OP64 (Irish College of Psychiatrists 2007).


Irish Hospice Foundation Survey (Irish Hospice Foundation 2010).


Irish Medical Council, Guide to Ethical Conduct and Behaviour (Irish Medical Council 2009).


Irish Medical Organisation (IMO), Irish Medical Organisation Position Paper on Mental Health Services (IMO 2010).


Katsakou C and others, ‘Psychiatric Patients’ Views on Why Their Involuntary Hospitalisation was Right or Wrong: A Qualitative Study’ (2012) 47 Social Psychiatry Psychiatric Epidemiology 1169.


Keogh F and others, ‘*We have no Beds...*’ An Enquiry into the Availability and Use of Acute Psychiatric Beds in the Eastern Health Board Region (Health Research Board 1999).


Lavelle E and others, Mental Health Rehabilitation and Recovery Services in Ireland: A Multicentre Study of Current Service Provision: Characteristics of Service Users and Outcomes for those with and without Access to These Services (Mental Health Commission of Ireland 2011).


Lyons F, Ireland since the Famine (Fontana 1985).


MacGabhann L and others, Hear My Voice: The Experience of Discrimination by People with Mental Health Problems (Amnesty International Ireland 2010).

Madden D, Medicine Ethics and the Law (Butterworths 2002).
Mahone I and others, ‘Shared Decision Making in Mental Health Treatment: Qualitative Findings from Stakeholder Focus Groups’ (2011) 25 (6) Archives of Psychiatric Nursing e27.


McCrone P and others, Paying the Price: The Cost of Mental Health Care in England to 2026 (King's Fund 2008).


McDaid S, Recovery ... What You Should Expect from a Good Quality Mental Health Service (Mental Health Law Reform Ireland 2013).

McEvoy R and others, Service User Involvement in the Irish Health Service (Department of Health and Children and Health Service Executive 2008).

McGruder J, ‘Life Experience is not a Disease or why Medicalizing Madness is Counterproductive to Recovery’ (2001) 17 (3) Occupational Therapy in Mental Health 59.


McSherry B and Weller P (eds), Rethinking Rights-Based Mental Health Law (Hart Publishing 2010).


Mental Disability Advocacy Center (MDAC), ‘Legal Capacity in Europe: A Call to Action to Governments and the EU’ (MDAC 2013).

Mental Health Advocacy Coalition (MDAC), Destination: Recovery (Mental Health Advocacy Coalition 2008).

Mental Disability Advocacy Center (MDAC), Legal Capacity in Europe: A Call to Action to Governments and the EU (MDAC 2013).


Mental Health Commission, Quality Framework: Mental Health Services in Ireland (Mental Health Commission 2007).


Minkowitz T, Submission to the Committee on the Rights of Persons with Disabilities on the Draft General Comment on Article 12, 22 January 2014.


Murphy S and O’Shea B, ‘Think Ahead: An Irish Care Planning Tool’ 3 (2) British Medical Journal Supportive and Palliative Care 270.

Murphy S and O’Shea B, ‘The Think Ahead Project: A Public Awareness Initiative’ Poster presented at the Irish Association for Palliative Care Education and Research Seminar, 7 February 2013.


National Disability Authority, Public Attitudes to Disability in Ireland (National Disability Authority 2002).


National Disability Authority, Public Attitudes to Disability in Ireland, Disability Research Series 8 (National Disability Authority 2007).


National Institute for Clinical Excellence (NICE), Schizophrenia Core Interventions in the Treatment of and Management of Schizophrenia in Adults in Primary and Secondary Care (NICE 2009).


O’Brien C, ‘Inspectors Seek Review of High Use of Sedatives in Mental Units’ The Irish Times (Dublin, 4 January 2011).


O’Brien M (Director for International Programmes with Atlantic Philanthropies), ‘Atlantic Philanthropies $1.1bn is drop in ocean next to what State can Invest’ Irish Times (Dublin, 5 December 2013).


O’Brien J in Liz Brosnan and others, Pathways Report: Experiences of Mental Health Service Users from a User Led Perspective (Western Health Board 2002).


O’Donoghue B and others, ‘A Descriptive Study of ‘Non-Cases’ and Referral Rates to an Early Intervention for Psychosis Service’ (2012) 6 (3) Early Intervention in Psychiatry 276.

O’Donoghue and others, ‘Service Users’ Perceptions about their Hospital Admission Elicited by Service User-Researchers or by Clinicians’ (2013) 64 (5) Psychiatric Services 416.


The Organisation for Economic Co-operation and Development (OECD), Health at a Glance: OECD Indicators (OECD 2009).


Regional Director of Operations, Health Service Executive South, ‘Moving West Cork Mental Health Service in a Recovery Direction: Developing an Integrated Mental Health Service in Line with A Vision for Change’ (Health Service Executive 2011).


Report of the Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (United Nations February 2013), A/HRC/22/53 89.
Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/64/272, para 74.


Rose D, ‘User’s Voices: The Perspectives of Mental Health Service Users on Community and Hospital Care’ (Sainsbury Centre for Mental Health 2000).


Sabatino C, ‘Eight Advance Care Planning Lessons that took me Thirty Years to Learn’ 34 (6) Bifocal 115.


St Patrick’s Mental Health Services, ‘Stigma still a Significant Factor’ 10 September 2013 <https://www.stpatricks.ie/stigma-still-significant-factor> [accessed 12 December 2013].

Stainton T, Autonomy and Social Policy (Ashgate 1994).


Tedstone Doherty D and others, *Happy Living Here... A Survey and Evaluation of Community Residential Mental Health Services in Ireland* (Health Research Board, Mental Health Commission 2007).

Tedstone Doherty D and others ‘Psychological Distress, Mental Health Problems and Use of Health Services in Ireland’ Health Research Board (HRB) Research Series 5 (Health Research Board 2008).


The Roeher Institute, *Social Well-Being* (Roeher Institute 1993).


Thornicraft G and others, ‘Clinical Outcomes of Joint Crisis Plans to Reduce Compulsory Treatment for People with Psychosis: A Randomised Controlled Trial’ (2013) 381 The Lancet published online March 26 2013.


United Nations, Interim Report of the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, UN Doc A/63/175 (July 2008).


Wainright W, ‘Key Issues in Staff Education to Support Advance Care Planning in the Hospital Settings’ Vancouver Health Authority <https://www.researchgate.net/post/Key_issues_in_staff_education_to_support_advance_care_planning_in_the_hospital_setting> [accessed 9 October 2013].


Whelan D, Mental Health Law and Practice (Roundhall 2009).


World Health Organisation Europe, ‘User Empowerment in Mental Health-A Statement by the WHO Regional Office for Europe’

World Health Organisation Europe, ‘Empowerment of Service Users and Carers’

World Network of Users and Survivors of Psychiatry (WNUSP), Position Paper on Principles for the Protection of Persons with Mental Illness (WNUSP 2001)

World Network of Users and Survivors of Psychiatry (WNUSP) and Bapu Trust, First Person Stories on Forced Interventions and Being Deprived of Legal Capacity (Bapu Trust 2006).


Appendix A
Ethical Approval Letter from NUI, Galway
Sent on behalf of Dr Saoirse NicGabhainn, Chairperson, Research Ethics Committee.

Dear Ms Morrissey

RE: Ethical Approval for “Advance Directives in Mental Health Care: Hearing the Voice of the Mentally Ill.”

I write to you regarding the above proposal which was submitted for Ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted APPROVAL.

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting an annual report to the Committee. The first report is due on or before 31st November 2011. Please see section 7 of the REC’s Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours Sincerely

Dr Saoirse NicGabhainn
Chairperson
Research Ethics Committee
Appendix B

Research Instruments

Service user invitation letter, information sheet, consent form, service user questionnaire.

Consultant psychiatrist invitation and reminder letters, information sheet, consent form and consultant psychiatrist questionnaire.
Dear Service User

You are being invited to take part in a research study on the possible use of advance mental health directives in Ireland. In recent years, several countries have introduced ways of allowing people with mental illness to say how they would like to be treated should they be unable to make decisions for themselves. Similar to “living wills”, advance mental health directives give people with mental illness the opportunity to state what treatments they would or would not like in the future. They allow you to sit down when you are well and work out what needs to be done and what works best for you should you become mentally unwell. Research in other countries has examined patients’ preferences for advance mental health directives sometimes called psychiatric advance directives. The study seeks to understand the views of Irish service users’ towards the use advance mental health directives.

You have been asked to participate in this study as a member of the Irish Advocacy Network. Participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. Please find enclosed an information sheet for your information. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. By participating in the study you will be asked to complete a postal questionnaire which will take approximately 15 minutes to complete. You will be asked some questions on your familiarity with advance mental health directives, treatment and care planning, mental health treatment choices, your past experience of mental health treatment, your opinion on advance mental health directives and how they might affect service users and some personal information. You do not have to disclose your name or address at any stage in the questionnaire. You can return the questionnaire anonymously in the prepaid envelope provided. The consent form can be returned in a separate envelope to protect your identity.

By participating you can help people with mental illness have more say in the management of their treatment and their lives. Advance mental health directives can potentially reduce the need for hospitalisation and involuntary treatment by allowing people to manage their mental health
treatment in advance. By participating in the study, you will be helping policy makers make important decisions in relation to treatment for people with mental illness. You will also be contributing to a change in how people think of mental illness and how it is treated in Ireland.

We look forward to hearing your opinion on this potentially important development in mental health treatment in Ireland.

Yours sincerely,

Fiona Morrissey
Participant Information Sheet

Service Users

Study Title:
Advance directives in Mental Health Care: the views of Irish service users

What are advance directives?
Advance directives give you the opportunity to state what treatments you would or would not like should you be unable to make decisions for yourself in the future. They allow you sit down when you are well and work out what works best for you should you become mentally unwell.

Example: You may want to write down which medication works or doesn’t work for you or if you don’t wish to receive certain treatments.

Objective:
This study seeks to find out the views of service users towards the possible use of advance directives in Ireland.

Study Investigators:
The study is being undertaken by Fiona Morrissey as part of PhD research on advance directives in mental health care under the supervision of Dr. Mary Keys at the School of Law, NUI Galway and is being funded by the Mental Health Commission.

Invitation to take part in the study
You are being invited to take part in a research study on the possible use of advance directives in Ireland. Advance directives outline what treatments you would or would not like should you become mentally unwell in the future. Before you decide, it is important for you to understand why the research is being done and what it will involve. The participant information sheet will tell you about the purpose, risks and benefits of this research study. If you agree to take part, we will ask you to sign a consent form. You will have 2 weeks to decide whether you wish to take part or not in the study. Should you decide to take part, your answers will be anonymous. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study.
when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

**Purpose of the Study**
The study seeks to understand the views and attitudes of service users’ towards the possible use of advance directives in Ireland. Several countries have introduced ways of allowing people with mental health problems to say how they would like to be treated should they be unable to make decisions for themselves. Advance directives give people the opportunity to state what treatments they would or would not like in the future. This can include the appointment of a trusted person to make treatment decisions on your behalf should you be unable to do so. Research in other countries has looked at service user preferences for advance directives sometimes called psychiatric advance directives. This study examines the views of Irish services users towards advance directives.

**Taking part-what it involves**

**Do I have to take part?**
Participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. Please find enclosed an information sheet for you to keep. If you do decide to take part you will be asked to sign a consent form and return it separately to the questionnaire to protect your identity. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

**What will happen to me if I take part?**
By participating in the study you will be asked to complete a questionnaire which will take approximately 30 minutes to complete. A smaller number of participants will be invited to attend follow up interviews should they be interested in doing so. The questionnaire will be pilot-tested among a smaller number of participants. You will be asked some questions on your familiarity with advance directives, participation in treatment care planning, mental health treatment choices, your past experience of mental health treatment, your preferences for implementing advance directives, how you think they might affect service users and personal information. You
do not have to give your name or address at any stage in the questionnaire unless you are interested in participating in a follow up interview.

**How long will my part of the study last?**
You will have 2 weeks in which to decide whether to participate in the study. Any questions regarding the questionnaire or the research can be directed to the researcher.

**What are the possible benefits of taking part?**
By participating you can help people with mental health problems have more say in the management of their treatment and their lives. Advance directives can potentially reduce the need for hospitalisation and involuntary treatment by allowing people to manage their mental health treatment in advance. The study on advance directives can help improve management of mental health crises, relationships between service users and psychiatrists and patient services. By participating in the study, you will be helping policy makers make important decisions in relation to mental health treatment. You will also be contributing to a change in how people think of mental health problems and how they are treated in Ireland.

**What are the possible disadvantages and risks of taking part?**
While participation in this study does not carry any obvious or serious risks, the study includes a questionnaire which measures your experience of mental health treatment in the past. You might find, while you are answering it, that you would like to talk to someone about some of the issues it raises. We will be happy to recommend someone to you.

**What happens at the end of the study?**
At the end of the study, the results of the postal questionnaire will be analysed and discussed as part of a doctoral thesis and published in relevant Irish publications. A similar study will also be carried on consultant psychiatrists’ views of advance directives.

**What happens if I change my mind during the study?**
You can change your mind about participating at any time during the course of the study without disadvantage or penalty to yourself.
Whom do I contact for more information or if I have further concerns?
You can contact the principal investigator, Fiona Morrissey if you need any further information or have any concerns. Email: f.morrissey1@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact ‘the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

Confidentiality
You will never need to indicate your name in this questionnaire as all information is anonymous. No information concerning your responses will be disclosed at any time to anyone except the principal researcher. The answers to the survey will be stored securely in a locked cabinet in the School of Law at NUI Galway. All information that is collected about you during the course of the research will be kept strictly confidential and will not be shared with anyone else. The information collected in this research study will be stored in a way that protects your identity. Results from the study will be reported as group data and will not identify you in any way. Consent forms will be returned separately to the questionnaire to protect your identity.

Summary
You can contact the researchers to clarify any points on which you remain unclear. You are free to refuse to take part in the study or withdraw at any time without any disadvantage.
Principal Investigator: Fiona Morrissey
Address: c/o Mary Keys, School of Law, NUI Galway
Email: f.morrissey1@nuigalway.ie

Thank you for participating in this study!
You will be given a copy of this information sheet and a signed consent form to keep.
CONSENT FORM-SERVICE USERS

Title of Project:
Advance directives in mental health care: the views of Irish service users

Name of Researcher: Fiona Morrissey, NUI Galway

Please initial box

1. I confirm that I have read the information sheet dated.................. for the above study and have had the opportunity to ask questions

2. I am satisfied that I understand the information provided and have had enough time to consider the information

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal-rights being affected

4. I agree to take part in the above study
   If you don’t want to provide your full name, you can sign your initials below

   Name of Participant    Date    Signature

   Researcher            Date    Signature

If returning by post, please put in separate SAE to Fiona Morrissey, Rinville East, Oranmore, Freepost, Galway.
Advance Directives in Mental Health Care Questionnaire (Service Users)

* Instructions-please tick one answer per question unless otherwise instructed

Section I-Familiarity & Opinions-In this section, you will be asked some questions about your familiarity with advance directives and your opinions on future mental health treatment.

1. Prior to this questionnaire, how familiar would you say you were with advance directives?

☐ Very familiar with how advance directives work
☐ I would be able to describe advance directives but not how they work
☐ I knew advance directives had something to do with planning for treatment but did not know how they were used
☐ I’ve heard about them but do not know what they are
☐ I’ve never heard of advance directives

If you are familiar with advance directives, how did you hear about them?

______________________________________________________________________

2. Do you think it would be helpful to have your treatment preferences and other life choices stated before you become unwell?

☐ Yes
☐ No
☐ Not sure

3. Do you think you should have the right to make decisions about your future treatment?

☐ Yes
☐ No
☐ Sometimes
☐ Not sure

4. Having read the information sheet on advance directives in mental health care, what do you now understand them to be?

______________________________________________________________________
Section II-Personal Experience-In this section, you will be asked about your personal experience and involvement in your mental health treatment.

1. How satisfied or dissatisfied are you with your involvement in planning for future treatment?
   - [ ] Very satisfied
   - [ ] Somewhat satisfied
   - [ ] Neither satisfied or dissatisfied
   - [ ] Somewhat dissatisfied
   - [ ] Very dissatisfied

2. Do you feel your psychiatrist listens to your treatment wishes or has done so in the past?
   - [ ] Yes
   - [ ] No
   - [ ] Not sure

3. Do you feel you have a choice regarding your future treatment?
   - [ ] Yes
   - [ ] No
   - [ ] Not sure

4. Have you ever expressed your future treatment preferences to your treating psychiatrist or other member of your treatment team? **Skip Q.5 if answer is No**
   - [ ] Yes
   - [ ] No
   - [ ] Not sure

5. If you did, were you given the treatment you preferred when you became unwell?
   - [ ] Yes
   - [ ] No
   - [ ] Not sure
6. Do you have a WRAP (Wellness Recovery Action Plan)?

A WRAP plan is a programme designed by you to help you manage your mental wellness and recovery. It includes a crisis plan (similar to an Advance Directive) that lets others know how you want them to respond when you cannot make decisions for yourself.

☐ Yes
☐ No
☐ Never heard of a WRAP plan

7. Would you be interested in having an advance directive included in a WRAP crisis plan? Please see previous question for explanation of WRAP crisis plan.

☐ Yes
☐ No
☐ Not sure

8. How many times have you been hospitalised due to mental unwellness?

☐ More than 5 times
☐ 4-5 times
☐ 2-3 times
☐ Once
☐ Never

9. Have you ever been held against your will or without your consent under the Mental Health Act?

☐ Yes
☐ No
☐ Not sure

Please skip next two questions (Q. 10 & Q.11) if answer to above is No.
10. If you were held against your will or without your consent, which Mental Health Act were you treated under?

☐ Mental Health Act, 2001

☐ Mental Treatment Act, 1945

☐ Both Acts

☐ Not sure

11. If you were treated against your will or without your consent while you were an involuntary patient, what type of treatment did you receive?

☐ ECT

☐ Medication

☐ Seclusion

☐ Psychotherapy

☐ Other. Please specify__________________________

☐ Not sure

12. How much control do you feel you have over your treatment when you are unwell and are being treated by the mental health services?

☐ Very in control

☐ Somewhat in control

☐ Neither

☐ Somewhat lacking in control

☐ Not in control at all

13. Do you feel confident enough to manage your mental health?

☐ Yes

☐ No

☐ Not sure
Section III-Preferences for Implementation-In this section, you will be asked what you would like to see included in any form of advance directive introduced in Ireland

1. What information might you like to include in an advance directive? **Tick as many boxes as you wish**

   - Treatment preferences
   - Medication preferences
   - Preferences to be treated or not treated with ECT (Electroconvulsive Therapy)
   - Counselling therapies
   - Place of treatment
   - Life management choices e.g. household finances, childcare.
   - Other____________________

2. Which of the following would you like to use an advance directive for prior to a mental health crisis? **Tick as many boxes as you wish**

   - Opt into certain treatments/medications
   - Accept all treatments/medications
   - Refuse certain treatments/medications
   - Refuse all treatments/medications
   - Treatments/medications agreed between you and your treating psychiatrist
   - Other. Please specify______________________________
   - I would not use an advance directive

3. Would you like to see some form of advance directive that stops you being treated with ECT even if you are admitted to hospital involuntarily in the future?

   - Yes
   - No
   - Not sure
4. Would you like to see some form of advance directive that allows you to opt into future ECT treatment?

☐ Yes
☐ No
☐ Not sure

5. Would you like somebody to communicate your wishes as outlined in your advance directive when you are unwell?

☐ Yes
☐ No
☐ Not sure

If yes, who would you like to communicate on your behalf_______________________________

6. Which of the following people would you like to help you draw up your advance directive? **Tick as many boxes as you wish**

☐ Treating psychiatrist
☐ Independent psychiatrist
☐ Other mental health professional e.g. social worker, nurse, counsellor
☐ Other medical professional e.g. GP
☐ Legal professional
☐ Peer advocate
☐ Family member/ trusted friend
☐ Drawn up by yourself without help
☐ Other. Please specify__________________________________________
7. Who should decide whether you are well enough to make decisions by yourself for an advance directive? An advance directive is made when you are well and activated when you are unwell.

- [ ] Treating psychiatrist
- [ ] Independent psychiatrist
- [ ] Other mental health professional e.g. social worker, nurse, counsellor
- [ ] Other medical professional e.g. GP
- [ ] Multidisciplinary team i.e. combination of people from different backgrounds
- [ ] Legal professional
- [ ] Family member/trusted friend
- [ ] Other. Please specify___________________________

8. Do you think an advance directive will help your family/carers know what you want?

- [ ] Yes
- [ ] No
- [ ] Not sure

9. Do you think an advance directive should be taken into account by a Mental Health Tribunal when making a decision?

- [ ] Yes
- [ ] No
- [ ] Not sure
10. Which of the following issues might discourage you from making an advance directive?  

**Tick as many boxes as you wish**

- Don’t understand enough about advance directives
- Not knowing what to say or write in the document
- Difficulty getting somebody you trust to communicate on your behalf
- Difficulty getting somebody you trust to help you complete it
- Having to get information from your treating doctor as to what to include
- Not understanding the legal implications of an advance directive
- The potential for my wishes to be ignored or overridden by medical staff
- Having to reflect on your experience of mental illness
- Risk of having changed my mind since I made the advance directive
- The time and trouble it takes to draft an advance directive

11. To what extent would you like to be treated in accordance with advance directive wishes?  

**Tick as many boxes as you wish**

- Followed when I am unwell and allowing me to change my mind when I’m well
- Followed regardless of the wishes of my treating doctor or family
- Used as a reference without a legal right to respect for my wishes
- Followed as much as possible but allowing me to change my mind even if I am unwell
- Not sure
12. How often would you like to review your advance directive so that you can make changes?

- [ ] After each episode of mental unwellness
- [ ] Every 6 months
- [ ] Every 12 months
- [ ] Every 2 years
- [ ] Every 3 years or more
- [ ] Not sure

13. Do you think you should have a legal right to have your advance directive wishes respected? Advance directives can be made available without a legal right to have your wishes respected.

- [ ] Yes
- [ ] No
- [ ] Not sure
Section IV - Perceived Impact - In this section, you will be asked about what might encourage or discourage you from making an advance directive and their impact on you.

1. Which of the following factors might encourage you to make an advance directive? 
   Tick as many boxes as you wish

   - More control over my future treatment
   - Plan for future periods when my ability to make decisions may be impaired
   - Improve my future treatment experiences
   - Provide information to treating doctors on my treatment history
   - Reduce the need for hospitalisation
   - Reduce the need for involuntary treatment against my will or without my consent
   - Help me reflect on past mental health experiences
   - Previous negative experiences with hospitalisation and medication
   - Enhance my relationship with my treating doctors
   - Provide a forum where my wishes can be listened to

2. Do you think the process of making an advance directive will improve or disimprove your relationship with your treating psychiatrist?

   - Improve
   - Disimprove
   - Neither improve nor disimprove
   - Not sure

3. Do you think an advance directive could help in your recovery? e.g. prevent future mental health crises or help you recover from mental unwellness.

   - Yes
   - No
   - Not sure
4. How do you think developing an advance directive may impact on your self-esteem?

- Improve self esteem
- Dis-improve self esteem
- Neither improve nor disimprove
- Not sure

5. Do you think you would be more willing to adhere to treatment if you had an advance directive?

- Yes
- No
- Not sure

6. How helpful or unhelpful do you think an advance directive would be during a future mental health crisis?

- Extremely helpful
- Somewhat helpful
- Don’t know
- Somewhat unhelpful
- Not helpful at all

Please specify why you think an advance directive may be helpful or unhelpful to you?

7. Would you consider making an advance directive should they become legally available in Ireland?

- Yes
- No
- Not sure
Section V-Personal Demographics

1. Age
   - ☐ 18-30
   - ☐ 31-40
   - ☐ 41-50
   - ☐ 51-60
   - ☐ 61 or over

2. Gender
   - ☐ Male
   - ☐ Female

3. Is your main place of residence?
   - ☐ Urban
   - ☐ Rural

4. Relationship Status
   - ☐ Single
   - ☐ Married
   - ☐ Cohabiting
   - ☐ Separated
   - ☐ Divorced
5. Educational Attainment

☐ Primary level

☐ Secondary level-Junior Certificate or equivalent

☐ Secondary level-Leaving Certificate or equivalent

☐ Third level certificate/diploma

☐ Third level degree

☐ Third level post graduate

6. How long have you been a user of mental health services?

☐ Less than 1 year

☐ 1-2 years

☐ 3-5 years

☐ 6-10 years

☐ More than 10 years

7. Have you ever received a diagnosis or misdiagnosis for any of the following?

☐ Depressive disorder

☐ Anxiety disorder

☐ Bipolar affective disorder

☐ Schizophrenic disorder

☐ Eating disorder

☐ Other. Please specify_______________________
8. Where have you been mainly treated?

☐ Public mental health services

☐ Private mental health services

9. In which HSE region are you located?

☐ Dublin Mid Leinster

☐ Dublin North East

☐ South

☐ West

Section VI-Comments

1. Any other comments you may have on the introduction of advance directives in the mental health context and their potential impact on you?

If you are interested in participating in a possible follow up interview in the future, please include your contact details below when returning the form.
Dear Dr.

I will be writing to you in the coming weeks inviting you to complete a postal questionnaire exploring the introduction of **Advance Directives in Irish Mental Health Care.** The research is being conducted through the School of Law at **NUI Galway** & is partially funded by the **Mental Health Commission.** The questionnaire seeks to understand your views and preferences as a consultant psychiatrist towards advance directives in mental health care.

Advance directives are statements which allow capable individuals to plan their treatment preferences or other life choices in advance of a mental health crisis. High readmission rates warrant the consideration of measures which have the potential to reduce the need for hospitalisation and involuntary treatment. Previous research suggests advance directives can help promote empowerment, sustain treatment engagement, reduce the need for coercion and provide other therapeutic benefits. While advance directives are used in a number of other countries, (Scotland, Canada, United States, New Zealand) their legal status is currently uncertain in Ireland. The review of the Mental Health Act, 2001, the enactment of new capacity legislation and the ratification of the UN Convention for the Rights of Persons with Disabilities provides an opportune time for their consideration. Research in other jurisdictions has examined psychiatrists’ preferences in this area so it is important to consider them from an Irish perspective. It is crucial that your preferences are considered in any developments.

Your input is greatly appreciated
Yours sincerely

Fiona Morrissey B.A., LL.B., LL.M., DLIS
PhD Candidate
School of Law, NUI Galway
Email: f.morrissey1@nuigalway.ie
Tel: 087 9955582
Dear Dr.
I wrote to you recently inviting you to complete a postal questionnaire exploring the introduction of Advance Directives in Irish Mental Health Care. The research is being conducted through the School of Law at NUI Galway & is partially funded by the Mental Health Commission. Please ignore this letter if you have already returned a completed questionnaire.

The questionnaire seeks to understand your views and preferences as a consultant psychiatrist towards advance directives in mental health care. Research in other jurisdictions has examined psychiatrists’ preferences in this area so it is important to consider them from an Irish perspective. It is crucial that your preferences are considered in any future developments.

The closing date for receipt of completed questionnaires is the 6th April 2012. Participants who return by the above date will be entered into a draw for a further 5 book vouchers to the value of €40. If you wish to be entered into draw, please send your details on the consent form provided. Questionnaires should be returned to the above address in the stamped address envelope provided.

If you have any further queries or need an additional copy of the questionnaire, please do not hesitate to contact me.

Your input is greatly appreciated
Yours sincerely

Fiona Morrissey B.A., LL.B., LL.M., DLIS
PhD Candidate
School of Law, NUI Galway
Email: f.morrissey1@nuigalway.ie
Tel: 087 9955582
Study/Questionnaire Title: The proposed use of advance directives in Irish mental health care: the views of consultant psychiatrists.

Definition: An advance directive is a statement of a person’s preferences for treatment, should he or she lose capacity to make treatment decisions in the future.¹

Study Investigators: The study is being undertaken by Fiona Morrissey as part of a doctoral thesis on advance mental health directives under the supervision of Dr. Mary Keys at the School of Law, NUI Galway.

Objective: The aim of this study is to assess the knowledge, attitudes and perceptions of psychiatrists toward the proposed use of advance mental health directives in Ireland. While a number of studies have explored the attitudes of psychiatrists and mental health professionals towards psychiatric advance directives in other jurisdictions², similar research has yet to be conducted in Ireland. The generalisability of research on attitudes of service users and psychiatrists from other jurisdictions is useful but limited by its context. It is therefore necessary to explore the feasibility of implementing advance mental health directives from an Irish perspective.

**Invitation to take part in the study**
You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. The participant information sheet will tell you about the purpose, risks and benefits of this research study. If you do decide to take part, we will ask you to sign a consent form. If there is anything that you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

**Purpose of the Study**
The objectives of the study are to

- To assess knowledge, attitudes and perceptions of Irish psychiatrists towards the use of advance mental health directives.
- To assess whether Irish psychiatrists are willing to start using advance mental health directives.
- To identify predictive factors of psychiatrists familiarity and willingness to use advance mental health directives.
- To identify barriers that psychiatrists may see to using advance mental health directives in Ireland.

**Taking part—what it involves**

**Do I have to take part?**
Participation in this study is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign an online consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

**What will happen to me if I take part?**
By participating in the study you will be asked to complete an online web questionnaire which will take approximately 30 minutes to complete. A questionnaire has been pilot-tested among a smaller number of participants. You will be asked questions pertaining to your familiarity and views on advance mental health directives, consent to medical treatment, treatment and care planning, the perceived impact on patients and psychiatrists, your preferences for implementation and professional demographic information. A similar study will explore the attitudes of service users towards advance mental health directives.
**How long will my part of the study last?**
Your participation in the research will be for the duration of time it takes to complete the online questionnaire and submit it. Any questions regarding the questionnaire or the research can be directed to the principal investigator during this period. Participants will be given a period of one month to return the questionnaire.

**What are the possible benefits of taking part?**
High readmission rates for people with mental illness warrants the consideration of measures which have the potential to improve adherence to medication and reduce the need for hospitalisation and involuntary treatment. The importance of this research is to improve management of mental health crises, to improve the therapeutic relationship between patients and clinicians and to align legal and mental health policies in a manner that improves patient services through advance treatment planning. The study will inform legal and policy makers in future decision making when contemplating capacity, consent and advance decision making laws as they relate to treatment of mental illness.

**What are the possible disadvantages and risks of taking part?**
Participation in this study does not carry any obvious or serious risks.

**What happens at the end of the study?**
At the end of the study, the results of the web questionnaire will be analysed and discussed as part of a doctoral thesis and published in relevant publications.

**What happens if I change my mind during the study?**
You can change your mind about participating at any time during the course of the study without disadvantage or penalty to yourself.

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What if I have a complaint during my participation in the study?
Any complaints can be referred to the Chairperson of the Research Ethics Committee, Office for the Vice President for Research at NUI Galway.

Whom do I contact for more information or if I have further concerns?
You can contact the principal investigator, Fiona Morrissey if you need any further information or have any concerns.
Email: f.morrissey1@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact ‘the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

Confidentiality
You will never need to indicate your name in this questionnaire as all information is anonymous. No information concerning your responses will be disclosed at any time to anyone except the principal researcher. The answers to the survey will be stored securely on a PC with password protection and only accessible to the researcher. Your identity will be anonymised in all data.
All information that is collected about you during the course of the research will be kept strictly confidential and will not be shared with anyone else. The information collected in this research study will be stored in a way that protects your identity. Results from the study will be reported as group data and will not identify you in any way.

Summary
You can contact the researchers to clarify any points on which you remain unclear. You are free to refuse to take part in the study or withdraw at any time without any disadvantage.
Principal Investigator: Fiona Morrissey; c/o Mary Keys, School of Law, NUI Galway

Email: f.morrissey1@nuigalway.ie Thank you for participating in this study!
CONSENT FORM-CONSULTANT PSYCHIATRISTS

Title of Project:
Advance Directives in Irish Mental Health Care: the Views and Preferences of Consultant Psychiatrists

Name of Researcher: Fiona Morrissey, NUI Galway

Please initial box

1. I confirm that I have read the information sheet dated______________ for the above study.

2. I am satisfied that I understand the information provided and have had enough time to consider the information

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal-rights being affected

4. I agree to take part in the above study

Name of Participant Date Signature

Researcher Date Signature
Advance Directives in Mental Health Care Questionnaire
(Consultant Psychiatrists)

*Please tick one answer per question unless otherwise instructed.

Section I-Familiarity & Opinions-In this section, you will be asked some questions about your familiarity with advance directives (ADs) and planning for future mental health treatment.

1. Prior to this questionnaire, how familiar were you with advance directives in mental health care?

☐ Very familiar about how advance directives work
☐ I would be able to describe advance directives but not how they work
☐ I knew advance directives had something to do with planning for treatment but did not know how they are used
☐ I’ve heard about them but do not know what they are
☐ I’ve never heard of advance directives

If you are familiar with advance directives, how did you hear about them?
____________________________________________________________________

2. Do you think it would be helpful for your patients to have their treatment preferences or other life choices stated in advance of a mental health crisis?

☐ Yes
☐ No
☐ Not sure
3. How important or unimportant do you think patient involvement is in planning for future mental health treatment?

☐ Very important
☐ Somewhat important
☐ Neither important or unimportant
☐ Somewhat unimportant
☐ Not important at all

4. How satisfied or dissatisfied are you with current patient involvement in planning for future treatment?

☐ Very satisfied
☐ Somewhat satisfied
☐ Neither satisfied or dissatisfied
☐ Somewhat dissatisfied
☐ Very dissatisfied

5. Have any of your patients expressed future treatment preferences to you informally?

☐ Yes
☐ No
☐ Not sure

6. **Skip if answer to last question is No.** If they did, were you able to comply with their treatment wishes when they became unwell?

☐ Yes
☐ No
☐ Sometimes
7. Do any of your patients have a WRAP (Wellness Recovery Action Plan) plan?
A WRAP plan is a programme designed to help people manage their mental health and recovery. It includes a crisis plan (similar to AD) which lets others know how to respond during a crisis.

☐ Yes
☐ No
☐ Not sure

8. **Skip if you haven’t used ADs.** If you have used any form of advance directive, what did you find useful/not useful?

---------------

**Section II-Preferences for Implementation**

1. What information would you like to see included in an advance directive? **Tick as many boxes as you wish**

☐ Treatment/medication preferences
☐ Place of treatment
☐ Life management choices e.g. household finances, childcare
☐ Other_________________________________________

2. Would you like to see some form of advance directive which allows patients to agree to future treatment with ECT?

☐ Yes
☐ No
☐ Not sure
3. Would you like to see some form of advance directive which allows patients to refuse future treatment with ECT even if they are detained involuntarily in the future?
   - Yes
   - No
   - Not sure

4. Would you be more likely to follow an advance directive if someone is appointed to communicate the patient’s wishes when they are unwell?
   - Yes
   - No
   - Not sure

5. Who should help a patient draw up and document an advance directive? Tick as you wish
   - Treating psychiatrist
   - Independent psychiatrist
   - Other mental health professional e.g. social worker, nurse
   - Other medical professional e.g. GP
   - Legal professional
   - Peer advocate
   - Family member/friend
   - Other. Please specify_______________________________________________________
6. Do you think an advance directive is something that should be taken into account by a Mental Health Tribunal when making a decision?

☐ Yes
☐ No
☐ Not sure

7. Which of the following do you think might impede the use of advance directives in Irish mental health care? Please tick as many boxes as you wish

☐ Quality of the information in the directive e.g. vague instructions
☐ Patient’s desire to change the contents of a directive during a crisis
☐ Inappropriate treatment requests
☐ Risk of violence from treatment refusal
☐ Lack of time to review advance directive document
☐ Limited communication between staff
☐ Inaccessibility of advance directive document
☐ Lack of staff training/knowledge about how they should be handled
☐ Lack of resources to support advance directives e.g. staffing
☐ Other. Please specify_______________________________________________________
8. Which of the following factors would you consider in deciding whether to follow a patient’s preferred choice of treatment? Please tick as many boxes as you wish

- [ ] Family support of patient preferences
- [ ] Insight into illness
- [ ] Therapeutic collaboration between patient and treating psychiatrist
- [ ] Current cognitive functioning
- [ ] History of psychosis
- [ ] Suicide attempts
- [ ] Risk of violence
- [ ] Non adherence to treatment
- [ ] Respect for patient autonomy
- [ ] Decreased coercion
- [ ] Decreased stigmatisation
- [ ] Legal liability
- [ ] Other ________________________________

9. How often do you think an advance directive should be reviewed to make changes?

- [ ] After each acute mental health episode
- [ ] Every 6 months
- [ ] Every 12 months
- [ ] Every 2 years or more
- [ ] On patient request
- [ ] Not sure
III- Capacity & Legal Factors - The law generally does not require a clinician to follow an advance directive when it is considered inconsistent with clinical standards or where a person is detained under mental health legislation. In some instances, advance directives are legally binding or enforceable while in others they are accorded the status of non-binding advance statements and given consideration. Decision-making capacity is pivotal to executing, invoking and revoking advance directives. The proposed Scheme of the Mental Capacity Bill 2008 provides for an enduring power of attorney for healthcare which enables a capable person to delegate decision-making powers to an appointed person during periods when autonomy may be impacted. The UN Convention on the Rights of Persons with Disabilities (CRPD) provides for supported decision-making for persons with mental health disabilities and is due for ratification by Ireland in the future. In this section, you will be asked some questions on capacity.

1. Who do you think should determine decision-making capacity for the purpose of executing, invoking and revoking an advance directive?

- [ ] Treating psychiatrist
- [ ] Independent psychiatrist
- [ ] Other mental health professional e.g. social worker, nurse, counsellor
- [ ] Medical practitioner e.g. GP
- [ ] Multidisciplinary team i.e. combination of people from different backgrounds
- [ ] Legal Professional
- [ ] Family member
- [ ] Other. Please specify___________________________

2. Do you think your patients should have a right to make decisions about future treatment when they have the decision-making capacity to do so?

- [ ] Yes
- [ ] No
- [ ] Sometimes
- [ ] Not sure
3. How satisfied or dissatisfied are you with the provisions of the proposed Scheme of the Mental Capacity Bill 2008 for people with mental health conditions?

☐ Very satisfied
☐ Somewhat satisfied
☐ Neither satisfied nor dissatisfied
☐ Somewhat dissatisfied
☐ Very dissatisfied
☐ N/A

4. Do you approve or disapprove of the enduring power of attorney for mental health decisions?

Please see start of section for explanation.

☐ Approve
☐ Disapprove
☐ Not sure

5. How familiar are you with the UN Convention on the Rights of Persons with Disabilities?

☐ Very familiar
☐ Somewhat familiar
☐ Neither familiar or unfamiliar
☐ Somewhat unfamiliar
☐ Not familiar at all
6. Which of the following do you think should be a component of advance directives in the Irish mental health context? Please tick as many boxes as you wish.

- Co-operative arrangement between patient and treating psychiatrist
- Patient initiated advance directive
- Legally binding opting into certain treatments/medications
- Legally binding opting out of certain treatments/medications
- Non-legally binding opting into certain treatments/medications
- Non-legally binding opting out of certain treatments/medications
- Non-legally binding component of a treatment plan or Wellness Recovery Action Plan (WRAP) crisis plan
- Other. Please specify__________________________________________

7. Do you think advance directives should be made available under the Irish legal framework?
- Yes
- No
- Not sure

8. If yes to the above, where would you like to see them provided for?
- Mental Health Legislation
- Capacity Legislation
- Not sure
- N/A

9. Do you think minors between 16 to 18 years should be allowed to develop advance directives?
- Yes
- No
- Not sure
Section IV-Perceived Impact- In this section, you will be asked a number of questions in relation to the perceived impact of advance directives.

1. Do you think the process of making an advance directive will improve or disimprove your relationship with your patients?
   - [ ] Improve
   - [ ] Neither improve nor disimprove
   - [ ] Disimprove
   - [ ] Not sure

2. How important or unimportant is consultation with the treating psychiatrist when drawing up an advance directive?
   - [ ] Extremely important
   - [ ] Somewhat important
   - [ ] Neither important or unimportant
   - [ ] Somewhat unimportant
   - [ ] Not important at all

3. How concerned are you that some patients may refuse all treatments?
   - [ ] Extremely concerned
   - [ ] Somewhat concerned
   - [ ] Neither concerned or unconcerned
   - [ ] Slightly unconcerned
   - [ ] Not concerned at all
4. How concerned are you with leaving a patient untreated?
   - [ ] Extremely concerned
   - [ ] Somewhat concerned
   - [ ] Neither concerned or unconcerned
   - [ ] Slightly unconcerned
   - [ ] Not concerned at all

5. Do you think advance directives will undermine the clinical judgment of psychiatrists?
   - [ ] Yes
   - [ ] No
   - [ ] Not sure

6. Do you think you should be permitted to disregard instructions in an advance directive if evidence reveals better treatment exists?
   - [ ] Yes
   - [ ] No
   - [ ] Not sure

7. How do you think advance directives will impact on the decision making burden of family members/carers?
   - [ ] Increase significantly
   - [ ] Somewhat increase
   - [ ] Neither increase nor decrease
   - [ ] Somewhat decrease
   - [ ] Decrease significantly
8. Do you think the process of creating an advance directive might have a therapeutic value for individuals with mental health conditions?

☐ Yes
☐ No
☐ Not sure

9. Do you think advance directives will increase or decrease the need for involuntary treatment?

☐ Increase significantly
☐ Somewhat increase
☐ Neither increase nor decrease
☐ Somewhat decrease
☐ Decrease significantly

10. Do you think an advance directive could assist in the recovery process? e.g. prevent future mental health crises or help recovery from crises.

☐ Yes
☐ No
☐ Not sure
11. Which of the following possible implications might motivate you to use advance directives in clinical practice? **Tick as many boxes as you wish.**

- [ ] Plan for future periods when decision-making autonomy may be impacted
- [ ] Improve future treatment experiences
- [ ] Increase adherence to medication
- [ ] Reduce the need for hospitalisation
- [ ] Reduce the need for involuntary treatment
- [ ] Reduce economic costs
- [ ] Increase patient control over treatment
- [ ] Enhance therapeutic relationship
- [ ] Provide information on treatment history
- [ ] Improve quality of treatment decisions
- [ ] Provide forum for dialogue and reflection on past experience

12. Do you think any particular patient group might benefit from developing an advance directive?

- [ ] Yes
  
  Please specify________________________________________________

- [ ] No
  
  ______________________________________________________________

- [ ] Not sure
  
  ______________________________________________________________
13. How helpful or unhelpful do you think advance directives would be to you in clinical practice?

☐ Extremely helpful
☐ Somewhat helpful
☐ Neither
☐ Somewhat unhelpful
☐ Not helpful at all

Please specify why you think an advance directive may be helpful or unhelpful to you?

14. Would you be willing to start using advance directives in your practice?

☐ Very willing
☐ Somewhat willing
☐ Neither willing or unwilling
☐ Somewhat unwilling
☐ Not willing at all

Please comment on why you may be willing or unwilling to use advance directives?
Section V-Personal Demographics

1. Age

☐ 21-30
☐ 31-40
☐ 41-50
☐ 51-60
☐ Over 61

2. Gender

☐ Male
☐ Female

3. How long are you working in clinical practice?

☐ Less than 1 year
☐ 2-5 years
☐ 6-10 years
☐ 11-30 years
☐ More than 30 years

4. In which sector are you primarily working?

☐ Public sector
☐ Private sector

5. Have you worked in any jurisdiction with provision for advance directives in mental health care?

☐ Yes  Please specify______________________________
☐ No
☐ Not sure
6. Speciality

- General adult
- Liaison
- Elderly
- Addiction
- Forensics
- Learning disability
- Rehabilitation
- Other. Please specify_________________________________________

Section VI: Comments

1. Please include any other comments you may wish to include in relation to the possible introduction of advance directives in Irish mental health care below.

Please return questionnaires and consent forms in the freepost envelopes provided by the 16th of March 2012.
The first 10 fully completed questionnaires received will qualify for a book voucher to the value of €40. If you wish to qualify for the book voucher, please include your contact details in a separate freepost envelope with the consent form. Thank you for your participation.
Appendix C
Research Award (NUI Travelling Studentship) and Funding (Mental Health Commission)
National University of Ireland

This is to certify that, in 2011

Fiona Morrissey

National University of Ireland, Galway

was awarded the
Travelling Studentship in Law

[Signature]
Chancellor
November 2011
Memorandum of Agreement
between the
Mental Health Commission
and
Fiona Morrissey
July 2011
1. Parties

1.1 This Memorandum of Agreement is made between the Mental Health Commission and Ms. Fiona Morrissey.

1.2 The Chief Executive Officer of the Mental Health Commission, Ms. Patricia Gilheaney and Ms. Fiona Morrissey will have responsibility for ensuring compliance with this agreement.

2. Scope and Purpose

2.1 This Memorandum of Agreement outlines the basis of co-operation and collaboration between the Mental Health Commission and Ms. Fiona Morrissey.

3. Context in which this Memorandum of Agreement is made

3.1 Ms. Fiona Morrissey submitted a proposal for part support of a project entitled ‘The Introduction of a Legal Framework for Advance Directives in Ireland’ (See Appendix 1 attached).

3.2 The budget proposal submitted to the Commission from Ms. Morrissey of €6,000 which covers costs associated with the following:

- Costs for Postal Survey: €1,650
- Training Costs: €1,350
- Service User Survey & Interview Costs: €2,000
- Meeting Room Costs etc: €1,000

TOTAL: €6,000

Full details and costings in Appendix 1 attached.

3.3 Details of the project were submitted to the Mental Health Commission through Ms. Morrissey’s Academic Supervisor Dr. Mary Keys and subsequently reviewed by Dr. Fiona Keogh, Research Consultant, following some suggested amendments it was agreed to support the project as outlined in the updated proposal.

3.4 Schedule of payments:

July 2011: €6,000
4. Project Duration

4.1 The full study will take place in 2011/2012 for both service users and psychiatrists. It is envisaged that the surveys will be completed by year end 2013. The funding contribution made by the Commission represents a percentage of the overall costs associated with the study.

5. Governance

5.1 Ethical Approval

Ethical approval for the study was received by the Research Ethics Committee at NUI Galway. Full details are provided in the attached submission.

5.2 Data Protection

Ms. Fiona Morrissey shall adhere to the rules prescribed under the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003 and shall ensure that data is processed fairly.

5.3 Confidentiality

Ms. Fiona Morrissey agrees that data will be exchanged via agreed channels to specified contacts and shall be appropriately processed in a manner that ensures confidentiality.

6. Dispute Resolution

All disputes or differences arising between the parties in connection with this Agreement shall be referred to a single arbitrator to be appointed by the parties, or in the event of the parties failing to agree on the choice of a single arbitrator by an arbitrator to be appointed on the request of either party by the President for the time being of the Incorporated Law Society of Ireland.
Signed on behalf of the Mental Health Commission

Position

Date

Position

Date

Signature of Ms. Fiona Morrissey

Position

Date
Appendix D

Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013
Public Consultation Document
Public Consultation

Draft General Scheme for Advance Healthcare Directives for Incorporation into the *Assisted Decision-Making (Capacity) Bill 2013*

Overview

This consultation document relates to new legislative provisions for advance healthcare directives which will be incorporated into the *Assisted Decision-Making (Capacity) Bill 2013*.

An advance healthcare directive (also referred to as a living will) is a statement made by a person with capacity setting out his/her will and preferences regarding treatment decisions that may arise in the future in the event that he or she lacks the capacity to provide consent to or to refuse those treatments. For an advance healthcare directive to be considered legally-binding the directive must be made by an adult (18 years or over) who has capacity and must be made in writing and be witnessed. These directives represent an important means by which people can exercise their autonomy, which is an integral component of a patient-focused model of healthcare.

In line with the principles of non-discrimination and equality before the law, as outlined in the UN *Convention on the Rights of Persons with Disabilities*, the legislative provisions for advance healthcare directives provide a single legislative framework, which encompasses both general healthcare and mental healthcare. Incorporating provisions for advance healthcare directives into the *Assisted Decision-Making (Capacity) Bill 2013* represents an efficient and practical method of consolidating the law in this area.

These instruments predominantly relate to refusals of treatment up to and including life-sustaining treatments. The provisions of the draft General Scheme do not in any way pertain to euthanasia or assisted suicide. Given that a treatment refusal in an advance healthcare directive is intended to be legally-binding, it is essential that the directive state in clear and unambiguous terms the specific treatments to which the refusal(s) relates and also the situations in which the treatment refusal(s) is intended to apply.

An individual’s will and preferences can encompass both treatment refusals and treatment requests. However, accommodating treatment requests requires a balance to be struck between the wishes of the individual on one hand and the demand and opportunity cost this would place on healthcare resources, which would no longer be available to another patient. Therefore, requests for treatment outlined in an advance healthcare directive should be taken into consideration during the decision-making process but cannot be legally-binding.

The draft provisions enable an individual to appoint another person (called the patient-designated healthcare representative) to make treatment decisions on his/her behalf or to interpret the terms of his/her advance healthcare directive. In such instances the representative would be able to discuss the relevant treatment options with the attending healthcare professional at the time the treatment decisions needed to be made.
Outline of Legislative Provisions

The provisions for advance healthcare directives comprise of 9 Heads. The following points from each Head are highlighted due to their importance to the overall understanding of the provisions.

Head 1:
Outlines that the commencement of these provisions will be under the control of the Minister for Health.

Head 2:
Provides a detailed definition of key words and terms used in the provisions, including “advance healthcare directive”, “basic care”, “patient designated healthcare representative”, and “treatment”.

Head 3:
Sets out the purpose of and the principles underpinning these legislative provisions, including: the promotion of individual autonomy and respect for people’s will and preferences; the presumption that an individual has capacity to make an advance healthcare directive; and upholding the right to refuse treatment, including life-sustaining treatment, for any reason even where this refusal could result in death.

Head 4:
Outlines the particular conditions that need to be met for the creation of an advance healthcare directive i.e. an individual must be an adult and must have the capacity to do so. Head 4 also outlines the particular criteria for making a legally-binding refusal of treatment e.g. stating in unambiguous terms the specific treatments to which the refusal relates and also the situations in which the treatment refusal is intended to apply. The provisions state that advance healthcare directives must be documented in writing and witnessed and they allow an individual to revoke or alter his/her advance healthcare directive at any time, provided s/he has the capacity to do so.

Head 5:
Sets out the minimum criteria that need to be fulfilled to ensure the enforceability and effectiveness of an advance healthcare directive, including: that the individual had capacity at the time the directive was made; that the directive was made voluntarily; that the directive had not subsequently been altered or revoked; and that while the individual had capacity s/he did not do anything clearly inconsistent with the terms of his/her directive. The provisions detail the specific limited circumstances in which an advance healthcare directive would not be legally binding, i.e. where an individual’s treatment is regulated under Part 4 of the Mental Health Act (2001) and/or under the Criminal Law (Insanity) Act (2006). Head 5 also outlines the approach to be used when considering the applicability of advance healthcare directives during pregnancy.

Head 6:
Clarifies that a treatment refusal in a valid advance healthcare directive would have the same authority as a contemporaneous refusal by an individual who has capacity. It also provides that healthcare professionals who, acting in good faith, either comply with or fail to comply with the terms of a valid and applicable advance healthcare directive (e.g. because they were unaware of its existence and content) will not incur any civil or criminal liability. Importantly, Head 6 also clarifies that these provisions do not in any way pertain to euthanasia or assisted suicide.
Head 7:
Provides for an individual to appoint a legal representative (i.e. someone the individual trusts, usually a relative or close friend - called a patient-designated healthcare representative) who would be involved in the healthcare decision-making process on that individual’s behalf should s/he subsequently lose capacity. It also outlines the criteria and safeguards regarding who may be nominated as a patient-designated healthcare representative and what decision-making authority s/he may have.

Head 8:
Provides that, where an individual has nominated an attorney using an enduring power of attorney under the Assisted Decision-Making (Capacity) Bill 2013, s/he may confer on that attorney the authority to make personal welfare decisions regarding all forms of treatment including life-sustaining treatment. Head 8 also clarifies the mechanism by which disagreements between an individual’s enduring power of attorney and his/her advance healthcare directive (and/or patient-designated healthcare representative) would be resolved.

Head 9:
Head 9 clarifies that in the case of any doubts or disagreements in relation to the validity and applicability of an advance healthcare directive (for example, in the case of a pregnant woman), application can be made to the courts, with the High Court having the ultimate authority to resolve such cases.

Specific Questions for Consultation
The Department would be interested to hear your general views but would particularly like your views on the following questions:

1. What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?

2. Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed (e.g. every 2 years, every 5 years, every 10 years)?

3. Should a standard format be developed for advance healthcare directives?

4. If a standard format for advance healthcare directives was developed what information should it contain?

5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?
8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?

9. What do you think the role of the patient-designated healthcare representative should be? Should the representative’s role be limited to that of interpreting the individual’s advance healthcare directive? Should the representative have a broader role to advise as to what the individual’s will and preferences regarding treatment are likely to be?

10. What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

11. Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?

How to Respond

Written responses should be sent by e-mail to: advancedirectives@health.gov.ie or posted to: Bioethics Unit, Department of Health, Rm. 8.33, Hawkins House, Hawkins Street, Dublin 2.

Closing date for receipt of responses is: Friday 7th March 2014.

Submissions should be concise, focused and limited to ten pages.

How Your Response will be used

The Department will publish a summary of the submissions received as part of this public consultation on its website. The summary is likely to contain a list of those who have made submissions and may include direct quotes from some submissions. In such cases, it is intended to attribute these quotes to the person or group who made the submission.

If you do not want your submission to be referred to as mentioned in the outline above, please let the Department know at the time of your submission.

All submissions received will be subject to the Freedom of Information Acts 1997 and 2003 and may be released in response to a Freedom of Information request.

Department of Health
February 2014
Appendix E

The NUI Galway Centre for Disability and Law Policy Submission to the Department of Health on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013, 7th March 2014
A Submission to the Department of Health on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013

7th March 2014
1. Introduction

This submission is divided into three parts. The first part provides general guiding principles for formulating advance directives in the era of the UN Convention on the Rights of Persons with Disabilities. The second part responds to the Scheme of heads and identifies areas that may be problematic from a human rights perspective. The third part responds to the specific questions that were raised in the call for submissions. The final part comprises logos of all the organisations that have signed on to the submission.

This submission was developed in consultation with the organisations who have signed up to this submission and whose logos appear on Pages 13 and 14. In developing this submission, we also consulted individuals with lived experience of disability as well as those who have used mental health services, in particular, the Recovery Experts by Experience Group. Fiona Morrissey (PhD Candidate, National University of Ireland, Galway) also contributed significantly to the development of this submission.

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5 Recovery Experts by Experience group were formally known as Experts by Experience Advisory Group under the Amnesty International Mental Health Campaign, see http://www.amnesty.ie/mentalhealth
2. Guiding Principles for formulating advance directives in the era of the UN Convention on the Rights of Persons with Disabilities

1. Everyone (regardless of decision-making ability) has the right to make a (written) advance directive and should be given the opportunity to do so. A choice of instructional, proxy and a combination of both forms of advance directives should be legislated to accommodate various preferences. Support should be provided to complete the advance directive and makers should be encouraged to review advance directives regularly.

2. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person in the text of the directive and should not be based on a medical assessment that the person lacks mental capacity.

3. Once an advance directive has entered into force, third parties should be under a legal obligation to respect them. Advance directives should continue to have effect in situations of involuntary detention.

4. There may be an exception to the obligation to respect an advance directive where there is an imminent threat to the life of the person. ‘Imminent threat to the life of the person’ should be strictly construed and should apply equally in physical and mental healthcare. The refusal of life-sustaining treatment should also be addressed in the legislation. Authorisation to breach an advance directive must be provided by the court and priority should be given to delivering these decisions as quickly as possible, given the urgent nature of the circumstances.

5. The individual can specify what will constitute revocation of an advance directive in the text of the directive (whether revocation must be oral/ or in writing/other).

6. All advance directives can be revoked at any time by the person to whom it pertains – there will be no distinction between advance directives for mental health treatment and advance directives for physical health treatment in this respect. There should be the possibility for all advance healthcare decisions to be integrated.

7. An individual can choose to insert a ‘Ulysses clause’ into their advance directive, stating that their written will and preference as contained in the directive takes precedence over the individual’s own verbally expressed will and preference once the advance directive has entered into force. The Ulysses clause should only be used
by individuals who clearly want their advance directive wishes to stand during specified periods and should be subject to independent execution safeguards to ensure it reflects the will and preference of the person.

8. The same registration criteria would apply to advance directives as to other support agreements (e.g. assistance agreements) under the Bill.

9. Where a person is nominated in the text to ensure that an advance directive is carried out, their duties must be clearly stated in the text of the Bill, and must include a requirement not to exert undue influence on the author of the advance directive. The conflict of interest in relation to healthcare providers acting should be stipulated in the legislation. The legislation should allow one or more nominated persons to be appointed for different decisions.

10. Where a person makes specific positive request(s) in an advance directive (e.g. for a specific type of medication only to be administered or to only be treated in a specific hospital or by a specific doctor) the same standard should be used to decide whether this can be honoured in both physical and mental health care.

11. Clear accountability and monitoring mechanisms should be provided to ensure that advance directives are adhered to. The Mental Health Commission and/or the Office of Public Guardian should have an oversight role in the monitoring of advance directives in the specific context of mental health. There is need for an independant adjudicator, for example an Ombusman, so that people who believe their advance directive was not adhered to, have a point of redress and independent adjudication. This needs to be a body independent of mental health services, or HIQA who do not have a role in considering an individual’s experiences of care.

12. An obligation should be placed on health care providers to find out whether someone has an advance directive before treating them. There should be serious penalties where a health practitioner or any other third party acts against the person’s wishes as stated in an advance directive.

13. There should an online registry of advance directives, accessible to health service providers when needed. However, data protection obligations to respect individuals’ privacy must be met.
14. Court decisions determining whether advance directives are overridden must be published in order to have a body of knowledge, for example to help in defining what constituted a ‘life threatening situation’ or ‘imminent danger’, etc. However, it may be necessary to anonymise the details of the individuals in these cases given the sensitive nature of the issues under discussion.

3. General Response to the Scheme of Heads

The following aspects of the Scheme of Heads raise concerns:

1. **Non recognition of universal legal capacity for all**

The Scheme does not recognize universal legal capacity for all. The possibility of making a binding directive depends on the individual passing the functional test of mental capacity. This approach is in conflict with Article 12 of the UN Convention on the Rights of Persons with Disabilities. Since the publication of the UN Committee on the Rights of Persons with Disabilities’ Draft General Comment on Article 12 in September 2013, it is now clearer than ever before that the Convention prohibits the use of mental capacity as a justification for denying or restricting a person’s legal capacity. As suggested by a coalition of civil society groups in a response to the Bill, everyone should have the right to benefit from the positive, support-oriented provisions of the Assisted Decision-Making (Capacity) Bill 2013. This principle extends to the ability to make a binding advance directive and would suggest that the person’s clear expression of her will and preferences and adherence to the registration and notice provisions of the Scheme should be sufficient to create a binding directive. Otherwise, the dichotomy between capacity and incapacity will continue to prevail, and many of those who wish to make advance directives may not be found ‘capable’ of doing so.7

Head 3 (2)a provides that the presumption of capacity shall exist ‘unless there is evidence to the contrary’. It is not clear what such ‘evidence to the contrary’ might

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be or who would make this determination. The Scheme does not provide further detail on who is responsible for determining whether an individual has sufficient ‘capacity’ to make an advance directive. Ideally, a valid advance directive should not be made on the basis of a person ‘having mental capacity’. An advance healthcare directive should be valid as long as it is made by a person over the age of 18, witnessed by a person who is over 18 years of age, and the witness can demonstrate that they know the person making the directive.

2. **Provisions relating to overriding an advance healthcare directive**

The law should provide that only the court can authorize the overriding of an advance healthcare directive. When an advance healthcare directive is sought to be overridden in a mental health context, a member of the Mental Health Tribunal should be required to meet the person whose directive is sought to be overridden and give evidence to the court. Alternatively, the Office of Public Guardian could develop a panel of experts who have experience in advance planning to give advice to the court as to whether an advance directive, for either physical or mental healthcare decisions, should be upheld. The person whose advance healthcare directive is being sought to be overridden should have an automatic right to legal representation including, where relevant, as should the patient designated healthcare representative. Finally, the party challenging the advance healthcare directive should bear the legal costs of the case.

3. **Applicability of advance directives to the administration of basic care**

The Scheme of Heads provides that advance healthcare directives are not applicable to the administration of basic care. Basic care is described as including warmth, shelter, oral nutrition, oral hydration and hygiene measures. Under current Irish law, an adult with the relevant legal capacity can make a valid contemporaneous refusal of medical treatment.8 The Supreme Court has acknowledged that artificial

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hydration and nutrition constitute medical treatment. Therefore, the legislation on advance directives must clarify that oral hydration and oral nutrition does not include artificial hydration and nutrition – and must ensure that individuals can make valid advance refusals of medical treatment on an equal basis with a valid contemporaneous refusal of treatment.

It is particularly important to ensure that palliative care, where necessary, can be provided, but the definition of basic care should explicitly exclude artificial hydration and nutrition.

Similarly, the general scheme should distinguish between ‘life saving’ treatment and ‘life prolonging’ treatment, and clarify that a valid refusal of ‘life prolonging’ treatment can be made, where the proposed course of treatment meets the definition of ‘medical treatment’.

4. **Implied revocation of advance healthcare directives**

Head 5(1) d provides for implied revocation of an advance directive where the person, ‘while he or she had capacity to do so, has done anything clearly inconsistent with the advance healthcare directive remaining his or her fixed decision’. The implied revocation of advance directives is problematic because it creates the possibility of an advance directive being questioned from a subjective reading of a person’s will and preferences. We recommend that this form part of best practice, i.e that people be encouraged to act consistently with their advance directive or to formally change the directive when it no longer represents their will and preferences.

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9 In Re A Ward of Court (withholding medical treatment (No. 2) (1996) 2 IR 79.
5. **Advance health care directives and Part 4 of the Mental Health Act**

Advance healthcare directives should be legally binding where an individual’s treatment is regulated under Part 4 of the Mental Health Act/where an individual is under involuntary detention and treatment, or for individuals subject to the Criminal Law (Insanity) Act 2006. If an advance directive can only be made when a person 'has mental capacity' (as the Scheme of Heads provides), a person's advance directive should apply even when they are involuntarily detained. This proposal conflicts with the Scheme’s principles of valuing autonomy and respecting will and preferences – as many of those who wish to make advance directives may have very specific concerns about what should happen if they are involuntarily detained. This creates a discriminatory standard for mental health as compared to physical health.

Instead of a blanket statement denying the use of advance healthcare directives in the case of involuntary detention, the law should limit the recognition of advance healthcare directives in the case of involuntary detention only when the situation is life threatening. For example, in the US State of New Mexico, a person's preferences regarding medication and other aspects of treatment while hospitalized are required to be followed even when a person is involuntarily committed.

Since this submission strongly recommends that a validly made advance directive be legally binding even where a person is under involuntary detention, this entails further amendment of the Mental Health Act. Unless the Mental Health Act is reformed to reflect the positive provisions of the Capacity Bill, there is a grave risk that respecting advance directives could be used to continue to keep people in involuntary detention under the Mental Health Act (where an individual has validly refused all treatment but still meets the criteria for involuntary detention). Article 14 CRPD states that no person can be deprived of their liberty on the basis of a disability, and the UN Committee has made strong statements to the 10 countries it has examined to date to the effect that this requires the abolition of discriminatory laws which authorise detention and involuntary treatment of
people with psychosocial disabilities in psychiatric hospitals (see for example the Committee’s Concluding Observations on Australia).

In light of the prohibition of the UN CRPD on forced treatment, and our proposal in this submission that advance directives must be respected unless there is an imminent and grave risk to the person’s life, this will also necessitate reform of the Mental Health Act 2001, since the current position under section 57 of the Act allows a consultant psychiatrist to administer treatment without consent where it is deemed necessary to “to safeguard the life of the patient, to restore his or her health, to alleviate his or her condition, or to relieve his or her suffering.”

Steps must be taken to accomplish the goal of abolition of involuntary detention in psychiatric hospitals, and these could include for example, greater scrutiny by the Mental Health Commission and increased safeguarding by the Mental Health Tribunals where involuntary detention is being authorised and the individual has made a valid advance refusal of treatment. Similarly, respect for an advance directive should not be used as a justification for greater use of restrictive practices, such as restraint and seclusion, where a person has made a valid advance refusal of treatment. In addition, where a person is detained under the Criminal Law (Insanity) Act, similar concerns may arise where their advance directive is respected, leading to a situation of indefinite detention. In our view, respect for an advance directive should not be used as a justification for continuing involuntary detention, since such detention could continue indefinitely if the person continues to meet the criteria. We strongly urge that the criteria for involuntary detention under both the Mental Health Act and the Criminal Law (Insanity) Act be reviewed and reformed in light of international human rights norms.

6. Ensuring that 3rd parties are aware of the existence of an advance healthcare directive

Currently, the Scheme of Heads provides that ‘A healthcare professional shall not incur civil or criminal liability if acting in good faith he/she was unaware of the existence and content of an advance healthcare directive’. We recommend that the
law should place an onus on third parties to find out if an individual has an advance
directive. Health care providers should be required to ask a person at the point of
admission whether they have an advance healthcare directive.

Secondly, as part of good practice, every person who has an advance healthcare
directive should be encouraged to carry a card that states that they have an advance
healthcare directive. However, we do not believe that this should be a legally
binding obligation on the individual.

Third, the Office of Public Guardian should establish an electronic database to
record advance healthcare directives. As discussed above, this database must
respect privacy and data protection laws, but should be easily accessible to
healthcare providers who may need to access it. For example, the 'Health Identifiers
Bill' should be expanded to include data on advance directives, and to provide
requisite privacy protection on the same. This proposal also requires further
consideration of an electronic health services and information database for the
health system as a whole.

7. Emergency situations

The Scheme of Heads provides that ‘in general, apart from emergency situations,
treatment cannot be provided to an individual without his/her consent’. We
recommend that in general, the authority to override an advance healthcare
directive should only be granted by the court where there is an 'imminent and
serious threat' to the person's life. However, the legislation should clarify that
'imminent and serious threat to life' does not provide sufficient justification to
override a valid refusal of care which has been made as part of an advance directive
on end of life decisions.'
8. **Ulysses Clause**

The Scheme of Heads states that ‘enabling a person who lacks capacity to revoke or alter his or her directive would defeat the purpose of preparing the directive’ without allowing the possibility that this limitation should be allowed only when the advance healthcare directive has a Ulysses clause.

The Ulysses Clause should only be used by individuals who clearly want their advance healthcare directive wishes to stand during specified periods and be subject to independent execution safeguards to ensure it reflects the ‘will and preferences’ of the person. This option addresses situations where a person with self-experience knows they will object when unwell, but wishes his/her expressed preferences to take precedence to avoid deterioration. The person can change the advance directive at any time unless he/she chooses to execute this clause. Where an advance directive does not have a Ulysses Clause, a person should be able to verbally revoke their directive in real time/contemporaneously.

9. **The requirement of anticipating future circumstance**

The Scheme of Heads places too much emphasis on anticipating future circumstances that could arise. Head 4(2)b states that ‘a treatment outlined in an advance healthcare directive must be followed provided the circumstances in which the treatment refusal is intended to apply is clearly outlined’. This provision allows for the invalidation of an advance directive on account of the fact that a person did not anticipate some of the surprises that happen in the course of life.

10. **Safeguards**

There is need for additional safeguards to prevent abuse. For example, the Scheme should expressly state that an advance directive should be completed ‘free from coercion’. ‘Coercion’ is defined elsewhere in Irish law in Section 9(1) of the Non-Fatal Offences Against the Person Act, 1997. This includes when a person ‘with a view to compel another to abstain from doing or to do any act which that other has a lawful right to do or to abstain from doing, wrongfully and without lawful authority,
(a) uses violence to or intimidates that other person or a member of the family, (b) injures or damages the property of that other.’

The advance healthcare directive sample form/draft form should have a statement to the effect that an advance directive should be made without duress, undue influence or coercion. The law should make coercing a person to make, revoke or alter an advance directive a criminal offence for which section 113 of the Bill on offences should apply.

There is a concern that elder abuse may arise with respect to AHDs. A response that prioritises autonomy and the will and preference of the individual must be developed with adequate safeguards.

11. **Liability protection for third parties who act in good faith**

The law should make it clear that where an adult refuses treatment with the result of deterioration is his/her health or where the refusal results in his or her death, the third party (hospital or individual doctor) is free from liability/protection for healthcare workers who abide by the advance healthcare directive in good faith.

12. **Positive requests**

Positive requests for specified treatment options should be honored where the request is budget neutral or would not impose a disproportionate burden. Where positive requests are declined, a written account of the reasons for declining should be entered into the person’s medical records.

13. **Support to families**

There should be a strong piece on support to families in terms of information, etc. One way to allow for the input of families is to incorporate advance directives into individual planning, which is usually completed with the input of family. The code of practice could have a statement which requires people to consider that their decision has an effect on other people.
Major life decisions for most people, including healthcare decisions, are rarely made in isolation. Family and other supporters are often present and may be affected significantly by such decisions. The safeguard provisions against undue influence and duress must be balanced against efforts to include family and supporters during important decision-making moments. Health professionals should promote family involvement as much as possible. Guidance can be sought from the 2013 National Carers Strategy, which provides a best practice guide for involving family and supporters in healthcare decision-making.

4. Responding to the Specific Questions for Consultation

1. What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?

The requirement that an individual obtain professional advice before preparing an advance healthcare directive should form part of best practice rather than a legislative requirement. It should be adequate to register one's advance directive with the Office of Public Guardian.

The sample advance healthcare directive form/draft form could have a statement to the effect that 'you are advised to seek advice from professionals but failure to do so will not be construed as invalidating the advance healthcare directive'.

2. Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed (e.g. every 2 years, every 5 years, every 10 years)?

Regular review of advance directives is important; however, review should form part of best practice rather than a stipulation in the legislation. If the review period is included in the legislation, the failure to review may render the advance directive invalid, even when the person would wish for the advance directive to apply.
3. Should a standard format be developed for advance health care directives?

A standard format may be developed, but this should act as a guide only – advance directives should not be invalidated merely because they are not aligned to the standard format.

Further, the standard format could have sections, to ensure adequate details for the different scenarios. For instance, advance directives in the mental health context are quite different from those in the end of life context and while it would not be ideal to have different forms, it would be advisable to have sections that address the specific issues that arise under different situations.

4. If a standard format for advance healthcare directives was developed what information should it contain?

Advance directives should contain:

a) Name and date of birth of the person
b) Name and date of birth of the person proposed to be appointed as representative under the advance directive
c) Date of making advance directive
d) Statement to the effect that the advance directive is made free of coercion and/or undue influence
e) Specific description of the point at which the advance directive enters into force and ceases to have effect
f) Express provision regarding means of revocation
g) An option for a Ulysses clause, which should explain in simple language what the effect of a Ulysses clause would be
h) Name of preferred healthcare professional if any
5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?
The Office of Public Guardian should establish an electronic database that keeps a record of advance healthcare directives. Further, the ‘Health Identifiers Bill’ should be expanded to include data on advance directives, and to provide requisite privacy protection on the same.

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?
The law should place an onus on third parties to find out if an individual has an advance directive. Health care providers should be required to ask a person at the point of admission whether they have an advance healthcare directive. As part of good practice (not legally binding), every person who has an advance healthcare directive should be encouraged to carry a card that states that they have an advance healthcare directive.

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?
Positive requests for specified treatment options should be honored where the request is budget neutral or would not impose a disproportionate burden. Where positive requests are declined, a written account of the reasons for declining should be entered into the person’s medical records.

8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?
See answer to Question 3 above
NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

NUI Galway

CENTRE for DISABILITY
LAW & POLICY

NEUROLOGICAL ALLIANCE
of IRELAND

AMNESTY INTERNATIONAL
Appendix F

Mental Health Commission Response to the Public Consultation on the Draft Scheme for Advance Healthcare Directives

March 2014

The Mental Health Commission acknowledges the assistance of Fiona Morrissey, School of Law, NUI Galway in the preparation of this Submission.
Introduction

The Mental Health Commission (the Commission) welcomes the publication of the Draft General Scheme for Advance Healthcare Directives (AHD) for incorporation into the Assisted Decision-Making (Capacity) Bill 2013 by the Department of Health. The Commission is of the view that the recognition of AHDs is a fundamental step towards a recovery-based approach. AHDs also represent an important means by which individuals can exercise their autonomy and capacity under the supported decision-making model in the UN Convention on the Rights of Persons with Disabilities (CRPD).

The Commission notes that the purpose of the proposed legislation is to promote autonomy; to enable persons to be treated according to their will and preferences and to provide healthcare professionals with important information about persons and their choices in relation to treatment. The Commission endorses autonomy and the right of persons to be treated with respect for their will and preferences. The concept of recovery endorsed by the Commission is described “in terms of the human right to autonomy and the self-fulfilment of the individual.” The Commission welcomes the presumption of capacity for all adults to execute an AHD and the provision of a single legislative framework, which encompasses AHDs for general and mental healthcare. Under the proposed Scheme, an individual is entitled to make an AHD for mental healthcare treatment, but these decisions may be limited for individuals detained under the Mental Health Act, 2001 (2001 Act). In the submission on the Assisted Decision-Making (Capacity) Bill, the Commission stated that it fully supports the introduction of AHDs into Irish law and submits that they should equally apply to all persons including those detained under the 2001 Act. However, it recognises the need for compatibility between the AHD provisions and Part 4 of the 2001 Act. These may be addressed in the review of the Act. The Commission, in this submission, has addressed the specific issues raised in the public consultation by the Department of Health and additional areas relevant to the use of AHDs for individuals with mental health conditions.

Mental Health Commission

The Mental Health Commission is an independent statutory body, which was established under the provisions of the Mental Health Act, 2001. The principal functions of the Commission are to promote, encourage, and foster the establishment and maintenance of high

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standards and good practices in the delivery of mental health services and to take all reasonable steps to protect the interests of persons detained in approved centres. The strategic priorities of the Commission include safeguarding the human rights of service users, incorporating these rights into practice and involving service users and their families in treatment and care. Other priorities include promoting service user-centred and recovery-oriented services. AHDs are a key driver in the transition to person-centred services. The implementation of AHDs can assist the ‘paradigm shift’ towards the recovery and supported decision-making approaches in Irish mental healthcare. The introduction of progressive human rights legislation is important in achieving attitudinal change towards individuals with mental health conditions and how they are treated in Ireland.

1. **What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?**

While users should be encouraged to discuss their AHD preferences with treating clinicians, the requirement to obtain clinical or legal advice before preparing an AHD may act as a barrier to completion. Service users should be encouraged to discuss their AHD preferences with treating clinicians after the document is developed with an independent support person. The discussion of the AHD with the clinician can have significant benefits for the therapeutic relationship and the promotion of trust. The involvement of the treating clinician in the preparation of the directive can raise undue influence concerns due to the power imbalance in the relationship. Time may also be a barrier for clinician involvement in development. Clinicians may be involved in introducing AHDs to the person and referring them to an independent trained support person for facilitation e.g. peer facilitator. This may form part of the Code of Practice. The evidence indicates that the majority of AHDs contain clear and valuable information² and are consistent with clinical practice regardless of professional involvement.³

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2. **Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed?**

The AHD should be reviewed periodically so changes in treatment preferences or personal circumstances are incorporated, but this should form part of the Code of Practice rather than a legislative requirement. The requirement for a specific, mandatory time period for review in the legislative provisions may impact on the validity and enforceability of the directive. The review of an AHD should occur on an annual basis, after each episode of illness or crisis or as the person requests. The Council of Europe recommends reviewing AHDs at regular intervals e.g. on a yearly basis.  

3. **Should a standard format be developed for advance healthcare directives?**

The Commission members support the development of a standard simplified form (s) for AHDs in the Code of Practice. However, the form should not be a legislative requirement for the AHD to be valid. Model forms should be provided in the Code of Practice, which capture the information in a clear and systematic manner. The form facilitates service provider recognition of the directive and provides a template for instructions. This decreases the likelihood of ambiguity or error.

4. **If a standard format for advance healthcare directives was developed what information should it contain?**

A standard integrated form should be developed to include all healthcare decisions i.e. physical and mental health decisions. A separate form should also be developed for individuals, who wish to document mental health decisions separately to protect confidentiality in other healthcare settings. The form for mental health decisions should include details of the person; any designated decision-making representative (s) or other support persons; the authority of the decision-maker; when the directive should be activated or deactivated; emergency contacts; details of treating doctors; treatment refusals/requests; reasons for preferences; Ulysses clause; preferences for life-sustaining treatment and life-saving emergency treatment; life management choices, hospitalisation preferences; relapse symptoms; organ donation and participation in research. The person should only be legally required to provide minimal details such as name, address, date of birth, witness signatures and the details of any designated representative (s) for the AHD to be valid. The details of

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4 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe 2012).
any support person with whom the directive was developed with, may also be included. If the person appoints a representative, but does not provide specific instructions or limit his/her power, the representative will be bound to make decisions based on the persons will and preferences or to make every effort to identify these where they are unknown.

The Commission is of the view that a standard format should be developed, which includes decisions specific to mental health and life planning issues. Any intersectional information from the Assisted Decision-Making Capacity Bill should also be included, including who should be contacted if there is lack of clarity. The format adopted by the New Zealand Medical Association is one example for consideration.5

5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?

In the absence of electronic medical records, AHDs should be kept in a secure online registry with confidentiality safeguards. The central registry should be accessible by healthcare providers with the consent of the person or the designated decision-making representative. The person should specify whether they wish mental health information to be made available to general healthcare providers to protect privacy. The register for decision-making agreements proposed by the Office of the Public Guardian may also include AHDs. In order to protect confidentiality, the Mental Health Commission may assume responsibility for access, where the AHD includes mental health decisions. The legislation should not require submission to the registry for the AHD to be legally valid, but registration should be recommended in the Code of Practice. The registry should be easily accessible to enable all individuals to submit their directive with support if needed. Copies of the document should also be valid and distributed to relevant treatment providers, family members and other relevant persons.

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?

There should be an obligation on clinicians to inquire whether a person has an AHD on admission to mental health services (community or inpatient settings) or as part of the

5 http://www.nzma.org.nz/patients-guide/advance-directive
clinical assessment. The existence of an AHD should be documented in a section on the person’s medical record and in the online registry. Crisis cards (similar to organ donation cards) should also be made available to alert healthcare professionals of the existence of an AHD. Individuals should be encouraged to discuss their AHD preferences with treating healthcare professionals and distribute copies to providers and family at execution. The development of an AHD should also be documented in the individual care plan. This should form part of the Code of Practice in the legislation.

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?
An obligation should be placed on healthcare professionals to provide treatment requested in the directive where it is reasonably available and clinically appropriate. Treatment requests should also be discussed with healthcare professionals after the AHD is developed to ensure requests are respected. A duty should be placed on the healthcare professional to inform the person and/or the designated decision-making representative and the monitoring body of the reasons why the requested treatment could not be provided (e.g. the Mental Health Commission) and to document it on the medical record. If the treatment is available through another professional or provider, reasonable efforts should be made to transfer the person to another provider or professional who is able or willing to comply with the request. The Commission is of the view that there should be equivalence such that voluntary patients and patients subject to detention under the provision of the Mental Health Act 2001 have the same rights and access to the same system.

8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?
The provisions should include both integrated and separate formats for mental health and general healthcare so that the individual has a choice of forms. An integrated form should be made available for both physical and mental health decisions. Many individuals with mental health conditions also have physical illnesses, which they may want to document. Other
individuals may want to document mental health decisions separately to protect confidentiality in general health settings. The form for mental health decisions should include details of relapse symptoms, crisis responses, support persons, recovery strategies, treatment refusals/requests, reasons, hospitalisation preferences, ECT preferences, life-saving emergency treatment, review date and a Ulysses clause for individuals who want their AHD wishes to stand over his/own objections during crisis periods. The Ulysses clause should be signed by an independent support person to ensure it reflects the person’s will and preferences. The form should also include life management choices when an individual is in crisis e.g. childcare, household finances.

9. What do you think the role of the patient-designated healthcare representative should be? Should the representative’s role be limited to that of interpreting the individual’s advance healthcare directive? Should the representative have a broader role to advise as to what the individual’s will and preferences regarding treatment are likely to be?

The legislation should place a duty on the healthcare representative to follow the person’s instructions or to make every effort to identify his/her will and preferences where instructions are not provided in line with the principles of the 2013 Bill and the AHD Scheme. The individual should specify the role of the designated healthcare representative in the terms of the directive at execution i.e. when they want the representative to be consulted and whether they wish them to have broad or limited decision-making authority, or respond to changes in treatment. The form should allow the person to specify whether the representative has a broad or limited decision-making role and the duration of such role. In certain circumstances, the person may wish to allow the representative to consent to hospitalisation for a limited period. This should be subject to independent review safeguards by a Mental Health Tribunal. The distinction between a representative’s authority to make decisions about mental health treatment and the authority to consent to hospitalisation should be clarified and set out separately. The Commission recommends that Guidelines are developed regarding the role of the healthcare representative.

The legislation should allow individuals to have a choice of executing a stand-alone instructional directive; a directive where a representative is appointed to communicate the person’s will and preferences or a hybrid directive where the person includes instructions and a representative. The research suggests that a significant proportion of mental health service users lack a trusted representative to act on their behalf so the option to execute a standalone
instructional directive and the development of support should be provided for in the legislation. The CRPD requires State Parties to facilitate the creation of supports, particularly for individuals who are isolated and may not have access to naturally-occurring supports in the community. Due to the conflict of interest, a healthcare professional should not act as a decision-making representative. The Scheme states that a provider of paid personal or healthcare services should not act as a representative. The importance of appointing a trusted representative with knowledge of the person’s will and preferences should be stated in the Code of Practice. The involvement of an independent support person in the development of the directive can safeguard against undue influence.

Primarily, the role of the healthcare representative should be to ensure the person’s directions are followed in the anticipated circumstances. However, this may not always be clear particularly where there are no instructions. There should be some enabling provisions in the legislation permitting the representative to have a more assertive role as anticipated in the 2013 Bill for supported decision-makers. The role of the healthcare representative may be context and person dependent and depend on the level of trust and knowledge in the relationship.

10. What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

In cases, where the person provides specific instructions, the representative should have a duty to follow these in treatment and other decisions. There should be some form of accountability mechanism where the representative does not follow the person’s instructions. In the absence of instructions, the representative should have a duty to make decisions in accordance with the person’s will and preferences and make every effort to identify them where they are unknown. The Code of Practice should emphasise the importance of appointing a trusted decision-making representative, who is familiar with the person’s values. An obligation should be placed on providers to help build trusted support networks for

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7 Committee on the Rights of Persons with Disabilities, ‘Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law’ GE 2013. Adopted by the Committee at its tenth session (2-13 September 2013) para 25(d).
individuals who lack a trusted person. A system of supervision should be established under which an independent authority is empowered to investigate, in cases of abuse by decision-making representatives. Education and training programmes should also be provided for individuals who are appointed healthcare decision-making representatives to safeguard against substitute decision-making and to ensure the person’s wishes are reflected in decisions. The legislation should allow more than one representative to be appointed for different decisions e.g. mental health and other decisions.

The Commission is of the view that the role of the decision-making representative and the instructions should be clearly stated in writing and signed by the person and healthcare professional (or other independent support person) involved in helping the person complete the directive. The Code of Practice should provide clear requirements in relation to how professionals approach this process. Conflicts of interest should be dealt with as far as possible in the legislation. The role of the Public Guardian and awareness raising and training will be essential to ensure that the representative carries out the wishes of the person.

11. Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?

11.1. **Formalities for Execution**

The legislation should include minimal formalities to ensure AHDs are easily executable by all persons. This suggests the need to remove limitations on adult witnesses and requirements for advice from legal or health professionals to encourage participation. The limitations on witnesses from a person’s family in the draft Scheme may also act as a barrier to AHD execution and should form part of the Code of Practice rather than a legal requirement. The involvement of independently trained support persons in the development of the AHD can help protect against undue influence. There should be some sanction in the legislation for coercing a person to execute or alter an AHD or intentionally misrepresenting his/her will and preferences. Limited provision should be provided for oral AHDs with independent witness safeguards and/or recorded evidence in circumstances, where the person is unable to communicate in writing.
11.2. Legal Status of AHDs during Involuntary Detention

AHDs should be legally binding for all healthcare decisions, including mental health decisions and equally applicable during periods of involuntary detention. In the submission on the Assisted Decision-Making (Capacity) Bill 2013, the Commission submitted that AHDs should apply equally to all persons including those detained under mental health legislation, but recognises the need to amend the provisions of Part 4 of the 2001 Act for treatment decisions to be binding.

The Commission is concerned with the provisions of Head 5(7), which state that AHDs will not be legally binding where treatment is regulated under the 2001 Act.

While non-legally binding AHDs with accountability mechanisms are ethically valuable, the use of differential standards for mental healthcare and general healthcare directives reinforces the notion that the rights of individuals with mental health conditions are not respected on an equal basis with others. The integration of AHDs for mental health decisions in the legislative framework on an equal basis with other treatment decisions is important symbolically in reducing stigma and discrimination. Stigma and discrimination have been identified as the greatest barriers to recovery.\(^8\) The use of differential standards for treatment decisions during involuntary detention conveys the message that the person is not respected and can act as a deterrent to seeking treatment.

The limitation on AHDs during involuntary detention in the Scheme is justified based on the State duty “to uphold the common good and to protect and maintain the rights and ‘best interests’ of its citizens … and override the rights of a given individual to protect that individual and/or the general population.” However, the evidence indicates that in the absence of substance abuse, the risk of violence is no greater than the general population.\(^9\) Risk does not therefore justify the exclusion of legally binding AHDs during involuntary detention. Involuntary detention can be used where there is risk to others and an emergency exception in the legislation can address situations where treatment is required due to an imminent risk to the life of the person. The fear that individuals will refuse all treatment or be left untreated often forms the basis for limitations on AHDs during involuntary detention.


However, the international research suggests that AHDs are rarely used to refuse all treatment and are generally used to express a preference for particular treatments or to inform providers of concerns. The evidence suggests AHDs increase treatment adherence and engagement.

The features of the Irish mental health system suggest a need for legally binding AHDs with accountability and oversight mechanisms until a cultural shift towards respect for treatment preferences is established. Several Commission reports have identified concern in relation to the low level of service-user participation and compliance with individual care planning.

The research with service users suggests a need and demand for legally binding AHDs during involuntary detention to address specific treatment concerns and to instil confidence that preferences will be respected. The threat of coercion in the mental health system impacts on voluntary and involuntary patients. Even if the AHD is legally binding for voluntary patients, the threat of involuntary detention, limits the impact of mental health decisions. AHDs are also associated with a reduced need for hospital readmission and involuntary detention.

This is particularly pertinent in view of the high readmission rates in the Irish mental health system. The establishment of a strong philosophical ethos of respect may be the most important aspect of AHDs for service users.

The Commission’s strong view in this regard, is that the current review of the Mental Health Act 2001 needs to fully consider and address this issue.

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15 Readmissions accounted for 66 per cent of the 18,173 admissions to Irish psychiatric units and hospitals in 2012.
11.3. Revocability
The Scheme of heads states that “… enabling a person who lacks capacity to revoke or alter his or her directive would defeat the purpose of preparing the directive.”\textsuperscript{16} The AHD development process confers recovery and capacity building benefits even if it is never legally invoked. The evidence suggests that a significant proportion of users have change of mind concerns and prefer the AHD to be revocable at any time, even though few are fully revoked in practice.\textsuperscript{17} The revocability of the directive during crisis periods should be specified by the user. Several jurisdictions allow the person to change the directive during periods when decision-making capacity may be reduced.\textsuperscript{18} The inclusion of a Ulysses clause in the legislation can address situations where individuals clearly want their AHD wishes to be followed over any changes they may try to make during crisis periods. The clause caters for individuals who have prior experience of crisis and clearly want their AHD wishes to be followed. Some individuals want to use the Ulysses clause to avoid deterioration, damage to interpersonal relationships or the need for involuntary admission. The clause should be subject to additional executional safeguards by an independent witness and/or healthcare professional to ensure it reflects the will and preferences of the person.

The Council of Europe recommendations state that the AHD should be revocable at any time and reviewed at regular intervals.\textsuperscript{19}

11.4. Support
The international research shows the need for support for AHD completion.\textsuperscript{20} This should be stipulated in the Code of Practice. Trained facilitators should be provided in a range of settings to support individuals to develop AHDS. The support person should be independent of the treating healthcare professional. The role of peer support should be recognised in the Code of Practice. The CRPD requires State Parties to provide access to supports to exercise legal capacity.

\textsuperscript{16} Head 4(6).
\textsuperscript{18} Arizona, Washington, Virginia.
\textsuperscript{19} Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012) Principle 7.6.
11.5. AHD Completion
The Code of Practice should place a duty on healthcare professionals to offer individuals the opportunity to develop an AHD as part of the recovery and care planning process. Designated members of healthcare staff should be assigned responsibility for offering individuals the opportunity to develop an AHD as part of the care planning process and/or referring them to a trained facilitator for support to complete the document. The AHD should be integrated with individual care plans. The legislation should include some form of accountability mechanism e.g. requiring professionals to document when individuals were offered the opportunity to develop an AHD and the reason for not developing one in the medical record and/or the individual care plan. Healthcare providers should be required to return annual figures on how many AHDs were completed in the service. These figures should be returned to the monitoring body. The Mental Health Commission and the Office of Public Guardian should report on AHD completion figures in annual reports.

11.6. Capacity Determinations
The Scheme does not specify how the AHD will be activated and who will determine capacity for the purpose of invoking and revoking the directive. This is a major issue that needs to be addressed and should be subject to independent review safeguards. Head 3(2) specifies that a presumption of capacity shall exist unless there is evidence to the contrary, but does not specify who will make this decision. Consideration should also be given to how the AHD might be activated outside of hospital settings. The CRPD requires AHDs to be separated from legal frameworks that are based on mental capacity and incapacity.

11.7. Basic Care
Head 5(4) provides that AHDs are not to be applicable to the administration of basic care and clarifies that this is distinct from treatment. The definition of basic care includes, but is not limited to, warmth, shelter, oral nutrition and hydration. The legislation should provide a clear distinction between the refusal of life-sustaining treatment in end-of-life situations and the provision of life-saving emergency treatment in the mental health context. The ability to refuse artificial nutrition and hydration may be limited to persons with terminal conditions to alleviate concerns in relation to the refusal of life-sustaining treatment in cases such as anorexia nervosa.

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11.8. Litigation
The healthcare decision-making representative should make the final decision in relation to the person’s will and preferences. In cases of unresolved conflict between family members or other parties and the decision-making representative, the decision should be referred to the court or the monitoring body to adjudicate. The research shows AHDs may assist family understanding of the person’s wishes and decrease decision-making burden rather than increase it. AHDs generally reduce the need for litigation due to increased communication between the person, professionals and family members.

11.9. Accountability and Oversight
The legislation should provide accountability and oversight mechanisms where treatment is provided in conflict with a valid AHD. The reasons for overriding the AHD should be submitted in writing to an independent body and documented in the person’s medical record. The person and the decision-making representative should be informed of the decision and it should be reviewed by the monitoring body. The Mental Health Commission may provide oversight for AHDs in mental healthcare, while the Office of the Public Guardian may provide oversight for general AHDs. The implementation of the legislation on AHDs should be co-ordinated by these bodies. The use of AHDs should be incentivised and measured within the system.

11.10. Education
Stakeholder education and consensus building are critical for the effective implementation of the AHD legislation. The Office of the Public Guardian and the Mental Health Commission should monitor the implementation of AHDs, promote public awareness and provide education to professionals, families, representatives and services users. Legal compliance training should be provided for health professionals. Community education and public awareness will also be vital. Consideration should be given to piloting AHDs on mental health sites prior to implementation.

11.11. Other Issues
The provision in Head 5(1)(d), which states that an AHD is invalid if the person has “while he or she had capacity to do so, has done anything clearly inconsistent with the advance healthcare directive remaining his or her fixed decision” may create uncertainty in relation to the applicability of the directive and the duty of the healthcare provider to determine whether
this occurred. This could result in an implied revocation of the AHD and subjective interpretations of the person’s will and preferences and delay key decisions. Users should be encouraged to communicate any changes to the directive as part of the review process.

The Expert Group currently reviewing the 2001 Act should give consideration to proposing amendment of the 2001 Act to allow AHDs to be considered by Mental Health Tribunals.
Appendix G

Response by Fiona Morrissey to the Public Consultation on the Draft Scheme for Advance Healthcare Directives, March 2014.
Response to the Public Consultation on Draft General Scheme for Advance Healthcare Directives

Prepared by Fiona Morrissey, B.A., LL.B., LL.M., DLIS, Ph.D. Candidate, School of Law, NUI Galway.

The response is based on international and national empirical research conducted by Fiona Morrissey and forms part of a PhD thesis on the introduction of a legal framework on advance directives in Ireland.

Fiona would like to thank John Oliver, attorney of law in the United States for his comments on aspects of the Draft Scheme.

Date: 10th of March 2014
1. What are your views on requiring an individual to obtain professional Advice (e.g. clinical and/or legal) before preparing an Advance healthcare directive?

The requirement to obtain clinical or legal advice before preparing an AHD may act as a barrier to completion. The Council of Europe recommendations state that AHDs should be accessible by all, thus complicated forms or excessive formalities should be avoided.\(^1\) However, users should be encouraged to discuss their AHD preferences with treating clinicians after the document is developed with an independent support person to facilitate communication and to ensure the AHD is respected. This may form part of the Code of Practice. The involvement of a clinical professional in the development of the directive can raise concerns in relation to undue influence. The discussion of the AHD with the clinician after development can have significant benefits for the therapeutic relationship and promoting trust. Clinicians may also be involved in introducing AHDs to the person and referring them to an independent support person for facilitation. The service user should be given the opportunity to complete the directive with the support of an independent person. The evidence indicates that the majority of AHDs contain clear and valuable information\(^2\) and are consistent with clinical practice regardless of professional involvement.\(^3\)

2. Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed?

The AHD should be reviewed periodically so changes in treatment preferences or personal circumstances are incorporated, but this should form part of the Code of Practice rather than a legislative requirement. The requirement for a specific, mandatory time period for review in the legislative provisions may impact on the validity and enforceability of the directive. The review of an AHD should occur on an annual basis or after each episode of illness or crisis.

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\(^1\) Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012) paras 3, 4, 6.


3. Should a standard format be developed for advance healthcare directives?
A standard simplified form(s) should be developed for AHDs in the Code of Practice. However, a form should not be a legislative requirement for the AHD to be valid. The form facilitates provider recognition of the directive and provides a template for instructions. This decreases the likelihood of ambiguous instructions and error.

4. If a standard format for advance healthcare directives was developed what information should it contain?
A standard integrated form should be developed to include all healthcare decisions i.e. physical, mental health decisions. A separate form should also be developed for individuals, who wish to provide for mental health decisions separately to protect privacy in general health settings. The form should include details of the person, any designated decision-making representative(s), the authority of the decision-maker, emergency contacts, details of treating doctors, treatment refusals/requests, reasons, ECT preferences, Ulysses clause, preferences for life-sustaining treatment and emergency treatment, life management choices, hospitalisation preferences, relapse symptoms, organ donation and participation in research. The form should also include details of end-of-life preferences. The person should only be legally required to provide minimal details such as name, address, date of birth, witness signatures and the details of any designated representative(s) for the AHD to be valid. If the person appoints a representative, but does not provide specific instructions or limit his/her power, the representative will be bound to make decisions based on the persons will and preferences or to make every effort to identify these where they are unknown.

5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?
In the absence of electronic medical records, AHDs should be kept in an online registry with confidentiality safeguards. The registry should be accessible by healthcare providers with the consent of the person or the designated decision-making representative. The register for decision-making agreements proposed by the Office of the Public Guardian may also include AHDs. The person may specify in the AHD, whether they wish mental health decisions, to be accessible by healthcare
professionals outside of mental health settings. The legislation should not require submission of the AHD to the registry for it to be legally valid, but registration should be recommended in the Code of Practice. The registry should be easily accessible to enable individuals to submit their directive with support if needed. The Council of Europe recommends that AHDs should be ideally registered in state registries.4

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?

There should be an obligation on clinicians to inquire whether a person has an AHD on admission to hospital and/or as part of the clinical assessment. The existence of an AHD should be documented in the person’s medical record and in the online registry. Crisis cards (similar to organ donation cards) should also be made available to alert healthcare professionals of the existence of an AHD. Individuals should be encouraged to discuss their AHD preferences with treating healthcare professionals and distribute copies to treatment providers at execution. Copies of the document should also be valid. This should form part of the Code of Practice in the legislation.

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?

An obligation should be placed on healthcare professionals to provide treatment requested in the directive where it is available and clinically appropriate. Treatment requests should be discussed with healthcare professionals after developing the AHD to ensure requests are available. A duty should be placed on the healthcare professional to inform the person or the designated decision-making representative and the monitoring body of the reasons why the requested treatment could not be provided and to document it on the medical record. If the treatment is available through another professional or provider, reasonable efforts should be made to

4 Council of Europe, Parliamentary Assembly Resolution 1859 (Council of Europe, 2012) paras 3, 4, 6, para 7.2.
transfer the person to another provider or professional who is able or willing to comply with the request. The treatment request should be dealt with in the same way as when the person has capacity and states a preference for certain treatment.

8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive? The provisions should include a choice of integrated and separate formats for AHDs in mental health and general healthcare. An integrated form should be made available for both physical and mental health decisions. Many individuals with mental health conditions also have physical illnesses, which they may want to document. Other individuals may want to document mental health decisions separately to protect confidentiality in general health settings. The form for mental health decisions should include relapse symptoms, crisis responses, recovery strategies, treatment refusals/requests, reasons, hospitalisation preferences, ECT preferences and a Ulysses clause for individuals who want their AHD wishes to stand over objection during crisis periods. It should also include life management choices when an individual is in crisis e.g. childcare, household finances etc. Consideration should be given to referring to AHDs as advance directives if they are to include other life choices.

9. What do you think the role of the patient-designated healthcare representative should be? Should the representative’s role be limited to that of interpreting the individual’s advance healthcare directive? Should the representative have a broader role to advise as to what the individual’s will and preferences regarding treatment are likely to be? The legislation should place a duty on the healthcare representative to follow the person’s instructions or to make every effort to identify his/her will and preferences where instructions are not provided. The individual should specify the role of the designated healthcare representative in the terms of the directive i.e. when they want the representative to be consulted and whether they wish them to have broader or limited decision-making authority beyond the instructions to respond to changes in treatment. The AHD form should allow the person to specify whether the
representative has a broad or limited decision-making role. In certain circumstances, the person may allow the representative to consent to admission hospital for a limited period, subject to independent review safeguards. The distinction between a representative’s authority to make decisions regarding mental health treatment and the authority to consent to hospitalisation should be set out separately. Some individuals may want to include this option to avoid the need for involuntary admission to hospital. Other powers of the representative not related to consent or refusal of treatment can also be specifically included such as the authority to consent to participation in research; access to medical records etc.

The legislation should allow individuals to have a choice of executing a stand-alone instructional directive; a proxy directive where a representative is appointed to communicate the person’s will and preferences or a hybrid directive where the person includes instructions and a healthcare representative. The research suggests that a significant proportion of mental health service users do not have a trusted person they can appoint as a decision-making representative so the option to execute a standalone instructional directive and to develop trusted support should be provided for in the legislation. The CRPD requires State Parties to facilitate the creation of supports, particularly for individuals who are isolated and may not have access to naturally-occurring supports in the community. Due to the conflict of interest, a healthcare professional should not act as a decision-making representative.

The draft Scheme states that a provider of paid personal or healthcare services should not act as a representative. The limitations on decision-making representatives should be provided for in the Code of Practice.

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10. What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

In cases, where the person provides specific instructions, the representative should have a duty to follow these in treatment and other decisions. There should be some form of accountability where the representative does not follow the person’s instruction. In the absence of instructions, the representative should have duty to make decisions in accordance with the person’s will and preferences and make every effort to identify these where they are unknown. The Code of Practice should emphasise the importance of appointing a trusted decision-making representative, who is familiar with the person’s values. A system of supervision should be established under which an independent authority is empowered to investigate, in cases of abuse by decision-making representatives. An obligation should be placed on providers to help build trusted support networks for individuals who lack a trusted person to communicate on their behalf. Educational programmes should also be provided for individuals who are appointed decision-making representatives to safeguard against substitute decision-making and to ensure the person’s wishes are reflected in decisions. The legislation should also allow more than one representative to be appointed for different decisions e.g. mental health and other decisions.

11. Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?

11.1. AHD Treatment Decisions during Involuntary Detention

Head 5(7) specifically states that AHDs will not be legally binding where treatment is regulated under the Mental Health Act 2001 and/or under the Criminal Law (Insanity) Act 2006. AHDs should be legally binding for all healthcare decisions, including mental health decisions and equally applicable during periods of involuntary detention. The integration of AHDs for mental health decisions into the legislative framework on an equal basis with other decisions is important symbolically in reducing stigma and discrimination. Stigma and discrimination have
been identified as the greatest barriers to recovery. The features of the Irish mental health system suggest a need for legally binding AHDs with accountability and oversight mechanisms until a cultural shift towards respect for treatment preferences is established. The powers to override consent to treatment are wide in the Mental Health Act, 2001 reiterating the need for legally binding directives. The threat of coercion impacts on voluntary and involuntary patients. Even if the AHD is legally binding for voluntary patients, the threat of involuntary detention, limits the impact of decisions in the mental health context. The service user research suggests an urgent need and demand for legally binding AHDs during involuntary detention to address specific treatment concerns and to instil confidence that preferences will be respected. While non-legally binding AHDs with accountability mechanisms are ethically valuable, the use of differential standards reinforces the notion that the rights of individuals with mental health conditions are not respected on an equal basis with others and can act as a deterrent to seeking treatment.

The limitation on AHDs during involuntary detention in the Scheme is based on the State duty “to uphold the common good and to protect and maintain the rights and ‘best interests’ of its citizens … and override the rights of a given individual to protect that individual and/or the general population.” However, the evidence indicates that in the absence of substance abuse, the risk of violence among individuals with mental health conditions is no greater than the general population. Risk does not therefore justify the exclusion of legally binding AHDs. Involuntary admission can be used where there is risk to others and an emergency exception in the legislation can address situations where treatment is required due to an imminent risk to the life of the person. The definition of emergencies should be clearly limited to these situations. The fear that individuals will refuse all treatment or be left untreated often forms the basis for limitations on AHDs during involuntary detention. However, the international research suggests that AHDs are rarely used to refuse all treatment and are generally used to express a preference for particular

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treatments or to inform providers of concerns. The evidence suggests directives increase treatment adherence and engagement. AHDs can also provide an alternative response to coercion by allowing the person to consent to hospitalisation and treatment in advance.

The use of differential standards for treatment decisions during involuntary detention can perpetuate stigma and limit their use in mental health settings. To achieve equal recognition before the law under the CRPD, legal capacity must not be denied discriminatorily. The right to equal recognition before the law and freedom from discrimination require that when the State is permitted to remove legal capacity it must be on the same basis for all persons. AHDs should therefore be legally binding for treatment decisions during periods of involuntary detention. Case law in the U.S., Germany and Canada has found that AHDs should be respected during involuntary detention. In Germany, AHDs are legally binding for treatment during involuntary detention and are viewed as reflecting the ‘natural will’ of the person in the context of the CRPD provisions.

11.2. Formalities for Execution

The AHD legislation should include minimal formalities to ensure directives are easily executable by all persons. This suggests the need to remove limitations on adult witnesses or requirements for professional advice or certification. The limitations on witnesses from a person’s family in the draft Scheme may act as a barrier to AHD execution and should form part of the Code of Practice rather than a legal requirement. The involvement of independent support persons in the development of the AHD can help protect against undue influence. There should be some sanction in the legislation for coercing a person to execute or alter an AHD or intentionally misrepresenting his/her will and preferences particularly for financial benefit. Limited provision should be provided for oral AHDs with independent


witness safeguards and/or recorded evidence in circumstances, where the person is unable to communicate in writing. The provision in Head 3(6)(a), which allows a person to revoke the AHD verbally would imply that there should some provision for oral execution. This should be recorded in the person’s medical record.

11.3. Revocability of the Directive and the Ulysses Clause
The informality for revoking the AHD in the Scheme is positive. However, the requirement for capacity to revoke the directive fails to comply with the CRPD requirements and can act as a barrier for users with change of mind concerns. While a proportion of users prefer directives to be revocable at any time, few are fully revoked in practice. The Scheme states that “… enabling a person who lacks capacity to revoke or alter his or her directive would defeat the purpose of preparing the directive.” The AHD confers developmental benefits even if it is never legally invoked. The communication and capacity building benefits may be the most important aspect of the measure. AHDs are also associated with a reduced need for hospital readmission and involuntary detention in mental health care. This is particularly pertinent in view of the high readmission rates in the Irish mental health system.

Several jurisdictions allow the person to change the directive during periods when decision-making capacity may be reduced. The revocability of the directive during crisis periods can be set out by the user at execution. The inclusion of a Ulysses clause can address situations where individuals clearly want their AHD wishes to stand over any objection they make during crisis periods. The clause should be subject to executional safeguards by an independent support person or healthcare

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13 In one study of 106 service users with AHDs and 487 crisis events, the directive was never revoked as a whole, although in 105 (22 per cent) of the crises, service users changed their minds about some specific instructions: Debra Srebnik and Scott Kim, ‘Competency for Creation Use and Revocation of Psychiatric Advance Directives’ (2006) 34(4) Journal of the American Academy of Psychiatry and the Law 501.
15 Readmissions accounted for 66 per cent of the 18,173 admissions to Irish psychiatric units and hospitals in 2012.
16 Arizona, Washington, Virginia.
professional to ensure it reflects the will and preferences of the person. Some individuals may want to use the Ulysses clause to avoid deterioration or the need for involuntary admission to hospital. Any change of mind in relation to the refusal of life-sustaining treatment should be respected whether a Ulysses clause has been executed or not. The AHD should also be revocable through physical destruction.

11.4. Capacity

The Scheme does not specify how the AHD will be activated and who will determine capacity for the purpose of invoking and revoking the directive. This is a major issue that needs to be addressed and should be subject to independent review safeguards. Head 3(2) also specifies that a presumption of capacity shall exist unless there is evidence to the contrary and does not specify who will make this decision. Consideration should be given to how the AHD might be activated outside of hospital settings.

The draft Scheme is predicated on the capacity to execute, invoke and revoke the AHD. Head 5 requires the individual to have capacity at the time the directive was executed for it to be valid, while Head 4 states that in order for the directive to be followed, the person must lack the capacity to make decisions. Head 4 proposes that the individual may only revoke the directive, while he/she has the capacity to do so. The CRPD requires the removal of capacity and incapacity distinctions that are used to deny legal capacity. The person should set out the circumstances they want the AHD activated or deactivated at execution e.g. on hospitalisation. This does not imply the person lacks capacity, but may need an AHD to communicate preferences. The burden of proof should be on the party challenging the directive, where any doubt exists as to the validity or applicability of the directive.

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17 Head 5(1)(a).
18 Head 4(2)(c).
19 Head 4(6).
11.5. Support
The international research shows the need for support for AHD completion.\textsuperscript{21} This should be stipulated in the Code of Practice. Trained facilitators should be provided in a range of settings to support development. The support person should be independent of the treating healthcare professional. The role of peer support should also be recognised. The CRPD requires State Parties to provide access to supports to exercise legal capacity.

11.6. AHD Completion
The legislation should place an obligation on healthcare professionals to offer individuals the opportunity to develop an AHD as part of the care planning process. Designated members of healthcare staff should be assigned responsibility for offering individuals the opportunity to develop an AHD and/or referring them to a trained facilitator for support to complete the document. The legislation should include some form of compliance mechanism e.g. requiring professionals to document when individuals were offered the opportunity to develop an AHD and the reason for not developing one in the medical record and/or the care plan. Healthcare providers should be required to return annual figures on how many AHDs were completed in the service. These figures should be returned to the monitoring body. The Inspector of Mental Health Services and the Office of Public Guardian should report on AHD completion figures in the annual report. There should be form of accountability for not offering individuals the opportunity to execute an AHD.

11.7. Education
Stakeholder education and consensus building is critical for the effective implementation of the AHD legislation. The Office of the Public Guardian and the Mental Health Commission should monitor the implementation of AHDs, promote public awareness and provide education to professionals, families, healthcare representatives and users. Legal compliance training should be provided for health professionals. Community education and public awareness will also be vital.

11.8. Accountability and Oversight

The legislation should provide accountability and oversight mechanisms where treatment is provided in conflict with a valid directive. The reasons for overriding the AHD should be submitted in writing to an independent body and documented in the person’s medical record. The person and the decision-making representative should be informed of the decision and it should be reviewed by the monitoring body. The Mental Health Commission may provide oversight for AHDs in mental health care, while the Office of the Public Guardian may provide oversight for general AHDs. The implementation of AHDs should be co-ordinated by these bodies.

11.9. Other Issues

In Head 9, the High Court may make a declaration as to whether an AHD exists, is valid or is applicable for the specific treatment. This does not stop a person providing life-sustaining treatment or doing any act which he/she deems necessary to prevent a serious deterioration in the health of the person. The provision of treatment, while a court decision is being sought, should be limited to life-sustaining treatment to safeguard against the administration of treatments against the will of the person in the intervening period e.g. ECT.

Head 5(4) provides that AHDs should not be applicable to basic care. The definition of basic care includes, but is not limited to, warmth, shelter, oral nutrition and hydration. This definition should explicitly exclude artificial nutrition and hydration. The legislation should also define life-sustaining treatment. The ability to refuse artificial nutrition and hydration can be limited to persons with terminal conditions to address concerns in other circumstances e.g. anorexia nervosa.

The provision in Head 5(1)(d), which states that an AHD is invalid if the person has “while he or she had capacity to do so, has done anything clearly inconsistent with the advance healthcare directive remaining his or her fixed decision” may create uncertainty in relation to the applicability of the directive and the duty of the healthcare provider to determine whether this occurred. This could result in subjective interpretations of will and preferences and delay key decisions.

The word ‘patient’ should be omitted from designated healthcare representative.
The definition of healthcare representative means a person appointed in the AHD to either clarify the terms of the directive or to make treatment decisions on behalf of the person. If the person appoints a representative and gives instructions, it is likely that they will want them to make treatment decisions reflecting those instructions.

Consideration should be given to allowing individuals between 16 and 18 years old to develop AHDs in line with the LRC recommendations.  

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