<table>
<thead>
<tr>
<th>Title</th>
<th>What's Fair? Realising the right to Independent Living for people with intellectual disabilities: what Ireland needs to do.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author(s)</td>
<td>Fox, Noelin</td>
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What's fair?

Realising the right to Independent Living for people with intellectual disabilities: what Ireland needs to do

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Thesis submitted for the Degree of PhD

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Abstract

Ireland has a long and shameful history of providing for the support and housing needs of people with intellectual disabilities in large institutions. This is not unique to Ireland, nor to people with intellectual disabilities. In recent years these large institutions are gradually being replaced by smaller, community-based residential models. The extent to which these models, and the legislative framework which supports them, can meet the ideals of Independent Living and Community Inclusion in Article 19 of the Convention on the Rights of Persons with Disabilities is the focus of this research. The research seeks firstly, to provide a philosophical foundation for the realisation of the right to Independent Living, and proposes that a Universalist approach based on Rawls’s Principles of Justice provides a good basis for this. Fairness is at the heart of Rawls’s principles, and any implications arising from the realisation of the Independent Living right must be fair, not just to disabled people but to all citizens. An examination of current legislation applicable in Ireland forms the core of the work. It includes an analysis of legislation and relevant case law at UN, COE, EU and national levels. It explores those aspects of legislation which support the core elements of the Independent Living right, the gaps in legislation and the barriers in current law. Finally it seeks to identify the legislative changes which are required to enable the right to Independent Living for people with intellectual disabilities in Ireland. While robust legislation is important in supporting human rights, the research recognises that it is only one aspect of what is required, and that broader cultural perceptions of people with intellectual disabilities is equally important. In this regard enabling people to live in their communities and recognising and supporting their legal capacity are fundamental.
This research was funded under the PRTLI Cycle 5 - the Programme for Research in Third Level Institutions - awarded to NUI Galway.

I wish to thank my supervisor, Dr. Padraic Kenna for his challenging and thoughtful direction in undertaking this work. His insights and thorough knowledge of the law, along with his practical suggestions about how to proceed were invaluable.

I thank Professor Gerard Quinn and all of the staff and students in the Centre for Disability Law and Policy in NUI Galway. The centre provided a rich and stimulating environment for developing ideas and for debate, which greatly helped in my understanding of the issues at stake for people with intellectual disabilities. I especially want to acknowledge the support and encouragement of my fellow PhD students in the centre.

I thank the Brothers of Charity Services, Roscommon who facilitated me in doing this research.

Every day I meet people with intellectual disabilities who live their lives with dignity despite the limitations placed on them by our laws, structures and attitudes. They remind me that this work is not only an academic exercise, but that the ideals of Independent Living and Community Inclusion are fundamentally important.

My sister-in-law, Maeve, reminded me regularly that I could do this work and provided invaluable support through the whole process.

Finally, I could not have begun or persisted with such a large task without the belief, encouragement and love of Diarmuid. I thank him and Eoin, Doireann and Colum for their understanding and their patience.

I started this work just over a year after my son Myles died. It has been my saving grace and I dedicate it to his memory.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables and Charts</td>
<td>7</td>
</tr>
<tr>
<td>List of Cases</td>
<td>8</td>
</tr>
<tr>
<td>List of Legislation</td>
<td>11</td>
</tr>
<tr>
<td>Chapter 1: Introduction</td>
<td></td>
</tr>
<tr>
<td>1.1 Introduction</td>
<td>12</td>
</tr>
<tr>
<td>1.2 The context of the research</td>
<td>13</td>
</tr>
<tr>
<td>1.3 Who and what is this research about</td>
<td>16</td>
</tr>
<tr>
<td>1.4 Aim of the study</td>
<td>18</td>
</tr>
<tr>
<td>1.5 Structure of the thesis</td>
<td>24</td>
</tr>
<tr>
<td>Chapter 2: Methodology</td>
<td></td>
</tr>
<tr>
<td>2.1 Introduction</td>
<td>26</td>
</tr>
<tr>
<td>2.2 The research question</td>
<td>28</td>
</tr>
<tr>
<td>2.3 Definition of terms</td>
<td>29</td>
</tr>
<tr>
<td>2.4 The research strategy</td>
<td>32</td>
</tr>
<tr>
<td>2.5 The research framework</td>
<td>34</td>
</tr>
<tr>
<td>Chapter 3: Social Justice and Disability: What’s Fair</td>
<td></td>
</tr>
<tr>
<td>3.1 Introduction</td>
<td>54</td>
</tr>
<tr>
<td>3.2 Social Contract Theory: A brief outline</td>
<td>58</td>
</tr>
<tr>
<td>3.3 A Theory of Justice – John Rawls</td>
<td>61</td>
</tr>
<tr>
<td>3.4 Critique of Rawls</td>
<td>66</td>
</tr>
<tr>
<td>3.5 Applying the Principles of Justice to people with disabilities</td>
<td>89</td>
</tr>
<tr>
<td>3.6 Conceptualising Disability</td>
<td>93</td>
</tr>
<tr>
<td>3.7 Conclusion: Rawls, Universalism, Human Rights and the Right to Independent Living</td>
<td>115</td>
</tr>
<tr>
<td>Chapter 4: Where People with Intellectual Disabilities in Ireland live</td>
<td></td>
</tr>
<tr>
<td>4.1 Introduction</td>
<td>119</td>
</tr>
<tr>
<td>4.2 CSO Census data</td>
<td>121</td>
</tr>
<tr>
<td>4.3 National Disability Survey 2006</td>
<td>130</td>
</tr>
<tr>
<td>4.4 National Intellectual Disability Database</td>
<td>133</td>
</tr>
<tr>
<td>4.5 Mental health Services and people with intellectual disabilities</td>
<td>142</td>
</tr>
<tr>
<td>4.6 Conclusion</td>
<td>144</td>
</tr>
<tr>
<td>Chapter 5: Independent Living as a human right</td>
<td></td>
</tr>
<tr>
<td>Section</td>
<td>Title</td>
</tr>
<tr>
<td>---------</td>
<td>-------</td>
</tr>
<tr>
<td>5.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>5.2</td>
<td>Evolution of the right to independent living and community inclusion</td>
</tr>
<tr>
<td>5.3</td>
<td>The CRPD – a new group-specific human rights instrument</td>
</tr>
<tr>
<td>5.4</td>
<td>Article 19: Living Independently and being included in the Community</td>
</tr>
<tr>
<td>5.5</td>
<td>Article 19 and other CRPD articles</td>
</tr>
<tr>
<td>5.6</td>
<td>The Independent Living right in mainstream human rights instruments</td>
</tr>
<tr>
<td>5.7</td>
<td>Conclusion: Proposed Minimum Core Obligations Arising from the Right to Independent Living</td>
</tr>
<tr>
<td></td>
<td>Chapter 6: Independent Living and the European Convention on Human Rights</td>
</tr>
<tr>
<td>6.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>6.2</td>
<td>Article 5: Liberty and security of person</td>
</tr>
<tr>
<td>6.3</td>
<td>Article 8 - Right to Private Life and positive obligations</td>
</tr>
<tr>
<td>6.4</td>
<td>Limitations of the Court</td>
</tr>
<tr>
<td>6.5</td>
<td>The Potential of the Court</td>
</tr>
<tr>
<td>6.6</td>
<td>The European Court and Irish Law</td>
</tr>
<tr>
<td>6.7</td>
<td>Conclusion - A Right to Independent Living?</td>
</tr>
<tr>
<td></td>
<td>Chapter 7: Disability legislation in the European Union</td>
</tr>
<tr>
<td>7.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>7.2</td>
<td>Models of Equality in EU law</td>
</tr>
<tr>
<td>7.3</td>
<td>The EU Treaties</td>
</tr>
<tr>
<td>7.4</td>
<td>The CRPD and EU law</td>
</tr>
<tr>
<td>7.5</td>
<td>The EU Directives</td>
</tr>
<tr>
<td>7.6</td>
<td>Definition of Disability in EU law</td>
</tr>
<tr>
<td>7.7</td>
<td>Discrimination and EU law</td>
</tr>
<tr>
<td>7.8</td>
<td>Reasonable Accommodation</td>
</tr>
<tr>
<td>7.9</td>
<td>Accessibility</td>
</tr>
<tr>
<td>7.10</td>
<td>Conclusion</td>
</tr>
<tr>
<td></td>
<td>Chapter 8: Independent Living in Irish Law</td>
</tr>
<tr>
<td>8.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>8.2</td>
<td>The Constitution of Ireland - Bunreacht na hÉireann</td>
</tr>
<tr>
<td>8.3</td>
<td>Definition of Disability in Irish legislation</td>
</tr>
<tr>
<td>8.4</td>
<td>The National Disability Strategy</td>
</tr>
<tr>
<td>Section</td>
<td>Title</td>
</tr>
<tr>
<td>---------</td>
<td>---------------------------------------------------------</td>
</tr>
<tr>
<td>8.5</td>
<td>The Disability Act 2005</td>
</tr>
<tr>
<td>8.6</td>
<td>Legal capacity in Irish Law</td>
</tr>
<tr>
<td>8.7</td>
<td>Equality legislation</td>
</tr>
<tr>
<td>8.8</td>
<td>Housing legislation</td>
</tr>
<tr>
<td>8.9</td>
<td>European Convention on Human Rights Act</td>
</tr>
<tr>
<td>8.10</td>
<td>Health and Personal Social Services</td>
</tr>
<tr>
<td>8.11</td>
<td>Conclusion</td>
</tr>
<tr>
<td></td>
<td>Chapter 9: Conclusion: Where to from here?</td>
</tr>
<tr>
<td>9.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>9.2</td>
<td>Summary of findings</td>
</tr>
<tr>
<td>9.3</td>
<td>Implications of the research findings for the law in Ireland as it impacts the right to Independent Living</td>
</tr>
<tr>
<td>9.4</td>
<td>Areas for further research</td>
</tr>
<tr>
<td></td>
<td>Bibliography</td>
</tr>
</tbody>
</table>
List of Tables and Charts

Table 1: Numbers of people with disabilities - various sources
Table 2: Disability 2006 – 2011
Table 3: Occupancy type of permanent private households
Table 4: Status in family of adults living in private households
Table 5: Economic status of people ages 15 years and over
Table 6: Marital status of people with disabilities
Table 7: Communal Establishments
Table 8: People with intellectual disability in Communal Establishments and age
Table 9: NIDD 2011 Adults in residential care centers and community group homes and level of disability
Table 10: Age profile of people living in communal establishments and private households
Table 11: Degree of intellectual disability 2002 – 2011
Table 12: Residential circumstances and age of people with ID 2011
Table 13: Residential Circumstances and age of Adults 2002 and 2011
Table 14: Residential Circumstances and Degree of Intellectual Disability 2002 and 2011

Figure 1: Arthurs Legal Research Styles

Chart 1: All disabilities and intellectual disabilities by age group 2011
Chart 2: Other forms of Residential Accommodation 2002 – 2011
List of Cases

Ireland:

Attorney General v Paperlink Ltd [1984] ILRM 343
Donegan v Dublin City Council and Others [2008] IESC 288
Donegan v Dublin City Council & anor and Dublin City Council v Gallagher [2012] IESC 18
Dublin City Council v Gallagher [2008] IESC 354
Foy v An t-Ard Chláráitheoir & Ors [2007] IEHC 470
Kennedy v Ireland [1987] IR 587
M v Mental Health Commissioners [2008] IEHC 441
M.X v Health Service Executive [2012] IEHC 491
Macauley v Minister for Posts and Telegraphs [1966] IR 345
McGee v Attorney General [1974] IR 284
Murphy v Stewart [1973] IR 97
O’Donnell (a minor) and others v South Dublin County Council [2007] IEHC 204
O’Donnell and Others v South Dublin County Council [2008] IEHC 454
Pullen and Others v Dublin City Council [2008] IEHC 379
Ryan v Attorney General [1965] IR 294
The State v Frawley [1976] IR 365
TD v Minister for Education and Others [2001] 4 259

Equality Tribunal Cases:

Thompson v Iarnrod Eireann/Irish Rail DEC – S2009-015
Mary Stokes (on behalf of her son John Stokes) v Christian Brother’s High School, Clonmel and Department of Education and Skills DEC – S2010-056

United States:

Albertsons Inc v Kirkingburg 527 U.S. 555 [1999]
Murphy v United Parcel Services 527 U.S. 516 [1999]
Olmstead v L.C 527 U.S. 581 [1999]
Sutton v United Air Lines 527 U.S. 471 [1999]
Toyota Motor Manufacturing v Williams 527 U.S 184 [2002]
European Court of Human Rights:

Airey v Ireland App. No 6289/73 (ECtHR, 9 October 1979)
Ashingdane v United Kingdom App. No. 8225/78 (ECtHR, 25 May 1985)
Bensaid v United Kingdom App. No. 44599/98 (ECtHR, 6 February 2001)
Bosphorus v Ireland App. No. 45036/98 (ECtHR, 30 June 2005)
Chapman v United Kingdom App. No. 27238/95 (ECtHR, 18 January 2001)
Connors v United Kingdom App. No. 66746/01 (ECtHR, 27 May 2004)
DD v Lithuania App. No. 13469/06 (ECtHR)
DH and Others v The Czech Republic App. No. 57325/00 (ECtHR, 13 November 2007)
D.N. v Switzerland App. No. 27154/95 (ECtHR, 29 March 2001)
DeWilde, Ooms and Versyp v Belgium App. No. 2832/66; 2835/66; 2899/66 (ECtHR, 18 June 1971)
Glor v Switzerland App. No. 13444/04 (ECtHR, 30 April 2009)
Guzzardi v Italy App. No. 7367/76 (ECtHR, 6 November 1980)
HL v United Kingdom App. No. 45508/99 (ECtHR, 5 October 2004)
HM v Switzerland App. No. 39187/98 (ECtHR, 26 February 2002)
Herczegfalvy v Austria App. No. 10533/83 (ECtHR, 24 September 1992)
Kedzior v Poland App. No. 45026/07, (ECtHR, 16 October 2012)
Koua Poirrex v France App. No. 40892/98 (ECtHR, 30 September 2003)
Marzari v Italy App. No. 36448/97 (ECtHR, 4 May 1999)
Niemietz v Germany App. No. 13710/88 (ECtHR, 16 December 1992)
Price v United Kingdom App. No. 33394/96 (ECtHR, 10 July 2001)
Sentges v The Netherlands App. No. 27677/02 (ECtHR, 8 July 2003)
Shtukaturov v Russia App. No. 44009/05 (ECtHR, 27 March 2008)
Stanev v Bulgaria App. No. 36760/06, (ECtHR, 17 January 2012)
Storck v Germany App. No. 61603/00 (ECtHR, 16 June 2005)
Thlimmenos v Greece App. No. 34369/97 (ECtHR, 6 April 2000)
Tsfayo v United Kingdom App. No. 60860/00 (ECtHR, 14 November 2006)
Winterwerp v the Netherlands App. No. 6301/73 (ECtHR, 24 October 1979)
X v United Kingdom App. No. 7215/75 (ECtHR, 5 November 1981)
Zehnalova and Zehnal v Czech Republic App. No. 38621/97 (ECtHR, 14 May 2002)
United Kingdom:

*Barry R v Gloucestershire County Council & Another* [1997] UKHL 58
*Birmingham City Council v M, G and H* [2011] EWHC 1147 (Admin)
*Burnip v Birmingham City Council & Anor* [2012] EWCA Civ 629
*Isle of Wight Council v JM and NT* [2011] EWHC 2911

European Court of Justice:

Case T-10/93 *A v Commission* [1994]
Case C-13/05 *Chanon Navas v Eurest Colectividades SA* [2006]
Case C-303/06 *Coleman v Attridge Law and Steve Law* [2008]
Case C-61/94 *Commission of the European Union v Federal Republic of Germany* [1996]
Case C-178/03 *Commission of the European Communities v European Parliament and Council of the European Union* [2006] ECR I-107
Case C-344/04 *European Court of Justice International Air Transport and European Low Fares Airlines Association v Department of Transport* [2004]
List of legislation

Constitution of Ireland

Competition Act 2002
Criminal Law (Sexual Offenses) Act 1993,
Disability Act 2005
Employment Equality Act 1998
Equal Status Act 2000
Equality Act 2004
European Convention on Human Rights Act 2003
Health Act 1947
Health Act 1953
Health Act 1970
Health Act 2004
Housing Act 1966
Housing (Miscellaneous Provisions) Act 1979
Housing Act 1988
Housing (Miscellaneous Provisions) Act 1997
Housing (Miscellaneous Provisions) Act 2009
Lunacy Regulations (Ireland) Act 1871
Mental Health Act 2001
Planning and Development Act 2000
Chapter 1: Introduction

\textit{Nil aon tinteán mar do thinteán féin.}

\textit{There's no hearth like your own hearth.}

1.1 Introduction

This saying is one of the best-known Irish proverbs and a version of it can be found in almost all other languages of the world. It expresses the universal desire to have a home of one's own, and encapsulates the sense of warmth and security we seek at home. Gaining and sustaining a safe and secure home in which to live with dignity and respect is essential for all of us if we are to grow and develop and find our place in the world. For without a safe and secure home it becomes almost impossible to sustain other areas of life such as work, relationships, support networks, health and education. But many people with intellectual disabilities (PWID) in Ireland never get to have a home of their own in the same way as their brothers and sisters do, when they move away from their family. The idea of home is an enormously powerful and evocative concept bringing to mind ideas of security, belonging, family, warmth, privacy, connectedness, roots and safety. It is a concept that has been widely studied across several disciplines and 'home' appears to have three essential elements. Firstly, the physical structure which provides shelter, security and a fixed location. Secondly, the social relationships within the home and with others in the wider environment of the home – neighbours, relatives, and other social networks. And thirdly, the atmosphere within the home, which provides warmth, privacy, control and a place for self expression and the development of self identity.\textsuperscript{1}

There are few who would contest the importance of home to our sense of well-being and our place in the world and it can perhaps be best comprehended in its absence, that is being homeless. This begs the question 'if home contributes to people's psychological and social identity and well-being in such fundamental ways, what then are the implications if ones home is an institution, a group home

or other congregated setting, shared exclusively with other unrelated people with broadly similar disabilities?’ ‘What are the implications if one does not have any legal security in ones home - either as a home owner or tenant - and can be moved for reasons that may have little or nothing to do with what one wants?’ For many Irish people with intellectual disabilities this is the everyday reality.

1.2 The context of the research
In general when adults with intellectual disabilities in Ireland leave their family homes their housing pathways diverge markedly from those of their peers. And for most the only home they will have access to is within a segregated housing system where they have little choice about where or with whom to live. Ireland, like many other European countries, has historically placed PWID who could not be cared for at home in large institutions. Of course this was also the experience of many other ‘social misfits’, but in recent years much progress has been made in abolishing institutions such as the Magdalene laundries and downsizing the large psychiatric hospitals. For PWID progress has been much slower, with over 4,000 people still remaining in residential institutions of one form or another and a further 4,000 living in group homes. The Ombudsman, Emily O’Reilly contends that we are continuing the practice of institutionalizing older people in nursing homes because it is easier and more manageable than supporting people to live at home. She suggests that ‘... institutions are easy to manage, easier to administer. Far more difficult, much more of a nuisance, is the job of devising individual care plans for people, messily and inconveniently scattered across a wide area, and not sitting tidily together in a home with the institution deciding what services they ought to get.’ This statement could equally be made about PWID in this country. An institution can be defined as ‘... any place in which people who have been labeled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.’ The extent to which group homes conform to this definition is at least questionable and is largely determined by the agency which

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4 Definition used by Inclusion International and by the Institute for Independent Living.
operates the home. The extent to which people can experience the important features of home in these settings is also open to question. What is clear is that people living in these settings do not have security of tenure, perhaps the most important feature of adequate housing as defined by the UN Committee on Economic, Social and Cultural Rights, and can be moved without regard to their wishes.

In Irish law residential accommodation for PWID is framed as a health issue, rather than a housing issue, with ‘institutions’ for people with disabilities being defined under the Health Acts – not housing legislation. This sets in train a pattern whereby PWID in need of housing are more likely than not to have their housing needs met within a separate system, which is distinct from that which deals with the housing needs of others. This separate system, because of the almost exclusive availability of personal support therein, is only accessible to PWID and becomes, in effect, the primary housing option open to people once they leave the family home. This is not to comment on the quality of the housing, but rather to note the segregated nature of this system and it represents another example of how we treat PWID as different and in need of ‘special’ services.

According to the census of 2011 there are 57,709 people with intellectual disabilities living in the state representing 1.2% of the population. The National Intellectual Disabilities Database (NIDD) in the same year tells us that 27,324 PWID were in receipt of or required specialist intellectual disability services. There is clearly a discrepancy here and it must be assumed that many that PWID who do not require or want disability support services are not registered with the NIDD – and it is likely that this is largely people with milder levels of ID. And of the 9,158 adults on the NIDD adults not living at home with their families only 1,107 are described as living in independent settings with the remainder living in residential centres, group homes or other forms of congregated settings.

The census data also shows that PWID are much less likely to become home owners, get married or have a job and are much more likely to live in communal establishments than other people.

Article 19 of the CRPD asserts the right of people with disabilities to Independent Living (IL). Today group homes or residential centres are the main housing

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options open to PWID when they move out of the family home, and for as long as this remains the case few are likely to experience independent living.

Having worked with PWID for many years it is clear that great strides have been made in Irish law and policy as it affects PWID and there is no doubt that the quality of the services available to people and their families are a vast improvement on what was provided heretofore. However, despite these improvements there remains an ingrained pattern, which sees people’s choices about how to live their lives being severely limited and this is nowhere more obvious than in the housing sphere. The limiting of people’s lives arises from cultural, social and political beliefs about PWID and our supposed need to ‘care’ for and ‘protect’ them from the harsh realities of life. There are, however, also barriers arising from our laws and policies which can more easily be changed and which are necessary in order to create the space where people can make real choices about their lives and have the support they need to live in their communities along with everyone else.

We are at a point when active consideration is being given by government to how best to form policies and law to support people to lead more fulfilling lives. Over the past two years there has been a steady stream of policy documents issued by various arms of government,\(^7\) which appear to indicate a willingness and a wish to change and improve how we support citizens with intellectual disabilities. These policy documents speak of the need to have ‘person-centred’ supports, facilitate individual choice and self-determination, inclusion and participation in the community, equality of opportunity, access to the mainstream and independent living. They also acknowledge that we are operating in a difficult economic climate and that all of these aspirations must also achieve greater cost-efficiencies.

1.3 Who and what is this research about?

In 2006 the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD), marking a leap forward for the rights of disabled people across the globe. For although the human rights outlined in the CRPD may be only an aspiration for many people, it sets the standard to which all states must aim for their disabled citizens. At the heart of the CRPD is the right to Independent Living at Article 19, and it can be seen as one of its core drivers along with its sister article, the right to equal recognition before the law. IL is defined as the right to choose, on an equal basis with others, where and with whom to live and not be obliged to live in any particular living arrangement, the right to support for living and participation in community and the right to accessible and responsive generic community services. This is the first time the right to IL has been named in an international human rights instrument giving rise to the question of whether it is a new right only applicable to disabled people. In fact, as pointed out by Parker and Clements, the right to IL is an amalgam of pre-existing rights and Article 19 explicates what is required to ensure that people with disabilities can exercise these rights. The idea of IL has been a fundamental part of the disabled people’s movements from the beginning, but it presents different challenges when we consider how it can be made real for PWID. The very idea of ‘independence’ as a state to which people should aspire has been challenged by some, including Asch, Smith and Kittay. This feminist perspective asserts that none of us is actually independent, that we are all dependent and inter-dependent with each other and that it is within relationships with others that we flourish. Article 19 can be seen as resolving this conflict by inter-linking the ideas of IL with that of participation in the community. Part of the difficulty with the idea IL for PWID is that ‘independence’ is rarely, if ever, envisaged as something which they could, or indeed should, aim for. This may also be true for everyone else, but it misconstrues what IL is about because the right to IL is first and foremost about individual choice. It concerns people being able to make the same choices as

everyone else about where and how they live their lives. For PWID who have been given very limited choice in these crucial personal decisions, often in the guise of protection, the idea of IL has a special significance. Perhaps because of the cultural dissonance with the idea of ‘independence’ for PWID, IL for them is often termed ‘community living’ or ‘supported living’ but the basic tenets of the idea remain the same.

The focus of this study is people with intellectual disabilities. The CRPD does not provide a definition of ‘disability’ as such, but the description of ‘persons with disabilities’ at Article 1 is fully inclusive of PWID. For the purposes of this research ‘people with intellectual disabilities’ is defined using the World Health Organisation definition12. This definition was used as it includes reference to the impairment of intellectual and social functioning but avoids any classification of people by level of IQ or specific diagnosis and is sufficiently broad to include people with autistic spectrum disorders. I decided to concentrate on this group primarily because of a realisation that, regardless of how well those of us who work in the area try to support people to achieve the ideals of IL, we work within a legal and policy framework which hinders what people can actually do in the world. If a person with an intellectual disability wishes to open a bank account, purchase a house, move in with a partner or even get the bus into town they are immediately presented with obstacles. These obstacles arise from what we believe about people’s capabilities, our concerns for their safety, questions about their legal capacity, inaccessible systems and a lack of acceptance that they should be able to do and be what they want in the same way as everyone else.

I use the term ‘disabled people’ and ‘people with disabilities’ interchangeably in this work. I do this in order to avoid the debate about terminology, which, while it may be interesting, is not the point of this study. Secondly, people including PWID, may be disabled by their environments, but they also have impairments which have an impact on their lives and their abilities. So they are people with a disability, and they are people who are disabled by their environment.

1.4 Aim of the study

If we are to take the idea of Independent Living seriously for PWID there is a need to look at how the existing legal framework either helps or hinders the realisation of the core elements of this right. This study aims to discover how the right to IL can be made real for PWID – but in a way that is fair, and can be seen to be fair, not only to PWID themselves, but to all members of society including other groups and individuals. The use of the term ‘fair’ in the title indicates that this is a central value of the work. Simply arguing for additional resources to realise rights or for special treatment for PWID because of their ‘special’ needs is not the best route. It has in fact contributed in a fundamental way to the sense that PWID are different from the rest of humanity, are not quite entitled to hold rights and responsibilities in the same way as everyone else and that their rights are somehow conditional. In order for any redistribution of resources to PWID to be fair, and be seen to be fair, it must entail firstly, a recognition that PWID are full rights holders and are an inherent part of the human family. Secondly, the realisation of rights for PWID must be in the context of the realisation of rights for all, including other groups who experience marginalisation.

The study aims to establish a philosophical/political framework within which the right of PWID to realise IL could be supported in a way that is equally fair to all citizens and which treats them as an intrinsic ‘... part of human diversity and humanity’. In coming to an understanding of how this can be achieved at a philosophical level the work of Rawls and his critics were foundational to the study. Philosophers, including Silvers, Francis, Wong and Kittay and the feminist and critical race perspectives of Okin, Mills and Hampon were relied on to broaden Rawls’ original theory to be fully inclusive of PWID as well as all other perceived ‘outliers’. Silvers challenges us with the contention that the direction of extraordinary resources to disabled people, because of their perceived neediness, actually damages disabled people by inducing greater neediness and competition for resources among them. Wong’s insight that what is actually required is

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'enabling conditions', to facilitate inclusion can equally be applied to any excluded group, and in fact the enabling conditions required by the majority of the population are already built into society's structures and institutions. Some groups or individuals may require adaptations to existing structures or particular supports to enable inclusion, but in justice these must be available, otherwise sections of the population will remain unfairly excluded.

Concomitant to a philosophical framework the study aims to identify a conception of disability which supports this understanding and which is broad enough to include all disabled people as a matter of justice, while also being inclusive of all other citizens. The social model of disability, in all of its guises, can be credited with a great many of the advances which disabled people have made in realising rights. However, it also faces criticisms, especially in relation to PWID. The most significant of these criticisms, from the point of view of this study, is that it does not fully address the situation of PWID and they remain largely excluded from many of its basic tenets. The social model originated in the experiences of physically disabled men and is based on the premise that what is needed to enable disabled people live independently is accessible environments and personal assistance. As Morris\(^\text{16}\) points out however, most disabled people are not young healthy men who use wheelchairs needing only physically accessible environments. The largest group of disabled people is actually those with intellectual disabilities and the majority of physically disabled people are older women with chronic or progressive conditions. Most PWID do not have difficulties with physical access and the assistance they require may be quite different from that of physically disabled people. In addition PWID are subject to very different stigmatising stereotypes than people with physical disabilities, the most powerful of which is that they are childlike people who will never achieve independent living.

The idea of a universal approach to disability, proposed at the early stages by Zola\(^\text{17}\), is based on the premise that we are all more likely than not to experience disability, either personally or in someone close to us, at some point in our lives. Therefore, disability should not be seen as an unusual or unexpected part of

\(^{16}\) Morris, J. 'Impairment and Disability: Constructing and Ethic of Care that Promotes Human Rights' (2001) Vol 16 Hypatia p 9

human experience. What is needed, as proposed by Bickenbach\(^\text{18}\), is a broadening of what is considered to be ‘normal’ to realistically include empirically-grounded human variation. Disability is a near universal experience and this reality should be taken into account in the ways we design our laws, policies and environments. Advocates for this approach suggest that our laws and policies should not be specifically for disabled people, but that law and policy should be applicable to all. Or rather that disability policies should be seen as policies for everyone. This does not preclude the development of particular supports where these are needed. In fact with a universalist approach which aims at inclusion, such targeted supports are, as suggested by Imrie\(^\text{19}\), fully mandated. Such an approach has the potential to address the famous ‘Difference Dilemma’ posed by Minow\(^\text{20}\) which asks whether it best to treat different people differently and stigmatises them on that basis or to ignore their difference and stigmatises them on that basis. For if we can conceive of PWID as more like everyone else than they are different, and we realise that most of us are likely to become disabled at some point, then we can properly set about the task of ensuring that all citizens, whether currently disabled or not, have access to their rights on the basis that this is the just and fair thing to do.

The work of establishing a philosophical/political framework to support the full inclusion of PWID and a conception of disability which dovetails with this, addresses what can be seen as the first part of the question posed in the title. The second task was more technical and practical in nature. The aim of this part of the work was to attempt to answer questions such as: How well do our laws enable PWID to achieve the basic elements of independent living? Are there any legal barriers which hinder people in exercising this right? As one of the countries which has committed to ratifying the CRPD, what are the obligations we must meet in order to create the conditions necessary to enable IL for disabled people. Ms Justice Mary Laffoy asserts that the Irish Constitution, Bunreacht na hEireann, is the ‘...primary and most effective source of the protection of human rights in the


State. This is indeed a large claim, but within the Constitution most of what are recognized as civil and political rights are present. In terms of socio-economic rights in the Constitution, however, the picture is not so clear-cut with the Courts, up until 2001, spelling out ‘unenumerated’ or implied rights under Article 40. Some of these unenumerated rights are part of the IL right, such as the right to privacy, but their explication by the Courts on an ad hoc basis dependent on the presentation of relevant cases, rather than by the Oireachtas, was problematic. The 1996 Constitutional Review Group observed that the list of unenumerated rights identified by the courts is incomplete and omits many of the rights in international human rights instruments. The Constitution holds both a practical and symbolic place in Irish law. All legislation must be in conformity with its principles and the rights and obligations in the Constitution have a particular significance. Whether the Constitution could more effectively serve to uphold human rights for all citizens, including socio-economic rights such as the right to housing, is debatable. However, there is scope to assert more fully the equality of all citizens as holders of human rights in the Constitution. This may be an area which the recently established Committee on the Constitution could usefully address.

The key pieces of legislation which impact on the right to IL in the Irish legislative canon are in the areas of housing, health, equality and non-discrimination, human rights, legal capacity and disability-specific legislation. In examining these Acts of the Oireachtas the aim was to discover how well each supports or hinders the main elements of the IL right, identify any legislative gaps and suggest how legislation could be changed or developed to better support the right – all within a universalist approach inclusive of all citizens. Several ways in which Irish legislation supports the right to IL are identified, in particular recent developments in housing legislation, the equality legislation and aspects of the Disability Act. Areas which present difficulties arise primarily within the health and legal capacity fields. Health legislation, which, as noted above, provides the legal framework for residential accommodation and personal support services for

22 Kennedy v Ireland [1987] IR 587
PWID, is inappropriate and is incapable of effectively providing the conditions necessary to enable the realisation of the right to IL. As long as residential accommodation for PWID remains within the health framework, it will be a separate ‘special’ housing system providing very limited choice to PWID. Alongside this the lack of a legal mechanism to allow PWID have access to support in their own home, represents a major hurdle. Some disability service providers operate in-home support services\textsuperscript{24} for individuals to enable them remain in their own homes, but these represent a small proportion of the organisation’s budgets for residential services. In both of these areas and in the area of legal capacity legislation fundamental change is required and although this is anticipated in respect of legal capacity, no such change is planned in the health area.

The Irish legal framework is subject to the influence of the European Union and the Council of Europe. EU Regulations and Directives have direct application in Irish law, although Directives leave room for member states to decide on the method of implementation. The passing of the Lisbon Treaty marked a major step forward for the status of human rights within the EU with the elevation of the place of the Charter of Fundamental Rights to that of equal value to the Union treaties, and the commitment to accession to the European Convention on Human Rights (ECHR) by the EU. This aspect of the study aimed to explore the implications of these developments along with the potential of the proposed Equal Treatment Directive in Areas Outside of Employment for disable people and its significance for Irish law.

Ireland is bound by the ECHR both as a member of the Council of Europe and with the incorporation of the ECHR into Irish law. The ECHR is the only human rights instrument which has been incorporated into Irish law and so holds a particular significance. The ECHR is a traditional civil and political rights instrument, nonetheless aspects of it are especially relevant to the right to IL. This aspect of the study aimed to ascertain the potential of the ECHR to further the right to IL both through the case law of the European Court of Human Rights and incorporation of the ECHR. It focused specifically on the right to liberty and security of person (Article 5), which speaks to the issue of institutionalisation, and the right to private life (Article 8). The jurisprudence in relation to Article 5 has been gradually evolving to more fully recognise the rights of people with

\textsuperscript{24} For example Western Care, Brothers of Charity Services, Walk and St Michael’s House
disabilities detained – whether voluntarily or otherwise – in residential institutions. The Article 8 case law as it refers to disabled people, on the other hand has made much less progress. There remains however, the potential to convince the Court that Article 8 rights are being breached when PWID are institutionalised, especially if taken in conjunction with the revised non-discrimination right under Article 14. A ruling of this nature could have major implications for how PWID are treated in Irish law, as was illustrated by the similar Olmstead25 judgement in the United States. However, it has yet to be considered by the Court.

Having ratified several United Nations human rights instruments Ireland has undertaken to respect, protect and promote these rights for all citizens and although these instruments are not directly applicable in national legislation, the reporting obligations and concluding comments of the relevant UN monitoring body can have a political impact and help to highlight where rights are being systematically infringed. This part of the research attempts to locate the core elements of the IL right within mainstream human rights instruments and consequently outlines what its minimum core obligations are likely be. The question of whether there should be a separate human rights instrument for disabled people, or indeed for any other group, is also explored in this section. In a universalist world there would be no need for such group-specific instruments as the structures would be in place to enable the realisation of rights by all. It is arguable that a special convention for people with disabilities contributes to the notion that they are different from other people and because of this require a different instrument. On the other hand, an equally valid argument is that the human rights situation of disabled people is significantly different, not because of their difference, but because of how they have been excluded and denied rights in ways which are specific to their experiences. This may also be true for other groups who may also experience a denial of rights in ways specific to them, for example rights infringements which are associated with pregnancy and childbirth. It is argued that the CRPD is an important tool for disabled people, but that the rights it contains should be available to everyone regardless of group membership. This is especially valid in the case of the right to IL, which is denied to many people across the globe on bases other than disability, including ethnicity, religion or gender.

1.5 Structure of the thesis

The thesis is divided into nine chapters. Chapter two describes the methodology used to gather and analyse the information needed to answer the research question. It sets out the research framework which was applied to each part of the work in order to systematically approach the subject and to provide consistency in the approach.

Chapter three considers how Rawls’ principles of justice can support a universalist approach to disability, which, it is argued, will provide the best route for the full inclusion of all disabled people in society. The major criticisms of Rawls’ theory from both feminist and critical race theorists are also discussed, several of which are equally valid in the case of people with impaired capacity. There is an analysis of how these criticisms can be overcome to enable the theory to be fully inclusive of everyone, not only PWID, and to provide a basis for universal accessibility and the provision of targeted supports to facilitate inclusion in particular cases.

Chapter four brings the research into the reality of people’s lives and paints the picture of where PWID in Ireland actually live. It describes the housing pathways and housing options open to PWID, and highlights the differences between these and the pathways and options open to the rest of the population.

Chapters five to eight form the core of the legal research of the thesis and they explore the relevant law at international, regional and national levels. To begin this, chapter five attempts to identify where the essential elements of the IL right are located within mainstream human rights instruments. It then outlines what are likely to be the minimum core obligations on states to implement the right to IL. Chapter six looks to the European Convention on Human Rights and the possible implications for the right to IL in Ireland arising from the case law of the European Court of Human Rights. Chapter seven discusses the impact of European Union law on Irish legislation relevant to IL, and particularly the implications of the passage of the Lisbon Treaty. Finally chapter eight gives a detailed analysis of those aspects of existing Irish law which are most closely associated with the right to IL and attempts to identify where and how this right is both supported and hindered in the law.
The conclusions are presented in the final chapter. This chapter attempts to bring together and analyse what has been learned from all of the preceding chapters and to offer suggestions as to what is required in our law to better support PWID in achieving IL. It also outlines the limitations of the research and suggests areas where useful research could be undertaken in the future.
Chapter 2 Methodology

2.1 Introduction

The overall question for this research is ‘What are the key conceptual, legislative and structural requirements to enable the right to Independent Living for people with intellectual disabilities in Ireland?’

At the outset it is important to situate the right to independent living (IL) within a philosophical framework that provides a firm foundation that will support the human rights of all citizens and the right to IL for people with intellectual disabilities (PWID) in particular. Historically PWID, and especially those with more significant levels of intellectual disability (ID), have not on the whole been treated in the same way as others in terms of human rights and in terms of the right to IL – rights have not been seen as applying to them in the same way, and, within the disability movement, the right to IL has been seen as applying primarily to people with physical/sensory disabilities. So there is a need to establish a political/philosophical approach and a conception of disability which are inclusive of all people with disabilities (PWD) and which enable the realisation of the right to IL for all, regardless of type or level of impairment.

The legal structures, in terms of legislation and relevant case law, provide the framework within which the right to IL and community inclusion are or could be played out. It is therefore, important to discover what this framework provides, what its limits are and what legislative changes are required to enable the full realisation of the right to IL for people with disabilities.

In order to clarify the problem it is also important to identify not only what the current law provides, but also what the reality of living options open to PWID is. To what extent are PWID accessing mainstream housing options and what are the barriers to access? This involves looking at existing housing systems and existing support systems. For if people require, and have a right to, support to achieve IL, then this support must be configured in ways which enable choice in living arrangements. So the two issues major issues in this regard are access to housing and access to support.

The work is structured to provide:
A) A philosophical approach and theoretical framework which supports a broad human rights framework for all citizens and in particular the right to IL for PWID

B) A conception of disability which is fully inclusive of PWID and supports the right to IL for PWID and which can be translated into mainstream law and policy

C) A statistical analysis which gives an overview of the extent of the problem, outlining the current living arrangements and housing pathways of PWID and identifying the blockages in access to mainstream housing.

D) A detailed account of current national and international legislation applicable in Ireland as it impacts on the right to IL for PWID. This includes an analysis of how legislation currently supports the right to IL, identifies any gaps in legislation and the potential of the law to better support the right. This aspect of the research is undertaken at three levels each of which impacts on the law in Ireland:

1. The international level
   United Nations (UN) human rights treaties, in particular
   United Nations Convention on the Rights of Persons with Disabilities (CRPD)
   International Covenant on Economic, Social and Cultural Rights (CESCR)
   International Covenant on Civil and Political Rights (CCPR).

2. The Regional level covering:
   The Council of Europe – the European Convention on Human Rights (ECHR)
   The European Union - The Framework Employment Directive (FED) and the draft Equal Treatment Directive (ETD) and the CRPD and the ECHR post the Lisbon Treaty

3. The national level covering constitutional and legislative instrument which impact on the right to IL

E) Conclusions on the route to IL and the key changes at philosophical, legislative and practical levels which are required to realise the right to IL for PWID in Ireland
2.2 The Research Question

As noted above the overall question for this research is ‘What are the key conceptual, legislative and structural requirements to enable the right to Independent Living for people with intellectual disabilities in Ireland?

This, of course, is a very broad and multi-dimensional question which needs to be broken down into more manageable sub-questions. Specifically the questions are:

**Political/Philosophical**

What political/philosophical framework best supports the human rights and the right to IL for PWID in a way which is fair to all citizens?

What philosophical/political framework is most inclusive of all citizens, including PWID?

**Models/concepts of Disability**

What model/conception of disability best supports the human rights and the right to IL for PWID?

What model/conception recognises the universal nature of impairment and overcomes the ‘specialness’ of disability?

**Statistical:**

Where do PWID live in Ireland?

What are the housing pathways of PWID in Ireland?

Are these pathways different from the majority of the population and if so how and why?

**Legislative:**

What are the minimum core obligations of the right to IL?

What does the law state about the core elements of the right to IL?

How has the law been interpreted in relation to the core elements of the right to IL?

What are the gaps in legislation and caselaw in supporting the right to IL for PWID in Ireland?
2.3. Definition of terms

a) Disability

It is necessary to clearly define what precisely is meant by the key terms used in the research. The questions arises from Article 19 of the CRPD and the terms 'independent living', 'community inclusion' and 'disability' are based on the definitions offered therein. The CRPD does not offer a definition of 'disability' as such but it defines people with disabilities as ‘...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ The WHO International Classification of Functioning, Disability and Health, 2001, (ICF) which was developed largely as a research and planning tool, provides a broad definition of 'disability'. The ICF focuses on the impact of various health conditions on human social and physical functioning taking account of environmental and personal factors. Thus 'disability' results from the interaction of individual impairments with personal factors and environmental factors, which jointly determine the level of functioning possible for the person. The ICF defines 'disability' as ‘an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).’

This definition recognises that knowing that an individual has an impairment is only one part of the equation, of at least equal importance is the capacity of the person to participate in the activities of daily life and this is determined by the environment in which the individual finds him/herself. I suggest that the definition developed by the ICF is reflective of the use of the term used throughout the CRPD i.e. it encapsulates the interactive relationship between individual impairment and the environment and recognises that any impairment which is not accommodated for in the environment constitutes a disability.

b) Intellectual disability

People with intellectual disability are subject to an inordinate amount of research, assessment and intervention as compared with other segments of the population.

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It can be argued that there is no requirement to define what ID is as the definition of ‘disability’ clearly includes people with ID. However, this fails to recognise that many of the barriers facing people with ID are different in important ways from those facing people with other types of disability. In particular, many of the barriers, which are attitudinal and cultural, make assumptions about the childlike state of adults with ID and the consequent limitations placed on them in terms of living what are regarded as ‘normal’ adult lives. It is these barriers primarily which need to be recognised and countered for PWID, and not the barriers to physical access which most often confront people with physical or sensory disabilities.

A variety of terminology, usually with negative connotations, has been, and is, used to describe people who have an intellectual disability and the assessment and response to ID is dictated largely by social and cultural beliefs. As stated by Felec ‘While the conditions which give rise to mental retardation or intellectual disability are universal, how the resulting condition is conceptualised, assessed and categorised, and the response which will be made, will and does vary between countries, cultures and economies.’

As generally understood people with an ID include those who have significantly impaired intellectual functioning and/or adaptive behaviour and these are evident from childhood. The CRPD correctly does not define any particular type of disability so for the purposes of this study the definition of ‘intellectual disability’ is that provided by the WHO i.e. ‘a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.’ This definition is chosen because it avoids the necessity for classifying people in terms of level of IQ, degree of ID (usually categorized as mild, moderate, severe or profound) or specific diagnosis and it is broad enough to include people with autistic spectrum disorders. PWID may also have additional physical or sensory disabilities or mental health problems, which may compound the effects of their impairments and they may face additional


environmental barriers as a result. The effects of ID on a person's intellectual functioning are clearly lifelong, but the effect of negative attitudes are equally lifelong. We actually have no evidence about how well PWID would fare in the absence of such negative stereotyping and will not have such evidence until we find ways of enabling them realize the right to IL and community inclusion.

While the definition of ID assumes that ID begins in childhood, there are many people whose intellectual or social functioning becomes impaired temporarily in adulthood whether from accidents, disease, mental illness, emotional trauma or age-related dementia. And while people in these circumstances will have experienced what can be considered ‘normal’ adult life, they are also likely to become the subject of many of the same negative attitudes as PWID. It may well be, therefore, some of the findings of this research have application beyond the group of people with intellectual disabilities.

c) Independent living and community inclusion.

The concept of IL has been an integral part of the disabled people’s movement for several years before it began to be recognized in international human rights law and policy. It has been variously described as a philosophy and a movement of people working for self-determination, the ability to decide and choose what a person wants, where to live and how, what to do, and how to set about doing it and as a way of disabled people accessing their human and civil rights. The concept has had a powerful influence on the disabled people movement internationally, however, it is perhaps a misnomer. The use of the term 'independence' belies the inter-dependent nature of all people and in fact Adolp Ratzka of the Independent Living Institute makes it clear that

‘Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we

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29 Note the 2011 report of the National Intellectual Disabilities Database recorded that 39.6% of people on the database had additional physical/sensory disabilities. Table 2.5 p33
demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.”33

In relation to PWID independent living is often termed community-living or supported living. The core of the concept remains the same however, being about equality of choice, self-determination, access to the same services and facilities as all other citizens and support to enable access. The CRPD relates the idea of IL directly to that of community inclusion and in this it directly addresses the notion that people can be or should be independent of others. In fact it fully recognises that we are all inter-dependent in our relationships with others and it is within communities that people’s personality and skills develop. The definition of ‘IL and community inclusion’ adopted for this research is, therefore, based wholly on Article 19 of the CRPD as follows:

**IL and community inclusion means people with intellectual disabilities living and participating in the community with choices equal to others. This includes, on an equal basis with others, people:**

a) choosing where and with whom they live and not being obliged to live in any particular living arrangement

b) having access to in-home residential and community supports (including personal assistance) to support inclusion and prevent isolation

c) having equal access to all community services and facilities which are responsive to their needs.

**2.4. The Research strategy**

The strategy adopted is inter-disciplinary including both qualitative and quantitative approaches. Chynoweth34 outlines a taxonomy of legal research styles based on the work of Arthurs which draws distinctions between Applied and Pure research on one axis and Interdisciplinary and Doctrinal research on the other axis. Using this framework, this work falls mostly within the law reform research/law in context bracket as it is intended to be of use in the formation of

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law and policy as well as having academic significance. It relies on traditional doctrinal legal research to determine what the law is, and how it is interpreted by the courts at national and international level. The research also uses data publicly available to draw a picture of the housing pathways of PWID in Ireland and highlight the ways in which these diverge from the norm. At the outset it seeks to establish a philosophical underpinning which is universally applicable and which supports human rights as rights rather than as charity.

Doctrinal legal research is defined by McConville and Chui as ‘... research which asks what the law is in a particular area ... the researcher's principal ... aim is to describe a body of law and how it applies ... the researcher may also provide an analysis of the law to demonstrate how it has developed in terms of judicial reasoning and legislative enactment.’

Doctrinal legal research was used to address the research question and sub-questions at a each level and included an analysis of legislative changes which would further the right to IL for PWID.

**Figure 1: Arthurs Legal Research Styles**

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This latter analysis moves the research leftward along the horizontal axis as, despite the fact that legal rules are normative in character in that they describe how the law stands and how it is interpreted, the analysis of required legislative changes takes account of social factors beyond the law. As Chynoweth describes it ‘In practice, even doctrinal analysis usually makes at least some reference to other, external, factors as well as seeking answers that are consistent with the existing body of rules. For example, an uncertain or ambiguous legal ruling can often be more easily interpreted when viewed in its proper historical or social context, or when the interpreter has an adequate understanding of the industry or technology to which it relates.’

The primary research methods used were:

a) Statistical analysis from publically available data sources
b) Literature review of philosophical, political and conceptual approaches to human rights, disability and inclusion.
c) Doctrinal legal research on legislation and case law at national, regional and international levels which impact on the right to IL for PWID in Ireland

The variety of methods used, then, span the qualitative-quantitative spectrum. Clearly statistical analysis is quantitative and where doctrinal research falls along the continuum is debatable but I suggest that in the case of this research it is qualitative as ‘[d]octrinal research is not simply a case of finding the correct legislation and the relevant cases and making a statement of the law which is objectively verifiable. It is a process of selecting and weighing materials taking into account hierarchy and authority (of sources) as well as understanding social context and interpretation.’

2.5. The Research Framework

The framework for this work is that outlined by Dobinson and Johns and which is based on the work of Arlene Fink. This framework was used as it provided a straightforward and logical means of working through the vast amount of materials from a variety of sources. The framework was used in relation to each

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38 Ibid p21-22
of the four major aspects of the work i.e. literature reviews of philosophical/political foundations and the models/conceptions of disability, the legal research at national, regional and international levels and the statistical research on living arrangements and housing pathways for PWID. The steps involved are:

1. Identifying the overall research question and the sub-questions in each of the four major areas of the research
2. Identifying the most relevant bibliographic and article databases for each area
3. Identifying the most relevant terminology and search terms for use in each area
4. Identifying the criteria to be used to select the most relevant data and information in each area
5. Analysing the information and relating it to that gathered in each of the other areas.

A matrix summary of each of the areas within the research framework is given below
Overall research question:
What are the key conceptual, legislative and structural requirements to enable the right to IL for PWID in Ireland?

<table>
<thead>
<tr>
<th>Research Question and sub-questions</th>
<th>Philosophical Foundations</th>
<th>Models of Disability</th>
<th>Statistical research</th>
<th>National and international legal research</th>
</tr>
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<tbody>
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<td>What political/philosophical framework best supports the human rights and the right to IL for PWID?</td>
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<td>What does the law state about the core elements of the right to IL?</td>
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<td>Are these pathways different from the majority of the population and if so how and why?</td>
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2.5.1. Philosophical, political and conceptualisation foundations

a) The research questions
The purpose of this aspect of the research was to answer the following sub-questions:

- What political/philosophical framework best supports the human rights and the right to IL for PWID?
- What philosophical/political framework is most inclusive of all citizens, including PWID?
- What model/conception of disability best supports the human rights and the right to IL for PWID?
- What model/conception recognises the universal nature of impairment and overcomes the ‘specialness’ of disability?

A literature review in the following areas was conducted:

- The theoretical framework
- Models of disability
- Independent Living
- Housing for PWID

This sought to provide an overview and analysis of current thinking on the right to IL for people with intellectual disability and to establish the gaps in knowledge and the current state of research in the area. It was necessary to conduct the review across a range of disciplines to achieve a broad understanding of the issues involved. This included looking to sociological, legal, housing and philosophical sources and relevant information sources were consulted in each area. These included academic literature – encyclopaedias, peer reviewed journals, textbooks, conference papers – and information available from government, semi-state and voluntary agencies active in the field. Information was accessed from internet websites of relevant agencies and relevant academic databases in each area as indicated above.

b) Databases and sources of information
The literature review in each area involved the collection of legal, academic and policy documents, agency information and publications. In locating relevant
academic work internet searches were conducted using primarily the following databases

- Hein On Line
- Lexus Nexus
- Project Muse
- Westlaw
- JSTOR

A review of the history of the development of law and policy in relation to PWID was undertaken and this covered the re-conceptualisation of disability from a purely medical approach to the social model and the evolving universalist approach which builds on the social model.

Sources used in this regard included the United Nations archive and the Disability Archive of Leeds University.

c) Search terms

As noted a variety of terminology is used to refer to intellectual disability in academic literature, legislation, policy and in everyday parlance. It was necessary therefore to use a wide variety of search terms to ensure that the widest range of relevant literature and commentary could be gathered, as listed above. This is also true for the idea of IL, which, particularly for PWID, is often called supported, assisted or community living. A key idea when discussing PWID is the levels of dependence of people with various degrees of ID and one of the most widely held beliefs is that PWID will always be dependent on the state or on their families to survive – that they have little to contribute and will always be users of public resources or those of their families. For this reason the idea dependence and how dependency needs are dealt with is an important aspect of the research and so search terms included those related to the idea of independence, dependence and inter-dependence.

d) Selection criteria

It was important at the outset to establish a theoretical basis for the right to IL and the criteria used were firstly, that the theory should be broad enough to support human rights for all citizens, not just those with disability. Secondly, it had to be a
theory that has general political credibility and not one providing a narrow marginal theoretical perspective. The following theories were reviewed using these criteria:

- The Capabilities Approach
- The Vulnerabilities Approach
- Group-based oppression
- Justice as fairness

Following extensive reading in the area the theory which best met the criteria and best supports the right to IL for PWID was identified as that of Rawls’ Justice as Fairness. The analysis of the theory, the justification for choosing it and its applicability to PWID are detailed in the theory section of this research.

The same criteria were used in deciding on models or conceptions of disability and approaches to housing for PWID. That is, the conceptions/models had to be generally applicable to all citizen’s – not just disabled people – and they had to have general political credibility. The model or conception of disability which best met these criteria was a Universalist approach.

2.5.2. Doctrinal Legal Research

The purpose of the law is to provide an authoritative framework for behaviour. It sets standards for what is acceptable and unacceptable behaviour by individuals, institutions and states. As defined by Raz law has three distinctive characteristics: it is normative, institutionalised and coercive. ‘It is normative in that it is meant to serve as a guide for human behaviour. It is institutionalised in that its application and modification are to a large extent performed or regulated by institutions. And it is coercive in that obedience to it, and its application, are internally guaranteed, ultimately, by the use of force.’\(^{40}\) To a large extent, the law determines how society treats its disabled citizens by outlining what is acceptable and unacceptable, what is desirable and what is prohibited in our treatment of them. Of course the law does not operate in isolation from society nor does it dictate to society. It is intricately linked to current social, economic, political, and cultural beliefs and practices and it both reflects and influences current norms. What makes the law

distinct from these other norms, however, is ‘... it possesses a binding or obligatory quality that is enforceable, either by means of punishment or a re-adjustment of rights and liabilities.’41 Discovering what the law says about the treatment of disabled people is a vital element alongside discovering what the social and cultural norms applicable are or are becoming. The legal research aspect of this study is qualitative in nature in that it recognises that the law in a particular area is not simply there to be discovered, rather that it is reasoned and interpreted. As Dobinson and Johns point out ‘Judges reason inductively, analysing a range of authorities relevant to the facts, deriving a general principle of law from these authorities and applying it to the facts in front of them. .... the principle is gleaned from a detailed analysis of all relevant precedent.’42

a) The research questions

This part of the research involved identifying the most relevant parts of the law which impact on the right to independent living for disabled people in Ireland at national, regional and international level. It included a literature review of the law as it impacts on the right using relevant search terms, along with traditional doctrinal legal research. The research questions to be addressed in this section were:

1. What are the core elements of the right to IL and what are the minimum core obligations on states to realise this right.
2. What parts of the law are most relevant to the right to IL and community inclusion for disabled people and for PWID in particular
3. How has relevant law has been interpreted in the courts when dealing with people with disabilities
4. What reforms in the law could better support the right to IL.

In addition to our own national legislation and the Constitution, Ireland is also subject to legal obligations derived from the European Union, the Council of Europe and the United Nations. It was necessary, therefore, to look not only to Irish legislation, the courts and tribunals, but also to the European Court of

41 Byrne, R 7 McCutcheon, P. The Irish Legal System. 5th edition (2009) Bloomsbury Professional, Dublin p2
Human Rights, the European Court of Justice and the UN instruments to which Ireland is a signatory.

(i) International law

At the outset the databases of the UN were used to seek to identify the minimum core obligations of the right to IL and community inclusion. As this right is new in international law it was important to locate its central elements within pre-existing human rights instruments to which Ireland is a signatory. In the negotiations prior to the adoption of the CRPD the right to IL was linked directly to the right to freedom of movement and freedom to choice of residence in the CCPR. The instruments included the CESCR and the CCPR and the associated General Comments. The General Comments issued by the UN Committee on Economic, Social and Cultural Rights and the Human Rights Committee provide authoritative guidance on the interpretation of the covenant rights, and with regard to the right to IL the most significant were:

- General Comment Number 3 on the Nature of States Parties Obligations
- General Comment Number 4 on the Right to Adequate Housing
- General Comment Number 5 on Persons with Disabilities
- General Comment Number 14 on the Right to the Highest Attainable Standard of Health
- General Comment Number 19 on the Right to Social Security
- General Comment Number 20 on Non-Discrimination in Economic, Social and Cultural Rights
- General Comment Number 27 on Freedom of Movement

As a signatory to both of these covenants Ireland is obliged to put in place the structures and laws which enable the realisation of these rights.

(ii) Regional law

At regional level the two institutions which directly impact on Irish law are the European Union and the Council of Europe. The EU ratified the CRPD in 2010 and, with the passage of the Lisbon Treaty, is now subject to both the ECHR and the CRPD.
The specific articles of the ECHR which most directly relate to the core of the IL right are Articles 5 and 8. Article 5 deals with the right to liberty and security of persons and it speaks directly to the issue of institutionalisation and legal capacity. Article 8 refers to the right to respect for private and family life, home and correspondence. This clearly is of direct relevance to the ideals of IL, and for many PWID living in grouped living arrangements in Ireland it is at least questionable whether the realisation of the right is present or indeed whether it is possible. The focus then of the research was on these two particular Articles.

The place of human rights in EU law gained significant leverage with the passage of the Lisbon Treaty in 2007. The most relevant instruments that impact on the right to IL in the EU are the Framework Employment Directive (FED), the Charter of Fundamental Rights (the Charter) and the draft Equal Treatment Directive (ETD). In addition, as noted above, the ECHR and the CRPD now form part of EU law. The Charter was enshrined in EU law as part of the Lisbon Treaty and under Lisbon accession to the ECHR by the EU is becoming a reality. The Charter holds special significance as it is the first mainstream human rights instrument which specifically names people with disabilities as a group to be protected from discrimination and it identifies integration of people with disabilities and their right to benefit from measures to ensure their independence and participation in the community. Directives are directly applicable in the laws of member states, while the Charter rights only apply to those area of law which fall within EU competence, and therefore, only to the actions of member states implementing EU law, and to the institutions and bodies of the EU. However, EU competence means that it can have a decisive influence on the laws of member states. Accession to the ECHR means that the rights contained therein form part of the general principles of EU law. The CRPD, the first international agreement ratified by the EU, falls between the Union Treaties and secondary law. It is applicable within the competencies of the EU but the fact that it has been signed and/or ratified by all EU member states gives it added force to bring about the realization of the right to IL.

(iii) National law

At a national level the following instruments were examined to ascertain their existing or potential impact on the core elements of the right to IL.
• The Constitution of Ireland, Bunreacht na hEireann
• Housing Acts 1966 – 2009
• Disability Act 2005
• Health Acts 1947 – 2007
• Equal Status Act 2000 and Equality Act 2004
• European Convention on Human Rights Act 2003
• Existing and proposed legal capacity legislation

b) Databases and sources of information

There were two aspects of the doctrinal legal research i.e. firstly, primary sources of law including legislation, statutory instruments, directives and United Nations human rights instruments. Secondly, secondary sources including journal articles and textbooks about the relevant aspects of the law. In terms of the first the databases used were:

A) The Irish government statutes database - www.irishstatutes.ie
B) Irish courts database - www.courts.ie
C) Caselaw from the Equality Tribunal - www.equalitytribunal.ie
E) European Court of Justice database - curia.europa.eu
F) Information on the development of disability policy and the negotiations of the CRPD - www.un.org/esa/socdev/enable/rights/adhoccom.htm
G) Caselaw emerging form the monitoring of the CRPD - www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx
H) Information on UN human rights treaties and instruments from the UN official website www2.ohchr.org/english/bodies/

In addition to using the above, key cases and associated commentary were identified from journal articles and textbooks. These databases were also used to locate secondary material and commentary on the relevant caselaw. The main databases used for this purpose were:

Hein On Line
Lexus Nexus
Westlaw
c) Search terms

The search terms used reflect the wide variety of terminology used in relation to people with intellectual disability in academic discourse and in the law. Thus the terms ‘intellectual disability’, ‘mental disability’ ‘developmental disability’ and ‘learning disability’ were the primary terms used. The same issue arises in relation to IL and so search terms used include ‘community living’, ‘supported living’, ‘assisted living’ and ‘semi-independent living’ along with the titles used in official statutes and related documentation.

Many PWID, along with people with mental illnesses, across Europe live in large residential institutions and in Ireland too, a significant number still live in such institutions. Many of the relevant cases which have come before the European Court of Human Rights concern people in institutions, particularly in relation the issues of consent, recognition of capacity, detention and the right to private life. Search terms used in the legal research aspect of this work therefore also included ‘institutions’ and related terms, along with terms related to housing and community living, supported living and IL. A key issue in law is the capacity to consent to any course of action and the legal capacity to act. Both capacity and consent have clearly legal underpinnings and for PWID both are frequently denied either by omission or by design. For this reason search terms centred on these two concepts were also included.

d) Screening criteria

The criteria used in screening information derived from the above sources were authority and relevance.

A) the authority of the source – greater weight was given to caselaw from the higher courts and related commentary which had a direct relevance to legislation and policy

B) the relevance of the information to the issue in question. This meant that while information from a related area (such as education for example) might potentially
have a relevance in the area of IL, this type of information was not weighted as highly as information directly related to independent living.

2.5.3. Statistical research

This aspect of the research is primarily descriptive and relies on publicly available official statistical databases, which can be accessed to provide information on the current living situations of PWID and some information about the support needs of people. It is qualitative in nature in that it is looks at the numbers in an objective and value-free way. Some of the advantages of using official statistics are that the data is readily available, usually free to access, includes large numbers of subjects, is repeated in the same format over a period of years and is collected to a technically high standard. Using official statistics does not however, dispense with the problem of bias, despite the apparent objectivity of the data. As highlighted by Payne and Payne there are difficulties ‘... arising from who has collected the data, by means of what processes, and for what original purposes.’ (authors emphasis) and the fact that ‘...official statistics are produced by the state, in the interests of those who run and control it, is a problem.’

This point is echoed by Levitas and Guy who warn that ‘...the definitions used in official statistics still produce measures which embody the interests of the state rather than the citizen. It is therefore only with the utmost care that such data can be interpreted for democratic purposes.’ In relation to people with disability this issue has, perhaps, a particular significance as the definitions of ‘disability’ used in official statistical vary and are often objected to by disabled people. This is exemplified by the variation in definition used by the sources accessed as part of this research: the Census data uses a self-definition, the National Intellectual Disability Database uses the ICF definition of intellectual disability and the annual reports of the Mental Health Commission define their population as people who use mental health services. In the area of housing ‘disability’ is usually defined in a primarily medical manner requiring confirmation by a medical consultant. All of these official statistical sources are used by the state to plan and monitor services for people with disabilities and to identify gaps in existing services in one form or

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45 See for example local authority social housing application forms
another. They do not, nor are they intended to, evaluate the quality of service, the quality of life nor the experience of disabled people. Abberley, commenting on the UK Office of Population Censuses and Surveys disability surveys in 1988 - which exhibited many of the same definitional issues - suggests that the methodologies used were overly individualistic and medical, a reflection of the medical model of disability. He suggests that such surveys cannot present a full picture because ‘... “disability” is a social construct, and definitions are inevitably contested. They depend on the interests, intentions and unexamined presuppositions of those with the power to define and the ability so defined to resist inappropriate conceptions of our reality.’ Social model advocates would draw our attention to how the environment disables people and suggest that the focus on impairment is counter-productive for disabled people. The question of how the environment disables people with impairments is difficult to formulate into an empirical research question despite its undeniable truth. As Bickenbach et al highlight, the questions of specifying which aspects of the environment are causing disadvantages and what interventions will help ’... are too vague, multi-factorial and imprecise to form the basis for research. As a result, very little empirical research has been done on the fundamental question of how intrinsic features of an individual interact with features of the social environment to produce disablement.’

Bearing in mind these reservations about the use of official statistical databases, it nonetheless remains important to have an understanding of the situation of disabled people so that the extent of the problem is fully understood – even if only from a statistical perspective.

a) The research questions

The research questions to be answered in this part of the research are:

- Where do PWID live in Ireland?
- What are the housing pathways of PWID in Ireland?

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• Are these pathways different from the majority of the population and if so how?

The purpose of the statistical aspect of the research was to describe the current living situations of PWID in Ireland and to compare this with this of the general population. This was essential for two reasons. Firstly, to get a clear picture of people’s current living arrangements and the pattern of living arrangements which PWID occupy over their lifetime. In other words defining the problem i.e. who lives where and with whom and what living options are currently availed of by PWID as compared to the rest of the population. Secondly, it was necessary in order to be clear about the extent of the problem if the right to IL for PWID is to be addressed. How many people currently live in situations which do not conform to the standards inherent in the right to IL, is this number likely to increase in coming years, what is the level of support needed and how should it be configured, and what are the most pressing issues which need to be addressed.

b) Databases and source of information

The databases were all publically available reliable sources compiled by state agencies. The sources used were:

• Reports of the 2011 and 2006 Census, compiled by the Central Statistics Office
• National Disability Survey 2006
• Annual Reports of the National Intellectual Disability Committee
• Health Research Board, Irish Psychiatric Units and Hospitals Census 2010
• Mental Health Commission Annual Report 2008
• Housing statistics produced by the Department of the Environment, Community and Local Government

The issue of definition, the type of data collected and the purpose for which these data were collected no doubt influenced the data eventually produced. This must
be borne in mind when interpreting the results and these issues are outlined in relation to each of the sources in the Statistical Analysis section of this study.

It should be noted that in compiling the statistical data, percentages were usually rounded off to facilitate ease of reading and interpretation. This may mean that some of the percentages are not fully precise, but the purpose of this part of the research was to identify the pattern, rather than to give exact figures.

c) Search terms
The search terms used for this part of the research were those used most frequently in relation to disability and PWID in official sources. The issue of definition raises its head here also so that for example ‘living independently’ or ‘semi-independently’ as used by the NIDD means living with no or a very limited amount of support at home. This clearly is not the same as IL as defined in this research. However, where these differences in meaning are relevant they are highlighted and account taken in the analysis. In this section the specific housing types availed of PWID in Ireland are important search terms so ‘group home’, ‘congregated setting’ and ‘residential centre’ were used. In addition, as a significant number of PWID continue to live in accommodation provided by the mental health services an attempt was made to identify and define these numbers and some of the salient the conditions therein. For this reason the search terms ‘mental illness’, ‘community residences’ and ‘psychiatric hospital’ were included.

d) Selection criteria
The criteria used in selecting databases and the relevant information in the statistical research were:
1. The authority of the source – only properly validated and credible research databases and sources were used. All of the research sources are state agencies which use the data to provide information to the public and in service planning.
2. Relevance of the data to the right to IL – this involved identifying the most relevant information related to the core concepts of IL and housing.
2.5.4. Analysis

The analysis of all of the data and information gathered for this research attempted to identifying a philosophical/political framework with wide political credibility, which best supports the human rights of all citizens including PWID and in particular the right to IL. It then sought to identify a model/conception of disability which recognises the universality of impairment and disability and the need to take account of this reality in law and policy. This conception of disability must be clearly linked to and supported by the philosophical underpinnings in order to be secure in its development, it must also be equally applicable to all citizens regardless of disability, economic or social status, beliefs, age, gender, ethnicity or sexual orientation. The philosophical foundation must be capable of supporting the human rights of all in practice. In order to set the scene the reality of current living arrangements for PWID in Ireland is explored along with their housing pathways and the ways in which these differ from the rest of the population. The research identifies the current legal framework as it impacts on the right to IL, the potential of existing law to more effectively support the right, seeks to identify which aspects of the law supports or hinders the right and the changes required if the right to IL is to be made fully realisable for PWID in Ireland.

This research was designed to provide insight into what is needed to realise the right to IL for PWID in Ireland. Drawing on philosophical, sociological, legal and statistical sources this research attempts to

A) Establish a set of values/principles which will support a human rights approach for all citizens, is fully inclusive of PWID and enable the realisation of IL regardless of level or type of intellectual impairment

B) Establish conception of ‘disability’ which harmonises with these political/philosophical principles and is likewise fully inclusive of all disabled people and supports the realisation of the right to IL for this population group

C) Identify the core elements of the right to IL as established in law at international level.

D) Identify those aspects of law that have effect in this state and are particularly relevant to the core elements of the right to IL, and how this has been interpreted by the courts. In this it seeks to identify general
principles of law which are most pertinent to the IL right. Analyse what reforms in the law are required in Ireland to fully enable the realisation of the right to IL for PWID

E) Identify the housing pathways of PWID in Ireland and their access to mainstream and specialist housing. It also seeks to identify the divergence between the housing experiences of PWDI and that of the rest of the general population and the possible reasons behind this.

To do this a research strategy and framework which systematically addressed each of the areas using a variety of research methods was used.
Chapter 3: Social Justice and Disability: What’s Fair?

3.1. Introduction

Most major political theories make little reference to disabled people, focusing instead on the wider general population. While this may well be justifiable in formulating a theory which is generally applicable, it ignores the fact that at any given time at least 10% of the population is likely to experience disability, that in reality disability is not an unusual occurrence, rather it is a common part of the human experience. And this has important implications for the individual, for families, for communities and for the State. Ignoring this fact in the development of political theory and in the formation of societal values has meant that the needs and wishes of disabled people have not been accounted for adequately, or at all, and has resulted in marginalization and mistreatment on a vast scale. The fact that people with disability have historically been excluded and segregated from mainstream life in western democratic societies reflects deep prejudice which derives in the first instance from our fundamental values and normative frame of reference. The need, therefore, is to settle upon a political theory or set of values, which are grounded in reality and are fully inclusive of all citizens, including those with disabilities. Establishing an inclusive normative framework, which supports the human rights of disabled people and in particular the right to independent living must be the starting point, for without such a foundational framework human rights can be seen as simply a list of demands which require resourcing from public funds – funds which are necessarily limited and which must also meet other equally important societal needs. Simply demanding that the human rights of disabled people be respected is insufficient, there must be a philosophical basis to these rights in order to ensure that they are realizable as rights which are due as a matter of justice rather than as welfare provision.

Human rights are those rights and freedoms, which people possess by virtue of being human and which are independent of individual social or personal circumstances or abilities. In this sense human rights can be seen as standards or principles by which appropriate treatment can be judged. The need to place human rights into a philosophical framework arises because rights are often presented as a list of entitlements due to people, with each right being seen as free-standing in its own terms. There is usually little reference to how each right impacts on others or indeed how it impacts on other important issues for society.
overall, such as economic productivity or security. A philosophical grounding to human rights provides principles or guidance on how to reach fair resolutions when rights conflict, which rights should have priority, which rights are so fundamental that they cannot be postponed and many other complex issues surrounding rights realization, while at the same time taking account of wider issues facing society. As Shestach suggests ‘... even where international law has established a conventional system of human rights, a philosophic understanding of the nature of rights is not just an academic exercise. Understanding the nature of the “right” involved can help clarify one's consideration of the degree of protection available, the nature of derogations or exceptions, .....and similar problems. ... [h]ow those answers emerge will be influenced, if not driven by, the moral justifications of the human rights in issue.’49 The need to have a framework within which to make decisions about rights is especially important when considering socio-economic rights which are, almost by definition, linked to the resources available to the state. Having a strong and consistent basis upon which to seek the implementation of a particular socio-economic right, which make demands on public resources, greatly strengthens the argument. The right to independent living and community inclusion in the CRPD includes elements of both civil and political rights (the right to liberty of movement and freedom to choose his residence, Article 12 ICCPR) and socio-economic rights (the right an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions, Article 11 ICESCR). In the case of PWD implementing both the socio-economic and civil and political elements of the right to independent living will necessarily involve expenditure or a reconfiguration of existing resources allocated to the sector. As Waldron points out ‘Theories of justice offer us principled ways of thinking about rival demands in politics that take seriously their individualized distributive dimension while at the same time not flinching from the fact that they do compete with other demands.’ and that ‘... a stronger and more compelling case can be made for them [socio-economic rights] if they are validated within the context of theorizing that enables other claims, other demands and other moral considerations to make their best pitch against them.’50 The conceptualization of disability within

this broader normative framework is a fundamental influence on the responses society makes in its legislation and policy to disabled people. How we see disability – as a burden which the person must bear, a disease for which a cure must be sought, as a creation of the social and physical environment or as a variation of the human condition - dictates much about what are seen as the appropriate policy responses. This in turn is largely influenced by the wider normative context within which society operates.

I will suggest that John Rawls’ theory of Justice as Fairness and his principles of justice provide a coherent framework, which can serve disabled people well as equal citizens and can provide a credible basis for the implementation of the right to IL. There are many who question whether Rawls’ theory can include people who do not meet his criterion of rational capacity and I will address this in some detail. While it could be argued that a preoccupation with whether disabled people can be participants in Rawls’ Original Position where the principles of justice are agreed, is purely academic and of little relevance to people’s real lives, their exclusion from such an influential theory is more worrying. For if people with disabilities are not included from the outset, then their aspirations and needs will always be secondary to those of the majority. Whereas Rawls’ himself appeared to exclude people with impairments, several writers have examined the ways in which the theory could be more inclusive and thus ensure that disabled people are considered as subjects of justice, not merely as objects of welfare or charity.

The more important question, however, is whether the theory and its justice principles are in fact good principles when applied to disabled people. Can they provide a fair basis upon which to build stable, inclusive societies, which are fully respectful of the human rights of disabled citizens? I will propose that these principles, when read in the light of some of the important insights from feminist and disability scholarship, can provide a foundation for the full inclusion and fair treatment of all people, including people with disability.

I will briefly outline a history of Social Contract theory and its main tenets followed by an outline of John Rawls’s theory of justice. I will then discuss the main criticisms of Rawls and attempt to illustrate its applicability to the situation of disabled people.
While the broad societal values and its philosophical underpinnings have a major effect on how we respond to disability and difference, the ways in which we conceptualize impairment and disability are equally important in identifying the causes of inclusion or exclusion and give some guidance on the proper policy and legislative responses. The predominant medical approach to disability is gradually giving way to a social model which focuses on the accessibility of the social and physical environment as a cause of disability, as opposed to locating the problem within the individual who is in need of cure, care or rehabilitation. The advent of the social model has been highly significant in empowering PWD and has seen the initiation of important social changes. The development of the social model has gone hand in hand with the development of the ‘minority group’ and civil/human rights strategies to tackling discrimination against PWD and expanding their freedoms. A third conceptualization of disability propose that society recognise that disability and impairment are inevitable parts of the human condition which we are all likely to experience at some point in our lives. This Universalist approach builds on the social model’s emphasis on barrier removal and asserts the right of all people to be fully included in all of life. I will discuss each of the three above mentioned models and propose that in relation to people with intellectual disability the Universalist/Human Variation approach offers most potential.

I will suggest that an inclusive reading of Rawls principles of justice form a sound philosophical basis for the realization of the rights of disabled people and the right to independent living in particular. Further I will propose that the best approach to adopt to achieve this objective is a universalist model of disability, which emphasizes inclusive environments but also mandates particular or targeted policies where environmental design cannot attain full inclusion. There is a clear link between the ideals of Rawls principles and those of a universalist approach to disability in policy and legislation, but it is necessary that the values underpinning the principles of justice first be incorporated into public consciousness – or in contractarian terms, into the terms of the social contract. I will also propose that the UN Convention of the Rights of Persons with Disability embodies Rawls’ principles and that in several of its articles and its overall intention, it combines a universalist approach with the provision of targeted supports. The advent of the CRPD, and the speed with which so many of the UN member states signed or ratified it, indicates that we are witnessing a sea-change in attitudes to disabled
people at international level, where it is no longer considered acceptable to segregate, isolate or mistreat people on the basis of their disability. The challenge, of course, is how to translate and embed this change into practice. Fundamental to this is the building of a public consensus i.e. achieving agreement that human rights apply equally to all and that the central elements of the Independent Living right, in Rawlsian terms, form part of the public conception of the good.

3.2. Social Contract Theory: A Brief Outline

John Rawls is one of the most influential political philosophers of the modern era and is credited with reviving the social contract (SC) tradition, which had been neglected by philosophers since the eighteenth century. His theory was developed at the same time as the international community, struggling to find a basis for lasting peace in the aftermath of the Second World War, adopted the Universal Declaration of Human Rights. The coherence between the two – the universal declaration and Rawls' Justice as Fairness – is indicative of the influence of Rawls' version of the SC on political developments at that time and indeed in the adoption of several human rights instruments since then. SC theory generally has been one of the most important determinants of political thought in Western democracies and is an ‘… enormously influential theory, which has been one of the most dominant theories within moral and political theory throughout the history of the modern West.’

It provides solid reasons as to why it is reasonable for us to follow rules of moral bahaviour and to forego some of our natural liberties to the state, which will enforce those rules and punish transgressors. The theory is based on the core idea that citizens of the state consent to be governed, that at some point, either hypothetically or empirically, citizens agreed to relinquish some of their so-called natural rights to the state or to the sovereign, in order that they could live cooperatively in society, thus experiencing a more just and secure life. It proposes that legitimate political authority must be grounded in the consent of the governed, and that this consent is achieved within a social contract process within which all citizens are participants.

Theorists use some version of an original bargaining situation to identify the terms upon which pre-political people in the ‘state of nature’ would agree as the

basis for the formation of society and the state. The logic of this is that in order to escape from the lawless, dangerous and chaotic conditions of pre-political society, it is rational for people to come together and to collectively agree to relinquish some of their inherent natural rights to a ruler, so that they can live more cooperatively and more peacefully. They consent to giving some of their freedoms to the ruler who is tasked with enforcing laws and meting out punishments to those who transgress these laws, thus ensuring conditions of security for all citizens.

SC theory holds that people’s obligations to each other, and the State’s obligations to its citizens, are determined by consensual agreement within the contract and it is this agreement which is the justification for the existence of any form of government. In the SC tradition, therefore, the contract can be seen as an agreement either among the citizens or between the citizens and their ruler. Lessnoff\(^{52}\) identifies four defining characteristics of SC theory as follows:

1. SC is **voluntaristic** in nature, that is, that political authority is only legitimate because those who are subject to it have willed to be subject to it.

2. Political authority is **consensual** in that there is consent among those subject to legitimate authority

3. SC theory is **individualistic**, as it proposes that legitimate political authority must be accepted by individuals i.e. individuals voluntarily agree on the terms of the social contract and agree to be subject to the political authority established within the contract.

4. SC theory assumes that the parties to the contract are **rational** beings, but that this rationality will lead them to agreement along very definite lines.

SC theorists make certain assumptions about the innate nature of human beings, which are held to be universally applicable, and they bring these universal attributes to their deliberations within the contracting process. In this it relies heavily on natural law which suggests that there are laws which arise from nature, and natural rights and attributes which people possess based on their inherent human nature. Early theorists (including Hobbes and Locke) believed that these natural rights and laws derived from a divine source, and, that as people are all

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children of God, breaking the laws of nature or interfering with another's natural rights was a sin against the person and against God.

The most important universal assumptions made about human beings is that all people are equal and free, and all are capable of rational thought. Also most SC theorists assume that people are primarily self-interested and self-regarding in nature, that they are motivated to achieve their own good first and foremost. There is some disagreement about the extent to which people are motivated by self-interest among SC theorists, however, all agree that self-interest is an important inherent motivator for all people.

Most of the SC theorists, using broadly similar methodologies, identified a basis for justifying different versions of legitimate political authority, ranging from absolute monarchy to republican democracy. In its most influential recent manifestation, however, John Rawls proposes, not one specific form of government, but rather a set of principles of justice upon which the state's basic institutions will be based. He made justice the subject of his contract theory and identified principles, which, he suggested, should be applicable across various forms of government, but in reality are most appropriately applied in liberal democratic states. The influence of SC thinking is evident in the evolution of democratic states across Europe and north America with their affiliation with the fundamental SC ideals of citizens consent to being governed, universal equality among people and universal freedom.

The enduring influence of the SC tradition can be garnered from the fact that it can be dated back as far as ancient Greece, when Socrates, using Social Contract -type logic, sought to explain why he ought to remain in prison, accepting the death penalty, rather than go into exile. His logic was that, as the state of Athens and its laws had made his very life up to this point possible, his obligation was to abide by its laws even if this resulted in his death. SC theorizing reached its peak during the latter half of the 17th century and throughout the 18th century when Hobbes, Locke, Kant and Rousseau were producing their foundational theories. The tradition was revised most significantly in the 20th century by Rawls, whose theory while drawing on the work of these earlier writers, gives a distinctly modern perspective on the SC.

Each SC theory, while seeking to be forward looking and describe a stable political framework, reflected the historical period within which they were developed, so
to some extent it could be said that each of the theories is limited in its applicability to different political, historical and cultural contexts. This is as true of Rawls’ as it is of his predecessors and, I will suggest, his views of disabled people (or rather his lack of consideration of disabled people) is one such time- and context-related aspect of his theory which calls for revision in the light of changing attitudes and the evolving recognition of the full citizenship rights of people with disabilities.

3.3. A Theory of Justice – John Rawls

John Rawls was born just after World War 1 and served with the American army during the Second World War. In reaction to the horrendous abuses of the war, where individual freedoms were completely disregarded, this period was characterized by an international recognition of the need to focus on and safeguard individual freedoms and rights. Rawls’ work was influenced by these concerns, namely the avoidance of totalitarianism and the achievement of stable and fair societies, where people can live in relative harmony enabling differing worldviews to co-exists.

Rawls’ work represented the end of the prolonged hiatus in the SC theorizing and his theory today holds a preeminent position in western liberal democratic thought. It has become the starting point for many scholarly work, either in opposition to, or as developments of the original work. As suggested by Shestack, Rawls’ work on justice has also been highly influential in the development of human rights law in the time since the second world war and ‘Human rights, of course, are an end of justice; hence, the role of justice is crucial to understanding human rights. No theory of human rights for a domestic or international order in modern society can be advanced today without considering Rawls’ thesis.’ Rawls first published A Theory of Justice in 1971. He revised parts of the work in the light of criticisms and the revised edition was published in 1999. It is this later edition to which I will refer.

Rawls identifies justice as the most important virtue of social institutions ‘... laws and institutions no matter how efficient and well-arranged must be reformed or abolished if they are unjust. Each person possesses an inviolability founded on

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justice that even the welfare of society as a whole cannot override ..... in a just society the liberties of equal citizenship are taken as settled; the rights secured by justice are not subject to political bargaining or the calculus of social interests.\textsuperscript{54} His theory describes principles, which if implemented, would lead to the development of an ideal society. In this ideal state everyone is presumed to act justly towards everyone else, to respect the laws of the state and not to exploit weaknesses in others. This has been criticized as fantastical and unrelated to the harsh realities of the world, where people’s rights and freedoms are routinely denied and wholesale rights infringements take place across the world on a daily basis. However, Rawls defends this position by suggesting that only by examining and describing the ideal, can we ever hope to achieve it, or indeed recognise when and how we fall short of the ideal. He states that ‘The reason for beginning with ideal theory is that it provides, I believe, the only basis for the systematic grasp of these more pressing problems. ... At least I shall assume that a deeper understanding can be gained in no other way and that the nature and aims of a perfectly just society is the fundamental part of the theory of justice.’\textsuperscript{55}

Rawls takes a Kantian view of the SC, viewing it as an abstract hypothetical situation where idealized people agree on certain moral principles to govern society. He aims to identify principles of justice, which would be accepted by citizens, to govern society’s basic institutions. These principles are presented as the basis upon which society’s basic institutions should be developed. The principles of justice ‘...provide a way of assigning rights and duties in the basic institutions of society and they define the appropriate distribution of the benefits and burdens of social cooperation.’\textsuperscript{56} There is a need to establish just principles for the basic institutions of society - which include the political constitution, the economy and the family - as they have such a profound impact on the lives of citizens, determining much about the opportunities and choices open to people as well as their attitudes and relationships. It is also within the basic institutions that the benefits and burdens of social life are determined for the citizens. The principles of justice are those which would be agreed by individuals through a process of bargaining in the what Rawls terms ‘The Original Position’. The Original Position is an imagined situation where the parties to the bargaining

\textsuperscript{55} ibid p8
\textsuperscript{56} ibid p4
process are roughly free and equal citizens who are charged with identifying principles for the operation of society’s basic institutions which are fair to all. The participants are imagined to be rational and to possess the ‘two moral powers’, which are a capacity for a sense of justice and a capacity for a conception of the good. The parties are characterized as being ‘mutually disinterested ...they are conceived of as not taking an interest in one another’s interests’, in this they are assumed to be self-regarding in their aims and to be interested in accessing more rather than less primary social goods. Importantly, the parties to the bargain are also imagined to be ‘...normal and fully cooperating members of society over a complete life...’.

The participants in the Original Position are imagined to be operating behind a ‘veil of ignorance’ where information, which is deemed to be morally irrelevant in deciding on the principles of justice, is hidden from the parties. This includes information about their own status in life including their race, gender, wealth or natural endowments. They also are unaware of the political system of the society or its level of economic development. The purpose of the veil is to ensure the impartiality of the participants who must decide among several possible principles on the basis, not of their actual position, wealth or talents, but on the basis of what would be fair regardless of what position one occupies in society. This forces the parties to consider what would be good and fair for themselves personally, as well as for others whether they end up relatively better off or less well off. In this way the conditions of the Original Position satisfies the self-regarding nature of the parties, as it ensures that they must look to their own interests taking account of the fact that they could occupy any position in society.

Rawls is only interested in social primary goods, which are those things which are essential for developing and exercising the two moral powers and for pursuing the individuals own conception of the good. Social primary goods include basic rights and liberties, opportunities and powers, income and wealth and the social basis of self-respect – all things which rational people are presumed to want. Rawls is not interested in natural primary goods such as health, intelligence and imagination which, although influenced by the basic structures of society, are intuitively more inherent to the individual person. The principles chosen by the parties in the original position for the governance of society’s basic structures are

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57 ibid p12
58 ibid p xiii
assumed to be bring stability as they have been established by the participants, are seen as fair to all and can therefore be justified to the citizens.

The two principles of justice which Rawls believes would be chosen in the idealized circumstances of the Original Position comprise ‘justice as fairness’. They are:

1. Principle of Equal Basic Liberties
Each person has the same indefeasible claim to a fully adequate scheme of equal basic liberties, which scheme is compatible with the same scheme of liberties for all.

2. Fair Equality of Opportunity and Difference Principle
Social and economic inequalities are to satisfy two conditions
(a) they are to be attached to offices and positions open to all under conditions of fair equality of opportunity
(b) they are to be to the greatest benefit of the least-advantaged members of society.

These principles express what Rawls terms a General Conception of Justice which would be accepted by citizens if given the opportunity to negotiate them in a position akin to the Original Position – ‘All social primary goods – liberty and opportunity, income and wealth and the bases of self-respect – are to be distributed equally unless an unequal distribution of any or all of these goods is to everyone's advantage’. The first principle asserts that there should be equality in the distribution of basic freedoms and rights - this includes traditional civil and political rights such as freedom of speech, the right to vote etc. It also affirms that none should be advantaged because of irrelevant traits such as race, wealth or gender.

Having access to equal basic liberties is an essential element in the development of the two moral powers in the same way as having access to equal civil and political rights are essential to the exercise of equal participatory citizenship. Part (a) of the second principle (Equality of Opportunity) requires that citizens with the same natural endowments and motivation to use them should have access to the same opportunities regardless of their position in society. This principle mandates not only equality of opportunity, but also non-discrimination actions

59 ibid p54
and policies which recognize the different starting points of individuals resulting from disadvantages created by society, such as poor access to education. Thus it encompasses formal equality of opportunity as well as substantive equality of opportunity, including affirmative action policies aimed at bringing the least advantaged to the common starting points. The challenge for society in this, is to ensure that ‘... the opportunities of others also should be protected. The object, therefore, is to give those who have had an unequal start the necessary handicap points and yet not denigrate the opportunities of others.’

The Difference Principle (Part b) affirms that any inequalities of wealth should work to the advantage of the least advantaged in society i.e. those who possess more natural talents than others may use these to make themselves better off so long as this also benefits those who are less well endowed. The Difference Principle ensures that a perfectly just society seeks to maximize the level of income and wealth of the least advantaged, thus allowing for redistribution to achieve this aim. Re-distribution may be required to ameliorate injustices arising from present circumstances of poverty or discrimination to from historical maltreatment – both of which apply to disabled people – and the Difference Principle allows for such actions. The principle does not suggest that the least well off be given a specific share of society’s resources, but rather that the basic institutions be organized in such a way as to ensure that any inequalities are to the advantage of the worst off members of society. Then, as suggested by Waldron, ‘With that criterion satisfied at the level of basic design, the institutions should be able to operate in a way that does not require subsequent second-guessing. On Rawls’s approach, we are not to meddle with the outcomes of a just institutional structure even if we think that by doing so we could make the array of outcomes even more just from a distributive point of view.’

These principles, Rawls suggests ‘...rule out justifying institutions on the grounds that the hardship of some are offset by the greater good of the aggregate. It may be expedient but it is not just that some should have less in order that others may prosper. But there is no injustice in the greater benefits earned by a few provided that the situation of persons not so fortunate is thereby improved.’ The ordering

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of the principles is important in that the role of the state is firstly to ensure that equal liberties for all citizens is applied before the principles of equal opportunity or the difference principle are applied. This means that liberty cannot be restricted for the sake of any of the other social primary goods such as income or wealth.

The principles of justice worked out by the parties in the Original Position form the basis of agreement at the constitutional stage which follows, and later at the legislative stage and finally at the policy and practice stages. As the parties proceed from one stage to the next the Veil of Ignorance is gradually lifted so they become increasingly aware of the state of well being of the society in which they live and of their own position therein. Thus the principles animate all of the basic structures of society at each stage of its development.

3.4. Critique of Rawls

Unsurprisingly Rawls’s Justice as Fairness has attracted much criticism from several sources. The most relevant for the purposes of this work are those objections raised by feminist, critical race theorists and disability theorists which focus on three aspects of his theory. These are firstly, the objection raised by many feminists and critical race theorists that SC theory is basically flawed in that it ignores the more fundamental sexual or racial contract which is predominantly influential and prior to any mythical social contract. In this regard the same arguments can be made about disability i.e. that the social contract proposed by Rawls’ and other SC theorists is premised on the possession of rational capacity thus it re-enforces the more fundamental ‘ableist’ contract that exists prior to the SC. Secondly, Rawls’ concept of moral personhood and the stipulation that parties to the SC must possess rational capacity with the consequence that only those who possess the requisite level of capacity are appropriately subjects of justice. In addition many critics suggest that this conception of the person is too individualistic and denies the reality of dependence and interdependence of all citizens (including those with disability) and that it makes ‘outliers’ of those who do not conform to the norm of the autonomous self-directing individual. Thirdly, the conception of the social contracting process as one of bargaining for mutual advantage puts people who do not possess the necessary mental capacity at a disadvantage even if it can be conceded that they can be participants in the
contracting process. Bargaining for mutual advantage entails the notion of reciprocal contribution, which cannot include the types of contribution that people with significant cognitive impairments can make. Because of these issues several writers have concluded that Justice as Fairness is untenable and that something else is needed to do justice to disabled people.

Each of these areas of concern I will address, however, I believe the more important question is not the intricacies of the construction of the Original Position nor the theoretical social contract, but rather whether the principles of justice as identified by Rawls are in fact good principles for supporting the rights of citizens, and in particular the core elements of the independent living right. I will suggest that they are, and that they offer a sound theoretical basis upon which to build inclusive societies. Although this is, I believe, the more fundamental question to be addressed it is, nonetheless, important that any theory of justice should be inclusive and be seen as such, for if disabled people are not included in the moral rules which govern the basic structures of society their exclusion, segregation and possible mistreatment is mandated, at least tacitly. While retaining questions about the ability of the theory to fully include people with impaired capacity, Rawls himself comments that 'Even if the capacity [for moral personhood] were necessary [for equal justice] it would be unwise in practice to withhold justice on this ground. The risk to just institutions would be too great.'

3.4.1 The a priori contract

Many feminist and critical race theorists have argued that the whole notion of the SC is premised on the myth that free and equal individuals come together in order to form agreement, which will enable them to successfully cooperate for their mutual advantage. Feminists suggest that this ignores the existence of an a priori sexual contract, which is patriarchal in nature and is more fundamental as it dictates all relationships of power between men and women. The sexual contract infuses all of society's institutions, and no account whatsoever is taken of this fact in Rawls' theory. Foremost among proponents of this view is Carole Pateman who writes that '... classic contract theorists have a crucial feature in common. They all tell patriarchal stories'. And further they all, apart from Hobbes, ‘... also insist that

men’s right over women has a natural basis. Men alone have the attributes of free and equal ‘individuals.’” Pateman is equally critical of Rawls' version of the SC suggesting that his intention in constructing the Original Position is to get to the ‘desired solution’, which is agreement on his principles of justice. But ‘[w]hat is often not recognized, however, is that the ‘desired solution’ includes the sexual contract and men’s patriarchal right over women’. Other feminist writers while discerning a major sexist bias in Rawls’ work are not quite so dismissive of his theory and are more sympathetic to his approach. Susan Okin outlines several criticisms of his work from the feminist perspective but nonetheless proposes that an application of his principles can be used to challenge the gender system of society even though Rawls himself fails to do this. She suggests that a feminist reader of his work will inevitably ask ‘does this theory apply to women?’ On a somewhat superficial level this question arises because of Rawls’ use throughout of generic male terms, but on a more basic level arises because of his assignation of ‘heads of families’ status to the parties in the Original Position. While Rawls appears to have taken this position in order to ensure that the parties care about the well-being of others in the next generation, it poses two problems for the theory form a feminist perspective and indeed for the theory overall. Firstly, as heads of families are predominantly male – and Rawls does not challenge this – the assumption therefore ‘... has the effect of banishing a large sphere of human life – and a particularly large sphere of women’s lives – from the scope of the theory.’ It is women who undertake the lion’s share of the work of caring for children and other dependents and most of this work takes place within the home and family. Yet this experience and knowledge cannot be taken into account by the male heads of families who are parties to the original contract and the decision-makers on the principles agreed therein. Secondly, even though Rawls identifies the family as one of the basic institutions of society to which his justice principles apply, he fails to apply these principles to the internal justice of families. In this he is falling into the public/private divide, which implies that what happens in the ‘private’ sphere within families is not properly the subject matter of a theory of justice. He is also making an assumption that families, which are so influential in

65 ibid p42
66 ibid p42
the moral development of future citizens, are just, which assumption cannot be
made, of course, in light of the fact that families are heavily gendered and are
shaped by social and cultural forces which may in fact be very unjust. Thus, Okin
suggests ‘If gendered families are not just, but are rather a relic of caste or feudal
societies in which roles, responsibilities and resources are distributed, not in
accordance with the two principles of justice, but in accordance with innate
differences that are imbued with enormous social significance, then Rawls’ whole
structure of moral development would seem to be built on shaky ground.’ The
internal justice of families and the gender system must then be subject to scrutiny
in order for justice as fairness to be sound as a theory. This entails, examining the
justice of internal relationships within families which, while not an area dealt with
by Rawls, is eminently possible as detailed by Jean Hampton. Hampton proposes
that the contract devise can be useful in ‘... illuminating the nature of distributive
justice, which I understand to be the “distribution of benefits and burdens in a
relationship consistent with the contractarian conception of the person”. Thus
exploitation, or distributive injustice, is a distribution inconsistent with that
conception.’ While philosophers have generally taken the position that
distributive justice has little to do with personal relationships of love or
friendship, Hampton believes that bringing an assessment of justice to bear on
such relationships can not only identify exploitation, but can also help to preserve
and strengthen them. She outlines circumstances in which injustice in personal
relationships, where the individuals are not being treated in a way that is
consistent with the contractarian conception of the person, can be highlighted by
the use of the contract devise or justice principles. These include unfair treatment
of one person by another, exploitation in relationships and inequality in
relationships. Within familial relationships then, ensuring that each person is
treated in ways that fully respects their worth as individuals is both possible and
necessary. Okin too perceives hope for women and families in Rawls’ theory,
particularly in the use of the Original Position, which she calls his ‘central brilliant
idea’. The veil of ignorance applied to the parties in the Original Position
ensures that the parties must think about the interests of everybody as they are
unaware of what personal, social or economic circumstances they will ultimately

69 ibid p99
70 Hampton, J. The Intrinsic Worth of Persons: Contractarianism in Moral and Political Philosophy
71 ibid pp30-32
occupy in society. And to do this requires ‘... at the very least, both strong empathy and a preparedness to listen carefully to the very different points of view of others.’

Because of this, the interests of all will be considered within the original contract and all will be taken seriously in deciding on the terms of the agreement – namely the principle of justice. This implies that it does not actually matter who, or what specific interests, are represented in the original contracting process, rather that what is important is that the perspectives of everybody is considered, and, as Rawls’ intended, the veil of ignorance ensures that this will happen. This is a very powerful argument and supports the contention that what is paramount is that the principles which are agreed are those which can be supported by all, that they take due account of the points of view and experiences of all, regardless of who or how they were devised.

Many feminists and others, including disability scholars, believe that it is not possible for others to adequately represent the views of individuals or groups without their direct input into the process. Anita Silvers for example asserts that it is impossible for non-disabled people to understand the perspectives of disabled people and that the non-disabled will always imagine that life with a disability is intolerable. This argument can also be made for a myriad of other human experiences such as bereavement, addiction or parenting a child with a disability i.e. that these experiences are opaque to those who have not directly experienced them and that only those with this experience can properly represent them. There may be some truth in this, but the logic of the argument is flawed. How people experience any life event will differ among individuals, being influenced by factors specific to the individual such as their beliefs, their culture, their personal attributes and their support networks among other things. And in fact no one individual can accurately or fully understand the perspective of another, yet we must find ways in which we can successfully live together. This forces us to listen carefully and take seriously the perspectives of those who are different from us so that whatever the eventual agreements on how we can live cooperatively are, it will be an agreement to which all can consent.

Critical race theorists have made a similar argument for the existence of an a priori contract which is more fundamental than any SC. In particular Charles

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73 ibid P101
74 Silvers, A. ‘Reconciling Equality to Difference: Caring (F)or Justice for People with Disabilities’ (1995) Vol. 10 No. 1 Hypatia p35
Mills\textsuperscript{75} suggests that the Racial Contract pre-exists and is more influential than any SC. Mills proposes that the racial contract, unlike Rawls’ SC, is an actual historical event (or series of events) which has led to the subordination and exploitation of non-white people over the past century. He defines the Racial Contract as a set of formal and informal agreements among white people which places non-white people in a sub-human and subordinated status and ineligible to be participants in the SC or to be subjects of justice. He suggests that the ‘… general purpose of the Contract is always the differential privileging of the whites as a group with respect to the nonwhites as a group, the exploitation of their bodies, land and resources, and the denial of equal socioeconomic opportunities to them.’\textsuperscript{76} The Racial Contract then determines who qualifies, on the basis of shifting racial categories, as full moral persons and who is excluded from the SC on this basis. The excluded non-persons encompass all non-white people who are consequently not deserving of equality or freedom. Mills suggests that the Racial Contract was an agreement, originally among European men, to distinguish themselves as ‘white’ and fully human and all others as ‘non-white’ as not fully human, thus enabling the whites to treat the non-whites, and their lands, as resources to be exploited. Although the extreme of slavery which resulted from this agreement – the Racial Contract – are no longer prevalent in Western society, racism is endemic and, as with the sexual contract, the racial contract permeates all of societies basic institutions and contracts to this day. For Mills the existence of the Racial Contract is so deeply embedded in Western society that it is invisible to most citizens and he proposes that, in order to overcome racism, the Racial Contract be made visible and that it should supplement standard SC debate. Mills accuses Rawls of being overtly Eurocentric in his views and of virtually ignoring the racist history of the western world, suggesting that he appears to have no interest in the remediation of the legacy of ‘white supremacy’ which is the distinctive injustice of the modern world. He goes on to accuse him of using ‘… the Western [contractarian] tradition as his reference point to begin with, and then he conceives of that tradition in an ethnically cleansed and sanitized way only possible if you restrict your attention to the norms governing the treatment of Europeans.’\textsuperscript{77} Mills also criticizes Rawls’ theory as methodological flawed as it uses an idealized original contract situation abstracted from actual events in history which is of no practical worth proposing.

\textsuperscript{76} ibid p11
that what is needed is ‘...non-ideal (rectificatory) ideal that starts from the reality of these injustices and then seeks some fair means of correcting for them, recognizing that in most cases the original pre-discrimination situation ... cannot be restored.’

Despite this criticism he believes that the contract framework need not, however, be abandoned. With appropriate modifications the contract framework should drop assumptions about the ideal original situation, retain the key ideas of human equality and the human creation of socio-political order and focus then on eliminating domination.

Both the feminist and critical race theory critiques highlight what they see as the pre-existence of a contract which is prior to and more fundamental that the SC, suggesting that these contracts are both ignored by Rawls and that they inform all that happens in the Original Position and the principles agreed therein. In effect the principles of justice which govern the social and political institutions are founded on a false idea that people are free and equal, while in fact they are not equal as they are shaped at a basic level by the sexual and/or racial roles, stereotypes, experiences and expectations of a sexist and racist society. This argument can also be made about the inherently ableist (or rather cognitive ableist) nature of society and ableist bias in Rawls’ theory. Carlson defines cognitive ableism as ‘...prejudice or attitude of bias in favor of the interests of individuals who possess certain cognitive abilities (or the potential for them) against those who are believed not to actually or potentially possess them.’ By virtue of the emphasis placed by Rawls on the possession of rationality as a pre-condition for participation in the contracting process, it can be argued that the theory itself is biased against people with intellectual disability and excludes them. On a more fundamental level, and similar to the race and feminist theorists cited, it can also be argued that the parties to the contracting process are shaped by ableist stereotypes, experiences and attitudes and that these, therefore, inform their deliberations on the principles of justice. The argument can also be made in relation to ageism, hetrosexism and classism among others i.e. that negative biases and beliefs about any or all of these groups are ingrained in the original position negotiators and thus that they fundamentally bias the principles developed and the basic institutions of society build on these principles. The argument for the overwhelming influence of one or more pre-existing contracts in

78 ibid p180
relation to marginalized groups seems to misread the basic aim of the original position with the veil of ignorance devise. The aim is to enforce an impartiality on the participants so that they must devise principles which will be fair to everyone, knowing that they, or someone they care about, could end up belonging to any of these groups. Taking the stance of self-interested individuals who are unaware of what circumstances they will eventually occupy in society, ensures that the interests of all are considered. As Okin points out the strength of he Original Position is that ‘... it forces one to question and consider traditions, customs and institutions from all points of view, and ensures that the principles of justice will be acceptable to everyone, regardless of what position “he” ends up in.’  This includes raising and answering the question of what principles of justice would be fair if I end up as a person with an intellectual or other disability. The essential commitment in Rawls to the ideas of universal equality and freedom means that those in the original position must regard themselves and all others as of equal worth, regardless of what their individual circumstances may be in the long run. This starting point is, as pointed out by Hampton, of immense value and can be of assistance to those who object that the theory fails to take account of powerful prejudices in society. For feminists who object that the self-interest of the parties to the original contract is not reflective of women’s lives, Hampton asserts that ‘... contractarian theory can also help the feminist cause, and it can do so because it unabashedly insists on the worth of each of us.’ For women this entails a healthy self-interest, which enables them to insist that they not be exploited in their caring roles or desires. This self-interested focus based on the fundamental value of equal moral worth ‘... is a form of thinking about moral relationships that not only encourages individuals to insist on the acknowledgement of their own interests and concerns but also (as a Rawlsian would wish) encourages them to attack societal and political sources of the exploitative roles in which women find themselves.’ Applying this same logic to people with disability is particularly important and is in many ways revolutionary for a group who have, throughout history, been regarded as of lesser moral worth. For individuals with disabilities to insist on their own equal moral worth as persons, and for others to perceive disabled people as possessing equal moral worth has an enormous transformative

82 ibid p30
potential for society. By affirming that each person is of equal moral worth, it ensures that the contractors must disregard what are morally arbitrary characteristics of a person, such as their race, abilities or sex. Rawls asserts that there must be an objection to any system which ‘... permits the distribution of wealth and income to be determined by the natural distribution of abilities and talents ... distributive shares [in such a system] are decided by the outcome of the natural lottery; and this outcome is arbitrary from a moral perspective. There is no more reason to permit the distribution of income and wealth to be settled by the distribution of natural assets than by historical and social fortune.’ So whether the natural lottery places one as black or white, female or male, disabled or not is irrelevant to ones worth as a person and in no way justifies unfair treatment as all such characteristics are arbitrary from a moral standpoint. Although many theorists correctly attest to the social construction of categories such as race, disability and gender, they nonetheless all originate in the assignation of stereotypes to particular characteristics of the person. But as Kernohan highlights ‘Each ism [racism, sexism, classism, ageism, ableism, hetrosexism] is based on a natural feature that is arbitrary from a moral point of view. So any belief that someone is less (or more) deserving of exercising her capacity for forming, revising and pursuing a conception of the good because of her possession of this natural feature must be seen as false by the egalitarian liberal’ [including Rawls].

Of course one’s circumstances, including ones level of cognitive ability and historic treatment or mistreatment, will impact on ones opportunities in life and such disadvantages must be recognized and compensated for in a just society, which may necessitate differential treatment and entail resource allocation. It is the equal moral worth of each individual person which mandates such differential treatment in order to equalize all, rather than the possession of a specific disadvantaging characteristic. Kernohan illustrates this as follows: Firstly, a person with a disability is of equal moral worth with an interest in pursuing her conception of the good. Secondly, her disability is an obstacle to her pursuit of the conception of the good. Thirdly, therefore, the moral equality of persons requires specific treatment to enable her to equally pursue her conception of the good.

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'The premise of moral equality carries the moral weight in this argument, not the assumption that the disabled deserve more because of their disabilities.'

There can be no doubt that there are many deeply entrenched prejudices in society which exert a powerful influence on the behaviour of individuals and on the structures of society. These prejudices may operate at a conscious or unconscious level and attempts to root them out has led to the widespread development of anti-discrimination law and policies and practices aimed at eliminating their effects. Those who suggest that such prejudices form a contract which is prior to and more foundational than the SC propose that the way forward is to make such prejudices visible and focus our efforts on eliminating the oppression and domination which arise from them. I suggest that this approach may yield some benefits, but that Rawls’ SC can achieve this and more. It does this by in three significant ways. Firstly, it centers on the equal moral worth of each person, regardless of their position in society or of any characteristic which may be used to stigmatise them. Secondly, it ensures that in considering the principles of justice upon which to build society that the standpoints of all are taken into account. As the parties in the original position are shielded from knowledge of the position they will occupy in society, they must consider what would be fair from the points of view of each and all individuals. Thirdly, and importantly in relation to disabled people, it allows for each person to assert their moral equality and to advocate for their own self-interests – something which has been denied to people with disabilities through historic segregation, isolation and silencing.

3.4.2 The concept of personhood

Rawls adheres to the social contractarian notion of personhood as inextricably linked to the possession of rational capacity and appears to propose that those who do not possess the requisite degree of capacity are excluded from the reach of justice. He postpones the issue of how justice applies to disabled people in order to focus on the main task of identifying a conception of justice and principles of justice to govern the basic institutions of society to which citizens could agree. This suggests that the question of justice for disabled people, while it is not the main focus, neither is it dismissed - it is, rather, an extension of the theory to be dealt with after the main issue has been agreed. Many have objected strongly to this postponement of the issue of justice for people with disability and with good

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85 ibid p59
reason. The importance of extending the theory to include people with disabilities is based firstly, on the danger posed by not including them – if disabled people are not included from the outset then this leaves open the possibility that they can be treated less well than others. Secondly, in societies committed to principles of justice, as defined most clearly by Rawls, excluding some people from full citizenship and from the scope of justice would be an anathema. The overarching framework of the theory and the principles of justice would be undermined if they are not equally applicable to all. It would be unjust to exclude a particular group on the basis of their possession (or absence) of a particular characteristic, and this would endanger the whole basis of the theory. Any society which legitimates the exclusion of a particular group on the grounds of individual or collective characteristics, leaves open the possibility of finding a basis for excluding others at a later stage. Finally, any theory of justice, which does not include everyone, can hardly be called just at all.

When considering Justice as Fairness one of the major objection is the apparent exclusion of people with intellectual disability from the theory on the grounds that they may not be fully cooperating over a complete life nor have the capacity to develop the two moral powers required to be cooperating. A related problem is that Rawls’ conception of the person appears to be that of the self-directed, autonomous individual which many assert is far from the reality of people’s lives. Several writers, including Martha Nussbaum86 have concluded that the theory cannot do justice to disabled people, particularly those with impaired mental capacity, and as such the theory should be abandoned or radically altered in favour of a more inclusive normative framework.

Philosophers have generally taken the view that the distinguishing feature of human persons is the possession of rationality. Rawls’s also takes this position when he stipulates that the parties to the original position must be fully cooperating over a complete life and have the capacity to develop and exercise the two moral powers. Having the two moral powers – or the potential to develop them - is what brings moral personhood, and presumably their absence indicates that the person is not a full moral person. In this stipulation he is following in the footsteps of a long tradition of social contract theorists, who have isolated intellect or rationality as that which sets human beings apart from other non-human animals. It is only to those who possess rational capacity to a certain minimum

degree to whom equal justice applies and to whom the principles of justice apply. Rawls assumes that this includes the vast majority of people and he states:

'It should be stressed that the sufficient condition for equal justice, the capacity for moral personality, is not at all stringent. When someone lacks the requisite potentiality either from birth or accident, this is regarded as a defect or deprivation. There is no race or recognized group of human beings that lacks this attribute. Only scattered individuals are without this capacity, or its realization to the minimum degree, and the failure to realize it is the consequence of unjust or impoverished social circumstances, or fortuitous contingencies. Furthermore, while individuals presumably have varying capacities for a sense of justice, this fact is not a reason for depriving those with lesser capacity of the full protection of justice. Once a certain minimum is met, a person is entitled to equal liberty on a par with everyone else. ... It is sometimes thought that basic rights and liberties should vary with capacity, but justice as fairness denies this: provided the minimum for moral personality is satisfied, a person is owed all the guarantees of justice.'

This idea gives rise to two objections. Firstly, confining the scope of justice to only those who possess rational capacity to a certain minimum degree is in itself unjust and secondly, it denies the real extent of impairment.

Philosopher Eva Feder Kittay, who is the parent of a daughter with severe intellectual and physical disabilities, argues strongly against the notion that personhood can be confined only to those who possess certain rational or intellectual capacities or are productive in an economic sense and calls for an alternative conception. 'But my daughter is a person. .... I propose that being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one's own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him- or herself ....It is a definition that brings our relationships (real and imaginative) with others to the center of any conception of personhood.' The question of why there is an almost universal tendency to isolate the intellect as the defining characteristic of personhood is one which has profound implications for people with intellectual disabilities. Why not, for example, concur with Kittay in focusing on relationships as the key? Kittay's eloquent description of her daughter's relationships with her family and carers, makes her conception of personhood intuitively correct. Quinn calls the traditional version of moral

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88 Kittay, E.F. 'When Caring Is Just and Justice Is Caring: Justice and Mental Retardation' (2001) Vol 13, No. 3 Public Culture p568
personhood the ‘myth system’ and states that ‘... when one’s conception of personhood is exclusively or largely based on cognition in order to set up a political theory - then much of significance seems screened away from view. ... There is something about the dignity of all humans that is left out of the picture by the focus on cognition – something that ordinary people are in fact generally willing to factor back in.’

While maintaining that some level of rational capacity is essential in order to be appropriately considered as subjects of justice, Rawls does recognize that capacity varies along a continuum and that justice cannot be denied to those with lesser levels of capacity. It is this point which opens up the possibility for extending the theory to include the full range of people with varying levels of capacity. An individual’s capacity can vary throughout life from childhood to old age and it can be impacted temporarily or permanently by accident, illness, genetic endowment, adverse social circumstances and life events. In addition an individual’s capacity can vary in relation to different aspects of life, for example one person may have strong capacity for logical reasoning yet have poor capacity in the intuitive or emotional sphere. Also advances in psychological and medical knowledge have demonstrated that people who, thirty years ago, would have been considered to have little or no capacity, such as people with autistic spectrum disorder or Down Syndrome, have in fact many capacities which can be developed with the proper interventions and attention. In effect capacity is not an either/or phenomenon and the drawing of a line between those who have capacity and those who do not is neither necessary nor indeed possible.

Rawls appears to conceive of disability as a distinct and unusual feature of persons when he speaks of just the ‘scattered individuals’ who completely lack capacity and his bracketing of the issue to be dealt with at a later stage. In reality disability and impaired capacity are prevalent throughout life and as Nussbaum points out ‘... the way we think about the needs of children and adults with impairments and disabilities is not a special department of life, easily cordoned off from the average case.’ She suggests that we need to recognize the extent of disability and the continuity between those with impairments and the phases of

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89 Quinn, G. ‘Rethinking Personhood: New Directions in Legal Capacity Law & Policy’ Paper presented at University of British Colombia, Canada, (29 April 2011) p12

90 ibid pp 12-13

'normal' life, and that if we can do this we can understand that ‘... the problem of respecting and including people with impairments, and the correlative problem of providing care for people with impairments and disabilities, are vast, affecting virtually every family in every society.’ The idea that people with disability represent a separate category of persons, identifiably different from ‘normal’ or ‘average’ people, represents, and in actual fact has proved to be, a dangerous conception which has facilitated the segregation and isolation of disabled people from society. Rather than focusing on identifying those with disability or impairment we need to recognize that disability is integral to the human experience. As Zola highlights in his influential work on disability statistics ‘[h]aving a disability is not a fixed status, but rather a continually changing, evolving and interactive process. It is not something one is or is not, but instead is a set of characteristics everyone shares to varying degrees and in varying forms and combinations.’ If we can conceive of disability as a feature of the human condition - which is more likely than not to affect us personally, or someone close to us - then we can see that it is something which it is in our interest to include in our considerations of fairness and justice for society. And this is precisely what the parties in the original position are asked to do.

Sophia Wong proposes that we should regard everyone as having the potential to develop the two moral powers, even those who may never actually achieve this, and therefore as moral persons, thus including all within the scope of justice. All individuals, regardless of their existing level of capacity, are rightly subjects of justice. She suggests that this is implicit the Rawls’s own account where he acknowledges that people have varying capacities for a sense of justice and that those with lesser capacity should not be deprived of justice on this basis. Instead, Wong proposes that all citizens should be treated as possessing the potential to develop the two moral powers – what she terms the ‘Potentiality View’, again drawing on Rawls as her source where he states that ‘One should observe that moral personality is here defined as a potentiality that is ordinarily realized in due course. It is this potentiality which brings the claims of justice into play.’ Necessary for the development of the two moral powers are ‘enabling conditions’ which should be included among the basic needs of all citizens that are required

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92 Ibid p101
by justice. In relation to people with disability enabling conditions ‘.... will be concerned with improving the accessibility of our social, cultural, educational and residential environments. Food, shelter and the Enabling Conditions are basic needs because they are jointly necessary conditions for the possibility of exercising other rights, such as Rawls’s basic rights and liberties.’95 Therefore, denying disabled citizens the ‘enabling conditions’ which would facilitate their developmental pathways towards becoming fully cooperating members of society, is unjust and incompatible with justice. People generally develop their capacities and skills by simply living their lives and dealing with the challenges presented along the way. None of us are born with a pre-existing set of skills or capacities which will allow us to live successful lives, but must develop these, so that as adults we can manage the quite complex tasks demanded of us. For most people this is an expectation and the pathways to acquiring the experiences and skills we need are open and supported by society - in effect the ‘enabling conditions’ required by most people to develop the two moral powers are built into the way society is organized. Where people are denied access to these pathways and experiences, because of an intellectual disability, they are in reality denied the opportunity to develop their skills and capacities or the two moral powers. As Daniels highlights ‘...under normal social conditions people develop skill at judging things to be just and unjust and have a desire to act accordingly and to have others do so as well. Meeting their needs as free and equal citizens means that people will have the capability to exercise and develop fully these moral powers.’96

Wong concludes that ‘The boundary between moral persons and nonpersons is indistinct and difficult to judge: we should include all human beings without trying to determine exactly where they are on the spectrum of cognitive functioning. The possibility of mistakenly denying someone’s personhood is a moral error far more troubling than the difficulty of establishing a society that includes all citizens.’97

Attributing moral personhood to all human beings and treating all as having the potential to develop the two moral powers enables the theory to include even those people with severely impaired capacity within the theory. The duties of

justice, then, owed to people with disabilities in terms of the enabling conditions necessary to develop the two moral powers, may well entail redistribution of resources from those without disabilities who are fully cooperating. The key here is however, is that these claims for additional resources needed by disabled people to develop the capacity for a sense of justice and a conception of the good are justice-based – they are not owed to people from a sense of welfare, paternalism or charity. And as citizens who are thus fully included within the scope of justice the same rights and liberties apply to them as to all other citizens.

3.4.3 The Interdependent Person

Rawls presents an idealised conception of the person in the original position who is charged with the task of agreeing the principles of justice. These individuals are taken to be free, equal, rational and independent and to be primarily self-interested and self-regarding. This idea of the person appears to favour rationality over feelings, as the basis for decision-making. Young suggests that this is a utopian fiction particularly as the veil of ignorance imposes an impartiality on the parties in the original position which ‘... separates each from any knowledge or connection with a particular history, set of group affiliations, or set of commitments, and the requirement of mutual disinterestedness ensures that none will develop among them as they talk.’ As such it seems to reflect a particularly male orientation, which feminists argue, ignores the extent to which emotions impact on our decisions, and indeed on the value of bringing emotions into decision-making. Feminists writers have also challenged this conception of the individual as false, in that it in does not reflects the reality of women’s lives which are, in general, embedded in and defined by relationships with others. The theory thus privileges white men and creates ‘outliers’ of all other groups and individuals who do not conform to this idealized norm – including people with disabilities. It ignores the fact that, in reality, we are all interdependent with each other and dependent on the State, regardless of our current level of ability, and that we all benefit from this interdependence whether or not we recognize it as such. Even individuals who seem to conform to Rawls’ ideal will be dependent on their relationships with others for their emotional and psychological well-being.

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p104
and on the State for supports such as education and infra-structure. Asch highlights the interdependencies of everyone and suggests that the issue for disabled people is the attachment of stigma to some forms of dependencies and not to others. Pointing out that most lawyers are dependent of mechanics to repair their cars but are not stigmatized for this, she proposes that ‘There is no reason to devalue, patronize or question the legitimacy of someone who obtains spoken information via an interpreter or real-time captioner, or who gets ready for work with the assistance of another human being who prepares meals or puts on clothes.’ In this she is supported by Smith who argues that the ideal of independence, which appears to be implicit in Rawls’ version of the individual, for people with disabilities is neither achievable nor desirable and that it masks the fact we are all inter-dependent and none is independent. The dependency of disabled people has been problematized, while this is not the case for the non-disabled, and ‘... understanding individual relationships and social relations as interdependent and symbiotic provides the basis for a more accurate account of the social and moral worlds we all occupy.’ The argument is that we need to acknowledge our inter-dependence in public policy and the value of these relationships for our individual well-being. The dependence of many PWD on others for assistance with daily living tasks is not inherently different from the dependence of non-disabled people on the state or family. The dependencies of PWD are, however, stigmatised and the notion of the autonomous self-sufficient citizen is held out as the ideal to which we should aspire. Smith proposes that we acknowledge the interdependency experienced by disabled people and that they have a positive and central role in providing the wider community with a better understanding of the interdependencies experienced by all people. According to Kittay the ideal of independence is unrealistic for anyone, whether disabled or not, ‘Independence ... is a fiction, regardless of our abilities or disabilities, and the pernicious effects of this fiction are encouraged when we hide the ways in which our needs are met in relation to dependencies. ... this fiction turns those whose dependence cannot be masked into pariahs, or makes them objects of disdain or pity.’

100 ibid p20
102 Kittay, E.F. ‘When Caring Is Just and Justice Is Caring: Justice and Mental Retardation’(2001) Vol
For disabled people and the disabled people’s movement generally, the ideal of independence perhaps holds more significance and power than it does for others. Disabled people have always been seen and treated as dependent and have been devalued, abused and exploited as a consequence of this status. Many disability theorists are understandably cautious of the idea of refocusing on interdependency as it appears to place disabled people in a position of weakness, as their dependency needs may be higher or of longer duration, and argue strongly that the aim should remain that of inclusion and enabling independence and participation. Silvers argues forcefully that disabled people must be wary of relying on the concept of inter-dependence as a means of achieving equality as it seems to imply that they must be needy and that this neediness becomes the focus, as opposed to the rights of people with disabilities. She suggests that ‘...interdependence masks dependence but cannot overcome it. Interdependence itself creates, rather than mitigates, inequalities of power because it so thoroughly and detrimentally heteronomous. For what appears to be called for by those promoting the theoretical significance of interdependence is a moral economy that privileges neediness by endorsing its claim against collective resources’103. Perhaps this difficulty relates to the fact that, for feminists, the issue of dependency and care has been more to do with the role of women as carers and the injustices and inequalities associated with these roles, rather than the injustices apportioned to the ‘cared for’. Kittay’s proposal that the need for care for the ‘inevitably dependent’ should be included as a principle of justice104 seems to reflect this. Her argument is that if the needs of the carer are not adequately attended to then the needs of the cared for will be neglected. There can be no doubt that people who attend to the dependency needs of disabled people should be properly respected and recognized and that frequently carers have poor working conditions, low pay and insecure employment105. However, there is a danger that by focusing on the needs of carers within an ethic of care that the disabled person becomes secondary. On the other hand, while there are dangers for disabled people in

104 Kittay, E.F. ‘When Caring Is Just and Justice Is Caring: Justice and Mental Retardation’(2001) Vol 13, No. 3 Public Culture p573
focusing on interdependence, it must be acknowledged that all people are in fact interdependent and far from impartial or independent in most areas of life. People in the normal course of events make decisions about careers, marriage partners, child-rearing and all manner of other things taking account of the wishes and needs of others, and relying as often as not on their feelings and the feelings of others. And this reality is not denied by Rawls’ conception of the person, despite first appearances. Rawls’ account of the moral development necessary for a just society, what he terms the Principles of Moral Psychology, clearly embed the individual in caring relationships, which are essential for people to develop a sense of justice. The principles recognize the value and the necessity of relationships of affection for a just society, and sees that these relationships are formed firstly within just families where children learn from their parents how to love. Thereafter children bring this capacity to form relationships outside of the family and form affective relationships with others with whom they associate. For Rawls then, people’s sense of justice depends on their attachments to, and consequent duties towards, other people, which arise in the first instance within just families. He states that ‘the active sentiments of love and friendship, and even the sense of justice, arise from the manifest intention of other persons to act for our good. Because we recognize that they wish us well, we care for their well-being in return.’

So although Rawls explicitly relies on the rationality of the parties in the original position he also recognizes that relationships and fellow feelings will be as important as reason in agreeing the principles of justice, and in this he is implicitly recognizing the inter-dependent nature of people. In addition the imposition of the veil of ignorance ensures that parties must consider the interests of others thus converting self-interest into equal concern for others. As Okin suggests ‘... Rawls’ theory of justice is most coherently interpreted as a moral structure founded on the equal concern of persons for each other as for themselves, a theory in which empathy with and care for others, as well as awareness of their differences, are crucial components ... [T]he only coherent way in which a party in the original position can think about justice is through empathy with persons of all kinds in all different positions in society, but especially with the least well off in various respects. ... [i]t is to think from the point of view of everybody, of every ‘concrete other’ whom one might turn out to be.’ This appears to acknowledge

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that, while people are rational beings who will want to act in their own self-interest, they are not exclusively so. They are also emotional beings who depend and inter-dependent on others for their well-being and they are motivated to act for the well-being of others, even if this is at some cost to their own apparent self-interest. So within Rawls’ theory despite first appearances, we do not need to think of people as autonomous, self-interested purely rational individuals who are only interested in pursuing their own self-interest. For, as he himself has acknowledged, this is not the full picture.

3.4.4 Reciprocity and Bargaining

One of the problems for the inclusion of disabled people within the theory, and consequently within the scope of justice, is partly centered on an understanding of the social contract as a process of bargaining for mutual advantage. If people do not have the requisite capacity to engage in bargaining they appear to be excluded from the process and, therefore, from its agreed principles and terms. At a methodological level it is questionable whether the parties in the original position are in fact contracting at all, as the conditions are such that they will inevitably come to the conclusion that the principles of justice as fairness are the best among those considered. In this sense, it could be just one single individual who, working through the logical process, comes to this conclusion. In fact Rawls’ recognizes this when he states that ‘... it is clear that since the differences among the parties are unknown to them, and everyone is equally rational and similarly situated, each is convinced of the same arguments. Therefore, we can view the choice in the original position from the standpoint of one person selected at random. If anyone after due reflection prefers a conception of justice to another, then they all do, and a unanimous agreement can be reached.’ In legal terms a contract entails the exchange of promises between people which are binding on the parties and which can be enforced by law. In this sense they are bargains between people. The work undertaken by the parties in the original position does not involve an exchange of goods or services, but does include undertakings to behave in agreed ways, that is, to adhere to the principles of justice. Hampton argues that Rawls does not have a contract basis for agreement to the principles of justice, that they

cannot be contractually justified. She proposes that ‘... understanding the deliberation in the original position as carried out by a single deliberator following the dictates of practical reason, rather than understanding it as carried out by many parties trying to forge a contract, is a far better way of showing how Rawls thinks a state organized according to the two principles is something to which we would voluntarily consent, its constraints and obligations recognized by us as self-imposed.’

109 The individuals in the original position agreeing the principles could, then be anybody, which liberates the theory from any obligation to include any particular individuals or groups – the original position simply sets up the conditions and the process whereby anyone would settle on the principles of justice with which all citizens would agree. It also takes out of the equation the need for individuals to be seen as contributors to, or bargainers in, the process and, therefore, opens the theory to include all persons within the scope of justice.

Silvers and Francis110 argue that the traditional conceptualization of the social contract is a narrow legalistic one, which is neither necessary nor helpful for disabled people or indeed for the contracting process more broadly. Social contract theory in itself does not exclude people with disabilities – rather it is the perception of the contracting process as a bargaining process which excludes. They suggests that ‘... social contract theory need not embrace the bargainer paradigm. Indeed, this interpretation bears the mark of a comparatively recent, nineteenth century legal theory of contracting, one that has continued to be influential but has also been the subject of ongoing criticism. Nor must philosophical understanding of the social contract, which is supposed to be prior to and foundational for the state, conform to prevailing definitions of a legally enforceable contract.’111 They propose that social contracting be understood instead, as a process of engendering trust, which would enable ‘outliers’, including people with impaired capacity, to participate as equals. Re-imagining social contracting in this way entails letting go of the notion that participation in social cooperation necessarily involves reciprocal behaviour between similarly positioned individuals - and can instead include elementary personal contact between people as well as sophisticated collective interactions. It also entails thinking differently about what constitutes a ‘contribution’ to the social good beyond the purely

111 ibid pp42-43
economic or productive. For people with significant disabilities this is of particular importance given that they are usually perceived as non-contributors who represent a burden on society. Neil suggests that there is a need to ‘... define a contribution as an act that furthers the social good of human fulfillment. One might contribute consciously or .... without intent.’\textsuperscript{112} Contributions in this context could include relationships, shared experiences which enhance ones appreciation, and what people with significant disabilities can teach the non-disabled about living well with impairments.

Silvers and Francis suggest that ‘Central to cooperative schemes are relationships that do not necessarily produce dyadic exchanges of benefits between pairs of parties but that result importantly in beneficial social by-products that are secured because parties with different levels and kinds of vulnerability successfully cooperate...... Disabled people and other “outliers” can participate actively in such triadic relationships. In doing so, disabled people and other “outliers” not only entrust themselves to, but also are trusted by, the rest of the community. Such relationships can be transformative for all parties.’\textsuperscript{113} Competition and conflict are not necessarily embedded in contract theory and it can in fact be compatible with assumptions about less selfish motivations of people. Creating the conditions in which participants can trust each other is in reality one of the major functions of contracting. Contracting is not only (or even mainly) about enforcement, rather contracting encompasses outlining and agreeing terms which each party trusts will be realized. Such trust-based contracting processes would allow for a principled redistribution of resources to less capable members of society in order to nourish a climate of trust by strengthening fairness and justice for all. This principle would be agreed in the ‘...expectation that one will be benefited not by the actual recipients of one’s own good deeds but by stimulating an environment in which people are disposed to help each other. Such indirect reciprocity may be more important than direct reciprocity in the evolution of justice.’\textsuperscript{114} Adopting a more expansive view of reciprocity and valuing the contribution of all would mean that we all could benefit, directly and indirectly, by living in a society where people are open to being of assistance and being assisted - and where we can trust that if we


\textsuperscript{114} \textit{Ibid} p70
individually become vulnerable through the vicissitudes of life, that we too will remain valued members of society and will get the assistance needed to enable us to pursue our conception of the good. Part of the general conception of the good is living in a society which values and includes all of its citizens equally.

This account of social contract theory takes a very positive view of the motivations of human beings and appears to provide a hopeful route to inclusion for disabled people. In it, however, the question remains as to whether we can realistically make such assumptions about people – is competition not endemic to western liberal democracies where social contract theory is pre-eminent? All agreements ultimately depend on a level of trust developing among the parties, even if this is very limited at first. And it is true that trust is something which develops over time, that people learn to trust each other as evidence of trustworthiness is established again and again. The key, according to Silvers is to institutionalize the nourishing of trust and to condemn as unjust practices that lead to trust-breaking. Part of this involves imposing sanctions on those who engage in trust-breaking actions and requiring them to engage in trust-building. Practices that nourish trust are a requirement of justice and should be a central aim of government. Such trust-building practices create stability, which for Rawls, is a core element of a desirable political system. In relation to people with disability - particularly those with cognitive impairments - whose experience is of not being trusted by the able-bodied, the challenge would be to two-fold. Firstly, able-bodied people must learn to trust that those with impaired capacity can know what they want and need, even if this is expressed in non-normative ways. Secondly, people with disabilities must learn that the able-bodied can also be trusted not to abuse or exploit the vulnerabilities of those with unusual ways of expressing themselves or with more limited mental capacity. Practices which would support such trust-building could include legislation recognizing people’s mental capacity in various situations and supported decision-making structures where the person’s wishes are central. Where people have vulnerabilities related to impaired capacity the potential for trust breaking is significantly magnified and sanctions for the breaking of trust would have to be clearly highlighted and fully accessible. This would include such practices as having in place robust complaints procedures and external monitoring.

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115 Via e-mail from Silvers 16/1/2011
3.5. Applying the principle of justice to people with disability

A pre-requisite of any theory which claims to be just is that it be fully inclusive of all citizens regardless of status, class or ability. This is true whatever the content or principles of the theory, for if any individuals are omitted from the scope of the theory then, by definition, it cannot be a theory of justice as it is patently unjust to those who are excluded, and it cannot claim to be just. I believe, as outlined above, that Rawls’ theory can be fully extend to all, including people with disability, if account is taken of the evolution in thinking and conceptualization about disability which has occurred since the latter part of the 20th century. Perhaps the most important change in thinking has been the advent and embedding in legislation and policy of the social model, which asserts that disabled people are people just like everyone and that as such they are holders of the full range of human rights, just like everyone else. This fact means that all of Rawls’ principles are equally applicable to all people with disability and that the state, and society at large, must ensure that they are fully included in all of the basic institutions in a fair and just manner. While political philosophers, including Rawls, may have focused attention on whether those with impaired capacity are full moral persons, there is in reality an increasingly widespread recognition that the possession of capacity is not a condition for the recognition of personhood. If the link between moral personhood and rational capacity is discarded, then it is clear that all human rights and the principles of justice apply to all citizens equally – and the question remaining is how to make these rights and these principles meaningful for disabled people. Article 1 of the Universal Declaration of Human Rights states that ‘All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.’ The argument that this could be taken as meaning that only those ‘endowed with reason’ are holders of rights, is debunked by the fact that in 2006 the UN adopted the CRPD which outlines what is required to ensure the human rights of disabled people. It may be that when the UDHR was adopted in 1948 that people with intellectual disability were not considered to be full citizens. However, the speed with which the CRPD was developed and adopted by the UN and signed and ratified by state parties indicates that this is no longer the case. What then is required to fully extend the principles and the scope of justice to disabled people? How can equal basic liberties, fair equality of opportunity and the difference principle be applied in a fair and just manner to disabled people?
What is owed to them in justice? The majority of the work undertaken with regard to the application of Rawls’ concept of Fair Equality of Opportunity (FEO) has referred to race and gender, however, the arguments are equally applicable to disabled people. Disabled people, in common with Black people and women, have a long history of marginalization, mistreatment and a denial of their human rights. Systemic and overt discrimination and prejudice against disabled people still persist. The disadvantages suffered by disabled people arise, therefore, from both past and current wrongful treatment. These disadvantages are, of course, compounded by the effects of impairment on the individuals’ well-being and range of physical or cognitive abilities. Whereas medical or rehabilitative interventions may ameliorate some of the effects of impairments for the person, the question to be addressed by society more broadly is what can or should be done to properly and fairly deal with the disadvantages arising from historic and current treatment of disabled people? What does Rawls’ FEO mean for people with disability? Can affirmative actions to compensate for the disadvantages be allowed? Or is pure procedural justice all that is required? This question necessarily brings us back to the criticism that Rawls’ SC is nothing more than an ideal theory which has little relevance to the realities of life and that it takes little or no account of, nor has much to offer in dealing with, a history of deep racism, sexism or ableism. However, Nagel116, noting that Rawls’ spoke - but did not write - about the importance of defending affirmative actions, suggests that Justice as Fairness and Rawls’ own deep egalitarianism would support affirmative actions and that these would be mandated in order to address historical racial injustices. Recognising that we do not live in an ideal world we can use Rawls’ justice standards to evaluate the justice of our institutions and identify systemic causes of injustice which may have historic or present day roots. We can then identify the actions which are required to fairly address these. Nagel suggests that racism is a particular form of failure of fair equality of opportunity then, actions such as affirmative actions programmes and other measures are therefore, mandated. He states: ‘So long as separateness and deprivation of blacks as a group continues, those born black will suffer from a systematic disadvantage in the competition for places in our highly competitive society. This is in itself an injustice, and it is the historical product of much worse injustice..... I believe ... that it is a natural consequence of his (Rawls’) ideal of justice that exceptional measures such as

affirmative action are warranted if they serve in the long run to rectify the distinctly non-ideal situation in which those injustices have left us.” Taylor addressed the issue of the precise types of positive discrimination or affirmative action measures allowable within the framework of Justice as Fairness in both ideal and non-ideal circumstances. He concludes that the use of a range of affirmative action measures is tightly constrained by the requirements of Justice as Fairness in both circumstances. In ideal conditions of justice only formal equality of opportunity, that is the elimination of legal barriers and the prohibition of discrimination is all that is required in order to ensure fair equality of opportunity. He concedes, however, that in the non-ideal circumstances of the real world that other measures such as external monitoring, sensitivity training and compensating supports can be provided, but that soft or hard quotas in recruitment cannot be justified as these violate the spirit of formal equality of opportunity i.e. the provision of fair conditions of competition, not the guarantee of fair outcomes.

This does not imply, he suggests, that the theory is ‘soft’ on racism or other historic legacies but that anything beyond these types of measures would in themselves by unjust. He proposes that ‘Patient and comprehensive political effort to eliminate systematic discrimination by way of sensitivity training, external monitoring and enforcement, and outreach efforts, combined with the devotion of substantial social resources over time to supplementary training, mentoring, and funding for disadvantaged groups, should eventually level the competitive playing-field and allow the internal priority of formal EO to be (re)established. What justice as fairness does imply is that even if soft and hard quotas would permit a color- and gender-blind society to be founded more quickly, they are almost always ruled out as inconsistent with the spirit of the ideal theory.’ However, this conclusion appears not to adequately address the ways in which Black people and indeed disabled people have been and continue to be excluded by our basic institutions. Disabled people, particularly people with intellectual disability, have been and continue to be viewed and treated as ‘other’, as ‘different’ and as requiring ‘special’ treatment. While formal equality of opportunity, sensitivity training and other compensatory supports may help to deal with this, it seems unlikely that until a critical mass of PWID are present in all areas of life that fair equality of opportunity will remain an unfilled goal. For example where housing, education and social service

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117 ibid p84
119 ibid p503
structures are designed to, or have the effect of, directing people into specialist or segregated systems all the sensitivity training in the world will not deal address this. As Valls suggests in relation to race and gender - and equally applicable to ableism - 'The bottom line is that if, or to the extent that, race and gender continue to be a potential source of inequality under ideal conditions, the basic structure of society must take them into account to provide fair equality of opportunity. This is, as it were, black letter Rawls.' The point of Fair Equality of Opportunity is to create fair conditions so that all can compete fairly, and this entails mitigating the effects of socially-created forces and naturally-occurring events on people’s prospects in life. If it is acknowledged that there is a direct connection between the relative invisibility of PWID within our regular systems and community places and their past and current segregation, then it must also be acknowledged that all types of positive action measures to address this inequality are required. In order for the basic institutions, which determine much about one’s life prospects and experiences, to be just these effects must be taken into account and it seems to be reasonable to conclude that the participants in the Original Position would do just this. Given that the parties would become aware, with the partial lifting of the veil of ignorance, of a history of racism, sexism and ableism, it seems reasonable that they would be concerned about this. This is particularly so given that they do not know what their own position will eventually be and as Rawls points out 'We do not deserve our place in the distribution of native endowments, any more than we deserve our initial starting place in society. That we deserve the superior character that enables us to make the effort to cultivate our abilities is also problematic; for such character depends in good part upon fortunate social circumstances in early life for which we can claim no credit.' Valls, in opposing Taylor, suggests that all types of affirmative action measures to counteract the effects of racism are required in order to ensure fair equality of opportunity in both ideal and non-ideal circumstances. He states that fair equality of opportunity demands ‘...that positions be open to all on terms of a competition that is fair; and that the basic structure of society be arranged so as to mitigate the effects of social and natural contingencies. .... [e]ven under ideal conditions, fair equality of opportunity permits, and may even require, race- and gender-consciousness. And non-ideal conditions

120 Valls, A. 'Reconsidering Rawlsian Affirmative Action'. Paper presented to Western Political Science Association, San Francisco April 2010 p4
provide additional grounds for taking race and gender into account. This surely also applies when thinking about disabled people, for they, like everyone, do not in any sense deserve the disadvantages or advantages arising from the natural lottery, from luck, family circumstances nor from the ways in which society has mistreated and segregated them throughout history. As fully equal citizens, in order to level the playing field and ensure fair equality of opportunity, society must take all necessary actions to enable people to effectively participate. This, of course, does not guarantee that all will achieve the same outcomes and it is likely that those who are better endowed will end up better off in any case. However, the Difference Principle means that whatever such inequalities arise that these should work maximally to the advantage of the worst off. Daniels suggests that the Difference Principle ‘...means that those who are worst off with respect to talents and skills are as well off as they can be. Rather than supporting a "trickle down" of gains from inequality, the difference principle mitigates the effects of the social and natural lottery by requiring a maximal flow downward.' And that mitigation, rather than the elimination of these effects, is all that is required by Justice as Fairness. His contention however, is that the combination of all three of the principles of justice (equal basic liberty, equal opportunity and the difference principle) and their lexical priority produces a strong tendency to equality: ‘despite the fact that there is no absolute limit on the amount of inequality allowed by the difference principle, its combination with the other principles and the priority that is given to them suggest that we would see much less inequality in a society governed by democratic equality than it might seem the principle alone would allow.’

3.6. Conceptualising Disability

In this section I will briefly outline the medical model of disability followed by a more detailed discussion on the social model and an exploration of the criticisms of the model as it relates to people with intellectual disability. I will propose that a universalist approach, aimed at inclusion, is needed to foster the full citizenship of people with intellectual disability and that this model is strongly supported by


124 ibid p252
Rawls’ principles of justice. As such it can support the rights of disabled people as well as those of all citizens including the most marginalised.

3.6.1 The Medical model

The medicalisation of disability has been variously attributed to increasing industrialisation in Europe and America in the 19th century, developments in medical science and the return of physically and psychologically wounded veterans from the First and Second World Wars. Each of these phenomena was focused on producing and maintaining fit able-bodied individuals who could contribute effectively to the workforce and society. For people with physical or cognitive impairments this meant that the aim was to cure or rehabilitate the person so that they could take up socially and economically useful roles, or, if this failed, to at least manage the effects of the impairment so that the person presented the least possible drain on the resources of the family and society. The medical model views disability primarily through a biomedical and health lens and it equates physical, emotional and cognitive impairment with ill-health or disease. It is based on the principle that health is the absence of disease and that diseases are deviations from normal or typical human functioning. It assumes that a person with a disability is unhealthy, or at least less than fully healthy, because of an impairment in functioning. From a sociological perspective this approach to disability is rooted in the work of Talcott Parsons, particularly his discussion of the ‘sick role’ and of ‘illness’, which he defines as a disturbance of normal functioning with biological and social features. Included as those who are, therefore, ‘ill’ are people who are ‘...suffering or disabled or both.’ Recognising that illness has a biological and social dimension, he suggests that there are societal expectations of those deemed to be sick and occupying the ‘sick role’ under this definition. These expectations include that the person is exempted from normal social responsibilities, that s/he is not responsible for his/her condition and needs to be taken care of and is not expected to get well without help and finally, because being ill is an undesirable state, the person should try to get well and cooperate with the physicians. Exemption from normal social roles and adoption of the sick role is subject to legitimation by medical doctors who act

127 ibid p296
as gatekeepers and ensure that society does not have to bear the costs of malingers who wish to remain in the sick role unjustifiably.\textsuperscript{128}

Of significant importance in the entrenchment of the medical model was the World Health Organisation’s International Classification of Impairments, Disabilities and Handicaps (ICIDH) issued in 1980. This became the international standard for research and debate on disability. The definition offered by the ICIDH draws a distinction between Impairment, Disability and Handicap which, while attempting to include both an impairment and an environmental focus, failed to do so.\textsuperscript{129} The definition appears to be based on the assumption that disabilities or handicaps result from impairments, with no reference to the aspects of the social or physical environment which limit people's abilities to participate or perform activities in the manner considered 'normal' for human beings. Bickenbach et al conclude that 'As far as the ICIDH is concerned, the social and physical world is immutable and benign. The underlying model does not clearly acknowledge that the presence of social barriers and the absence of social facilitators play any sort of role in the creations of the disadvantages that a person with a disability experiences.'\textsuperscript{130} The ICIDH was revised in 2001 and now recognizes that disability results from the interaction between a person with impairment and barriers in the environment. While the original ICIDH was in place, however, it served to re-enforce the notion that disabilities resulted first and foremost from individual impairments in functioning, and consequently that cure, management and rehabilitation of the impairment were mandated.

Viewed as a primarily medical problem the correct response to impairments is to attempt to restore the person to full health, to repair their impairment or, if this is not possible, to more effectively manage it so that the person can function as near to normally as possible. In focusing on limitations in functioning the model locates the problem within the individual, paying little or no attention to the impact of the environment. It seeks to identify the medical causes of the impairment and focuses on diagnosis and treatment. It assumes that the impairment in and of

\begin{itemize}
\item \textsuperscript{128} \textit{ibid} pp296-298
\item \textsuperscript{129} World Health Organisation, International Classification of Impairments, Disabilities and Handicaps (ICIDH) (1980) WHO, Geneva Impairment is defined as ‘... any loss or abnormality of psychological, physiological or anatomical structure or function’; disability as ‘... any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being’; handicap ‘...any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
\item \textsuperscript{130} Bickenbach, J.E., Chatterji, S., Badley, E.M. & Ustun, T.B. ‘Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps’ (1999) Vol. 48 \textit{Social Science and Medicine} pp1175-6
\end{itemize}
itself is the cause of the difficulties the person faces, and sets about the task of fixing or curing the impairment so that these difficulties will be eliminated or at least lessened. The medical approach to disabled people means that people are assigned to sick or patient roles, dependent on medical or para-medical experts who largely determine how best to cure or manage the impairment. Because people are seen as sick, or not fully healthy, they are often exempted from socially useful roles, and seen as incapable of performing normative social roles such as worker, student, partner or parent. As Amundson points out ‘The sick person is expected to participate willingly in a cure ("follow doctor's orders"), and to regard his or her condition as undesirable. These requirements resonate with the attitudes of society towards disabled people.’\(^{131}\)

While the medical approach to disability has led to major advances in diagnosis, treatment and management of impairments, it has also has profoundly negative effects on the lives of disabled people.

A danger inherent in the medical model is that it fosters the idea that disabled people's rights are 'special' rights arising from the individual's own biological misfortune, rather than seeing rights as universal and applicable to all citizens. This approach has contributed to the stereotyping of disabled people in many ways – from heroic survivors to passive victims, from being a burden on society to being angelic or childlike creatures and from being people to be feared to being people to be admired. Increased specialization of medical and related professions has led to the development a myriad of impairment-specific charities and self-help groups these often being initiated by medical personnel and/or families of the people affected by the specific impairment. This meant that the landscape of disability has been dominated by groups other than groups of disabled people themselves and that people with different impairments were isolated from each other - thus reducing the possibility of their forming a coherent grouping for political purposes. Specialization in the medical sphere was mirrored in social and educational policies resulting in the establishment of 'special' schools, training facilities, workshops, homes and sports events for children and adults with various types of impairments. Such services and facilities, which were intended to treat or train disabled people in preparation for socially useful roles, were often in segregated isolated settings. The medical view of disability is also evident in social welfare policies where the medical profession act as gatekeepers and

‘experts’ are required to prescribe appropriate treatment, rehabilitation plans and to determine eligibility for various forms of financial and other supports. The medical model has been almost unanimously condemned by people with disabilities as disempowering and as encouraging of the domination of their lives. Nonetheless it is arguable that it remains the predominant lens through which disability is viewed. Areheart suggests that ‘...amidst all that has informed and is informing a cultural view of disability, there is a single predominating paradigm— the medical model of disability. Despite the general trend toward social constructionist accounts of identity, and in particular, the shift to a social model of disability among activists and academics, society seems to have retained a medical paradigm for understanding disability.’

Despite the emergence of the social model of disability and its incorporation into disability legislation and policy, the medical model is still firmly rooted in the way society deals with its disabled citizens.

3.6.2 The Social Model

The social model encompasses a number of approaches to disability all of which have as a basic tenet that the focus of policy should be on the removal of barriers to access in order to counteract the exclusion of people with disabilities. Social model approaches include the civil or human rights approaches, the minority rights approach and the social constructionist approaches.

The social model locates the problems faced by people with disabilities within the organization of societal institutions and practices and the ways in which these fail to include disabled citizens. It moves the focus, therefore, away from the individual, and on to the environmental barriers to access. Thus it suggests that disability is socially constructed – and by implication can be deconstructed. As Lang states the social model asserts that ‘Disability is ... situated in the wider, external environment, and is not explicable as a consequence of an individual’s physical and/or cognitive deficiencies. Thus, ... the social model gives precedence to the importance of politics, empowerment, citizenship and choice.’

The origins of the social model can be traced to the 1960’s in both the USA and the UK, when physically disabled people began to demand greater access and control

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over their lives. In the USA young veterans of the Vietnam war on the campus of the University of California, Berkeley demanded the supports they needed to participate in college life and established the first independent living centres. The development of the disability movement in the US reflected that of other excluded groups, such as Black people and women, which had campaigned for recognition and civil rights. It reflected the broader American political philosophy of self-determination, self-reliance and individualism and had as a primary focus the realisation of civil rights and equal opportunity for people with disability. The focus on civil rights was, as highlighted by Hahn, accompanied by a recognition that disability arises from ‘...the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of a disabled individual to adapt to the demands of society.’  

In the UK, with its history of the Welfare state and strong trade unions, the disability movement focused not so much on the individual rights of people, but rather on the need for structural environmental reform. The UK movement originated in the demands by residents of Le Court Cheshire Home to have greater control over their daily lives, and in the work of the Disablement Income Group which was seeking an income for disabled people. The formation of the Union of the Physically Impaired Against Segregation (UPIAS) in the early 1970’s and the publication of its Fundamental Principles of Disability marked a watershed in the UK-based disability movement. UPIAS’s Fundamental Principles are that ‘Disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.’  

A defining characteristic of the social model is the distinction it draws between the impairments which people have and the disability experienced by virtue of environmental barriers to access. UPIAS, in naming this distinction, ‘... define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little

account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.’  

The early social model advocates asserted that impairments were purely a personal matter for individuals and that the role of the State was to bring about changes in organizational and institutional practices and in the physical environment to enable disable people live their lives in the community. They believed that the exclusion of disabled people in segregated environments represented social oppression or ‘social death’ and that this was rooted in the development of capitalism and the level of power given to the medical profession within this. Oliver suggests that the needs of capitalism and the development of industrialization entailed drawing distinctions between workers and non-workers needed to staff factories and that the medical profession were given the power to undertake this function. Those deemed not to be capable of performing effectively as workers were excluded and segregated in institutions of various types. Oliver states that ‘...disabled people could not meet the demands of individual wage earner and so became controlled through exclusion.’ Like many others in the early stages of the disability movement, he abhors the domination of disabled people’s lives by the medical profession and he sees that this prevalent in many non-medical areas of their lives ‘... doctors are also involved in assessing driving ability, prescribing wheelchairs, determining the allocation of financial benefits, selecting educational provision and measuring work capability and potential; in none of these cases is it immediately obvious that medical training and qualifications make doctors the most appropriate persons to be so involved.’ Thus, medicalisation is a key aspect of the social construction of disability. Abberley goes further suggesting that ‘the rise of scientific medicine resulted in the transfer of policing from legal to medical authorities.’

The social model proposition that disability, or what has been termed ‘disabilism’, is directly attributable to environmental rather than individual factors, enables the link to be drawn with the experiences of other groups which have been

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136 ibid p20
139 ibid
140 ibid
marginalized by society – including Black people, women and gay and lesbian people. Each of these groups have historically experienced discrimination and exclusion on the basis of a particular trait and because of characteristics or behaviours attributed by the dominant groups in society to the possession of this trait. Making the link between the experiences of disabled people and other minority groups has given disabled people a basis for building a political movement for change. The political movement for disability rights starts form the basis that the historic treatment and conception of disabled people is a form of social oppression akin to that of other marginalized groups. However, this analysis must take account of the fact that the mistreatment of women or Black people is based on a trait which is intrinsically neutral and carries no natural or essential disadvantage. Impairment is different. On a purely biological level impairment implies a less than fully functioning aspect of the person, an aspect which may interfere with the person's ability to undertake many or some everyday tasks. Speaking about impairment as the defining characteristic for a politically movement, Abberely states that 'What is required is essentially an attitude of ambivalence towards impairment ... [I]mpairment must be identified as a bad thing, insofar as it is an undesirable consequence of a distorted social development, at the same time as it is held to be a positive attribute of the individual who is impaired.'142 However, the experience of exclusion of people with disabilities is based on presumptions and prejudices about ability and behaviour based on the possession of impairments, rather than on any rational knowledge about the actual ability or behaviour of the individual. These prejudices and presumptions are incorporated into the institutions, policies and structures of society so that access to mainstream life is restricted for disabled people on an irrational basis. This is also the experience of other oppressed and marginalized groups.

3.6.3. Critique of the social model

The Social model has generally been acknowledged as the most significant force in bringing about changes in the lives of disabled people in the latter half of the 20th century. However, it has not been immune to criticism. These criticisms include questions about the desirability or possibility of distinguishing between impairment and disability, the inclusiveness of the model and its cultural relativity.

142 ibid
and the emphasis on independence as a central aim of the model. Each of these questions are perhaps political in nature, but on more foundational level the usefulness of the model must be assessed within a broader philosophical or normative framework. While the social model may identify the causes of disability as environmental or attitudinal barriers, the ‘correct’ response to this causation will be determined by the normative framework within which society operates. Exploring how Libertarian, Utilitarian and Egalitarian frameworks should respond to the identification of social or environmental barriers, Samaha suggests that each has a distinctly different ‘correct’ policy response. He concludes that a focus on disability rights alone is not helpful, and that there is a need is for broad agreement on the rights of all citizens within a given framework. He suggests that ‘The social model of disability is not a justification for any policy goal. A causal account of disadvantage, however insightful, is no substitute for norms. ... At some point ... disability rights proponents might choose to confront more effectively the problems of limited resources and competing claims of justice. Devotion to elevating the status of a single interest group is not conducive to that task.’ This criticism could also be made of all human or civil rights based groups which seek change and the debate about what rights mean in differing cultural contexts is far from settled. However, apart from the explicitly Marxist framework adopted by Oliver and Finkelstein, few social model theorists have outlined a normative structure which would best support the realization of the rights which arise from their causative analysis.

a) Aiming for independence

Inherent in the social model is the assumption that if all of the disabling barriers were removed that disabled people would have full access to the mainstream and become independent productive members of society. Many writers have argued that the aim of independence for many PWD is neither achievable nor desirable and that it conceals the fact we are all inter-dependent on each other and none is independent. This argument is essentially the same as that posed by feminists

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144 ibid p1308
against Rawls’ theory of justice, which, critics suggest, is built on the premise of the idealized independent self-sufficient citizen. Such a citizen is non-existent as we all depend on others and on the state in many aspects of our lives. The model of the idealized citizen is also unrelated to the lived experiences of women and of disabled people where interdependence and dependence are recognized and are an essential part of life. Several writers\textsuperscript{147} suggest that the distinction between the dependency needs of disabled people is not essentially different from the dependency of others on the State, the family or the community and that the problem is the attachment of stigma to the dependency needs of the disabled. This, however, is refuted by Morris, who states that 
\textit{When someone depends on someone else to do physical things for them, the more personal the task the greater the potential for abuse of human rights—and the greater the potential for the “caregiver” to protect and promote human rights. To depend on others for assistance in intimate tasks is not the same as depending on a mechanic to service your car.}\textsuperscript{148} Intuitively this is correct and Morris proposes that as vulnerability arises because of this type of dependence, what is needed is a focus on the human rights of the cared for, including the right to express preferences, to participate in decisions, to participate in the community and the right to support to exercise rights.

The disabled people’s movement and the social model acknowledge that independent living or autonomy does not imply that people will not require supports to live their lives, but rather that people should have access to the same choices as all other citizens.\textsuperscript{149} However, the main thrust of the social model is inclusion and independence for disabled people, focusing on environmental barriers to independence. Perhaps this argument is in reality a disagreement about the understanding of the terms ‘independence’ and ‘autonomy’ as used by both the disabled people’s movement and the social model. For social model advocates and the disabled people’s movement, ‘independence’ may be an


\textsuperscript{149}See for example quote from Adolf Ratzka of the Independent Living Institute, Sweden cited at Footnote 30 above. \url{www.independentliving.org}
incorrect term - as what is actually sought is choice, control, access and a right to participate, rather than independence or autonomy in the sense these terms are used by writers such as Kittay or Smith cited above. This fully recognizes that people with impairments may need, and should receive, supports needed to achieve these along with structural or environmental changes. This is evident from the fact that a key strategy adopted by the disabled people’s movement from the beginning was a campaign for the provision on Personal Assistants to enable people have access, choice and control.

b) Impairment and Disability

The social model draws a clear distinction between the concepts of impairment and disability – between the physical, cogitative or psychological impairments which an individual has and the environmental barriers which hinder or prevent disabled people’s access to mainstream society. The model, in its purest form, insists that impairment and how it is dealt with, is a personal issue for the individual and should not be the focus, as it had been in the medical model. Disability is the disadvantages imposed by the organization of society which impedes access to disabled people. This is a basic tenet of the model and it is one which has been challenged both from within and without the disabled people’s movement. Objectors to the distinction, including many feminist writers, assert firstly, that to ignore impairment is undesirable as it precludes the real life experiences of many disabled people, secondly, that it reinforces many of the oppressions experienced by disabled people outside of the disabled people’s movement and thirdly, that drawing the distinction is not necessarily possible or instructive as to the changes required. On the latter point Bickenbach suggests that despite the apparent benefit of assigning blame to the environment for the disadvantages experienced by disabled people, the causative connection is not as clear as it may appear. He asks ‘How do we identify which aspects of the social environment are responsible for disadvantage? Which interventions will make a difference, and can we measure the improvement?’ Asserting that the environment, not impairment, causes disability may be the foundational rationale for social model advocates, but it does not provide the full picture. Several disabled women have challenged the social model on the basis that it fails to

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sufficiently take account of the affect of impairments on people’s lives and assert that the feminist axiom ‘the personal is political’ must be taken seriously by the disability rights movement. While fully recognizing the enormous contribution which the social model has made in empowering people with disabilities, they believe that there are dangers for disabled people and for the disabled people’s movement in disregarding impairment. Morris states ‘If we clearly separate out disability and impairment, then we can campaign against the disabiling barriers and attitudes which so influence our lives and opportunities. This separation does not justify, however, ignoring the experience of our bodies, even though the pressures to do this are considerable because our bodies have been viewed as abnormal, as pitiful, as the cause of our lives not being worth living.’\textsuperscript{151} The danger posed by ignoring the experiences of living with impairment, she suggests, is that others will continue to define impairment and will further disempower disabled people. Challenging the disability movement she says that disabled people need to ‘get to the space where the courage of living with impairment is acknowledged without being accompanied by the unspoken “I would rather be dead”; where sympathy does not mean pity; where an expression of regret for what is lost through impairment does not mean that our lives are not worth living.’\textsuperscript{152} Naming this aspect of the social model as a flaw, Crow calls for the bringing back of impairment. She acknowledges that the removal of disabling barriers is essential, however, the ‘silencing’ of discussion about impairment creates a taboo around the topic, hinders people’s ability to deal with the difficulties arising from impairments and will ultimately undermine the whole disabled people’s movement.\textsuperscript{153}

In his critique of the social model, Shakespeare\textsuperscript{154} alleges that it alone, among all of the radical civil rights social movements has remained narrowly fixated on its founding assumptions and has failed to develop in response to criticisms and new understandings. The insistence on focusing on barrier removal and access, at the expense of the impact of impairment, while it may be understandable as a political strategy, ignores the reality of peoples’ lives. Shakespeare suggests that the social model must engage with impairment because it directly affects disabled peoples lives and that attention must be paid to medical interventions and research as

\textsuperscript{151} Morris, J. ‘Impairment and Disability: Constructing and Ethic of Care that Promotes Human Rights’ (2001) Vol 16 Hypatia p9
\textsuperscript{152} ibid p11
\textsuperscript{154} Shakespeare, T. Disability Rights and Wrongs (2006) Routledge, Oxen, UK p34
these are important factors for peoples’ lived reality.

While the debate about the place of impairment in the social model and the disabled peoples’ movement continues, it is perhaps worthwhile remembering that there is much work to be done in removing barriers to access, and we simply do not know how well people would do if all the social, physical and attitudinal barriers were removed. As Silvers points out ‘Pending evidence obtained under less biased conditions than presently obtain, we should avoid assuming that unusual suffering, let alone definitive neediness, characterises the disabled other than as the price extracted from them by exclusionary practices’.

c) Minority group and identity

The minority group approach, a variation of the social model, is based on the premise that people with disabilities are an oppressed group in society, which presupposes that they form a distinct group akin to others such as Black people or women. It draws heavily on parallels with the experiences of other marginalized groups particularly in the USA and suggests that the solution to the problems of disabled people is the enforcement of civil rights and anti-discrimination law. This approach, as suggested by Hahn, proposes that ‘... the attainment of civil rights could be a major solution to the difficulties encountered by people with disabilities.’ Hahn’s position is that the discriminatory treatment of disabled people derives from stigma and entrenched attitudes of paternalism within the legal system and more generally throughout society. The remedy pursued is to recognize that disabled people are a distinct social group which experiences marginalization and oppression because of systemic barriers and to enact legislation ensuring their full civil rights and outlawing discrimination. The most prominent and influential espousal of the minority group approach to disability was in the enactment of the Americans with Disabilities Act 1990 which states in the preamble ‘individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the

individual ability of such individuals to participate in, and contribute to, society.’

This necessarily demands definition of the group of people to be protected by such legislation and opens up the debate about who exactly is a disabled person and how can this be enshrined in law. These are many variations in the definition of disability in national law resulting in the necessity for people having to prove at the outset that they are in fact disabled as prescribed by the legislation. Also in proving their membership and, therefore, their entitlement to social benefits or protection from discrimination, people are forced to rely on what are often medicalised criteria of disability, thus reverting to the conceptions of disability condemned by the minority group approach and the social model more broadly.

Further as highlighted by Barry ‘...the minority group approach echoes the medical model’s focus on limitations on bodily functioning. Because stigmatized impairments are likely to be those that most severely limit bodily functioning, the minority group approach’s inquiry risks devolving into a search for those whose functioning is most limited, that is, the so-called “truly disabled” who are “most deserving” of protection.’ This is true also for social policies targeted at people with disabilities and designed to benefit them. The consequence is that the courts and social policy administrators spent considerable amounts of time ‘policing the lines’ deciding whether people fit into the category which will enable them to claim protection from discrimination or access to the support they need. This is in fact one of the major criticisms of the minority rights approach i.e. that it necessarily draws a distinct line between the disabled and non-disabled thus creating a ‘them and us’ situation where disabled people are cast as different from the norm and deserving of protection or special supports. Thus a minority rights approach, by defining disabled people as a social group, draws attention to their difference from the norm as a marker of identity and makes claims on society on the basis of their experience of marginalization because of this difference. This may well contribute to the very problems they are seeking to overcome. This is precisely the ‘difference dilemma’ described by Minow which poses the predicament whereby ‘The stigma of difference may be recreated both by ignoring and by focusing on it. Decisions about education, employment, benefits and other opportunities in society should not turn on an individual’s ethnicity, disability, race, gender, religion or membership of any other group about which some have

157 Americans with Disabilities Act 1990, Section 2.a.7
deprecating or hostile attitudes. Yet refusing to acknowledge these differences may make them to continue to matter in a world constructed with some groups, but not others in mind.\textsuperscript{159} The minority rights approach does not appear to offer a solution.

This approach is frequently criticized on the basis that disabled people cannot be said to form a distinct social group, and, even if they could be so defined, the group they represent is not inclusive of people with all types of impairments. Young defines a ‘social group’ as a group of people which is marked as different form others by cultural forms, practices, or way of life.\textsuperscript{160} Indeed disabled people experience most, if not all, of the five faces of oppression\textsuperscript{161} detailed by Young – exploitation, marginalization, powerlessness, cultural imperialism and violence. It is debatable, however, whether people with disabilities constitute a social group in this sense. What marks disabled people out from others is their impairment, rather than any cultural practices or way of life. In addition the wide variety in the degree and types of impairments among disabled people makes it questionable whether there they share a commonality of experience. As Bickenbach points out ‘... the required analogy between disability and, say, race, gender or religion, has always been forced and awkward. ... People with disabilities do not have common experiences ... nor, ... is there a unifying culture or language that people with disabilities can point to for establishing trans-disability solidarity.’\textsuperscript{162} In addition, as Asch points out, most disabled people are not born into natural communities of others who share their characteristics.\textsuperscript{163}

The minority group approach demands a positive disability identity on the part of its members. Many people with impairments choose not to identify as disabled, including people who acquire age-related disabilities and people with intellectual disabilities. For many, especially those who acquire impairments related to age, this is because their identity is multi-faceted and arises form other characteristics such as occupation and marital status and they incorporate impairment as another aspect of identity. Choosing to identify as disabled means positively identifying with a stigmatised and socially devalued group and where people have

\textsuperscript{159} Minow, M. Making All the Difference: Inclusion, Exclusion and American Law (1990) Cornell University Press, New York p20
\textsuperscript{160} ibid p43
a previously formed personal identity related to other aspects of their life, making this choice is less likely.

An inherent danger with a minority group approach is that in seeking to improve the situation of one group it may well do so at the expense of another equally marginalised group. Even within disability this is apparent where an impairment-specific grouping may exert influence because of greater political expertise or influence, while other less well-supported or popular impairment groupings may be neglected. The losers in this scenario are inevitably people with mental illness or significant cognitive disabilities – precisely the people who have suffered the greatest degree of marginalisation. It is difficult to find a morally justifiable basis for improved protections and resources for one group in society while other equally vulnerable people remain unprotected or unsupported, simply because they either do not form a coherent grouping or because they do not have the influence or expertise needed to assert their claims. From the point of view of the overall justice of society, according protection to people on the basis of their membership of an identifiable group, rather on the basis of their common human needs, is at least questionable as it fails to address the needs of people who do not or cannot identify in this way and provides lesser protection to group members who are less able or less well-resourced.

d) Representativeness of the social model

A major criticism of the social model is it does not adequately include all disabled people and that it is primarily built around the experiences of those with physical impairments – as such it does not address the oppression experienced by other groups, in particular people with mental illness or intellectual disability. This is evidenced by the emphasis within the Independent Living movement on the central role of personal assistants and the call for the removal of physical access barriers in public sphere. In addressing this point Lang points out that ‘Those with cognitive difficulties and mental illness may in fact have bodies that the majority would deem to be “normal”, but this does not necessarily mean that such individuals do not encounter the negative connotations and reality of experiencing impairment.’

Some PWID may benefit from improved physical access and the availability of personal assistants, however, for the majority, the deep-rooted

prejudice towards them is in reality the most disabling barrier of all - assumptions about their childlike nature, their incompetence and their innate difference from the rest of the population are directed towards them from birth. These assumptions are, Goodley asserts, not challenged, and may even be accepted, by the social model and the disability rights movement. ‘...whereas people with physical impairment are rightfully afforded a socio-historical position in the social model ..... people with ‘learning difficulties’ are consistently underwritten...... People with ‘learning difficulties’ are personal tragedies of their unchangeable ‘organic impairments’. ..... Are people with ‘learning difficulties’ really that non-human ... that they can be ignored by disability theory... [If so, this raises real concerns about the starting points of disability theory.]’

As with physical disability, the categorization of intellectual disability can be seen as socially constructed - in that people so categorized are usually viewed primarily by society in terms of their deficits and their behaviour interpreted in this light. The type of economy, geography, the level of wealth, religious values and family structures also have a significant impact on what is seen as an intellectual disability and how it is dealt with. All of these forces, and others, contribute to the social construction of intellectual disability, yet disability theorists have paid little attention to this area and, as a result, can be seen as exclusionary or at least as not fully inclusive. Morris suggests that the disabled people's movement has ‘...sometimes colluded with the idea that the “typical” disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment. In fact, the largest group of disabled people are those with learning difficulties ...’

Along with the assertion that the social model does not fully take account of the experiences of intellectually disabled people there is also the question of how well it deals with the intersection of disability with other significant social factors such as race, gender or sexual orientation and their impact on experience and identity.

3.6.4. Universalism

An alternative approach is that of universalism or what has been termed ‘disability as human variation’¹⁶⁷ which incorporates many of feminisms basic ideas about interdependence, the universality of disability, the common need for care and supports and the need to remove stigma from the provision and receipt of care. At the same time it also recognises the need for universally accessible environments. This approach is, I suggest, strongly supported by the Rawlsian principles of justice and is best suited to realize the human rights of disabled people, including the right to Independent Living.

The primary aim of Universalism is to achieve inclusion of the widest possible range of people. To this end it calls firstly, for a widening of the range of what is considered normal, secondly, seeks to design environments and policies with this aim in mind, and thirdly, where a universalist approach still fails to be fully inclusive it mandates the provision of specialist or targeted measures to achieve inclusion.

Universalism calls for universal policies and laws which ensure access, support and protection for all citizens including those with disabilities. It starts from the recognition that we are all vulnerable to disability and that in reality few people conform to the idealised norm of being fully functioning autonomous human persons. As Zola states the question in relation to disability ‘... is not whether but when, not so much which one, but how many and in what combination.’¹⁶⁸ It recognises that disability is not confined to a distinct identifiable group of people but rather that it is part of the common human experience and that ‘... all people have needs that vary in roughly predictable ways, over the course of their lifespan. Disablement policy is, therefore, not the policy for some minority group, it is a policy for all.’¹⁶⁹ It identifies the denial of the universal nature of impairment as a key factor in the problems of people with disabilities and asserts that disability is ‘... an essential feature of the human condition ... [which] ... has been treated as if it were not a normal feature of what it means to be a human being but rather as an aberration or abnormality. This is the source of the problem with disability policy

and the pursuit of human rights." The need to respect, expect and accept human difference as the starting point for the development of policy for disabled people is based not just on the numerical reality of the prevalence of impairment in the population but, equally importantly, on the recognition that the difficulties encountered by disabled people ‘... are not purely the result of some physical or mental impairment ... but rather of the fit of such impairments with the social, attitudinal, architectural, medical, economic, and political environment.’ Universalism denies the specialness of disability and proposes that we embrace a view which takes account of the fact that it is more the norm for people to have some form of impairments at some point in their lives, than not. This involves developing a broader and more inclusive conception of what is considered ‘normal’ and realising that ‘... there are no immutable boundaries to the range of human variation in human abilities.... [t]he ability-disability distinction is not so much a contrast as a continuum, and the complete absence of disability, like the complete absence of ability, is of theoretical interest only.’ The CRPD also asserts the need for ‘Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.’ Scotch and Schriner’s influential concept of ‘disability as human variation’ also expresses the theoretical basis of the universal approach. They propose that in thinking about disability we should recognise firstly that there is an enormous variability in impairments and in the social, physical and cultural contexts within which they are relevant or not, and that we need to see disability as an extension of the naturally occurring variation in attributes of the human species. Secondly, they suggest that disability arises from the current inability of social institutions to respond to this range of mental and physical attributes and that ‘... the problems faced by people with disabilities might be seen as the consequence of the failure of social institutions .... that can be attributed to the institutions’ having been constructed to deal with a narrower range of variation than is in fact present in any given population.’ Thus the obligation is placed firmly on societal institutions to

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be more responsive to a wider variety of human attributes, as, where an impairment is accommodated by an institution or system, it ceases to be a disability. The focus on the responsiveness of systems to impairment, the use of the concept of universal design and the universalising of disability policy are, this approach suggests, the best way forward for disabled people. Such systems would be designed to expect difference in attributes and abilities – as such variation is a normal part of the human condition – rather than ignoring difference until it presents itself.

Inherent in the universalist approach are the broadly feminist understanding of the interdependent nature of people and the need to recognise and provide for dependency needs in non-stigmatized ways. The approach takes account of the fact that we are all dependent in many ways and have heightened dependency needs at different stages of our lives. This should to be central in development of laws and policies for people with impairments, which is likely to include us all at some point over our lives.

The universalist emphasis on environmental change as the main strategy for improving the lives of disabled people, reflects the view that it is environmental mismatch which is the primary cause of the problem along with a belief that disabled people are a special case, requiring special measures rather than adapting environments to include all. The universalist approach incorporates an anti-discrimination element, but seeks changes in attitudes, systems and policy as a best way forward for disabled people – and indeed for all citizens. The approach suggests that the needs of people arising from impairments should be ameliorated as much as possible by the restructuring of institutions and systems so that impairments do not necessarily result in disabilities, and that disability policy should be integrated into general social policy. A central strategy, however, should be, according to Bickenbach, ‘negotiating the range of normal human variation as the basis for universal design175’ which necessarily involves looking at the issue of distribution of resources to ensure the broadest range possible is catered for. Where discrimination is not involved in the distribution of resources ‘... the injustice may well remain, if the distribution of society’s resources and opportunities ignores the full range of human variation in need, and caters, instead

to some frozen and arbitrary conception of the normal." Universal design of inclusive environments involves assessing each environment to ascertain the extent to which it is disables or excludes. Society must then decide how or whether to modify it so that it can include the widest range of people. Silvers imaginative device of ‘historical counterfactualizing’ – where we are asked to imagine what a given environment would look like if the majority of people in it had impairments - is one way of doing this. This devise ‘... facilitates our identifying what features of our artificial environment have been adopted in the belief that people with physical, sensory or cognitive impairments have no full claim on social participation.’ This, and other, means of approaching the issue of inclusion represent a major shift in attitude at political and policy making levels, as well as in society more generally. While universal design in relation to the built environment may be relatively easy (if perhaps more costly) to envisage, the deeper question of how to change attitudes to create more inclusive environments which expect and welcome human variation is a much larger challenge. Convincing people that this is the correct and necessary approach involves public education and awareness raising – not only about the benefits for people with disabilities, but also the benefits which would accrue to all citizens. As Asch states:

‘Until it is legitimate, respectable, and acceptable to be a person with a disability in the world, until the nondisabled majority recognizes how ubiquitous impairment is and how likely it is that everyone will experience it themselves or in someone they love, ... that world will fight against every legal or moral claim made upon it to change institutions, cultural practices, and institutional and physical structures to become readily inclusive. Disability policy and politics must speak to the economic and emotional needs of the nondisabled majority to convince them that the accommodations made for people with disabilities in many ways can benefit them, if not directly, then indirectly.’

So the issues which required to be addressed from a universalist perspective include

a) convincing people that universalist policies are or will be beneficial to them -
even if this involves elements of resource redistribution
b) integrating disability policy into general social policy
c) developing methods for policy makers and planners to assess environments for
their inclusiveness
d) focusing on designing and modifying social and physical environments so that
they are not disabling and
e) provision of targeted measures in non-stigmatised way to enable inclusion
where universalist policies fail.

These are major challenges and have led some to conclude that, while a
universalist world where impairments are seen as part of normal human variation
- rather than as a basis on which to categorize people - is a laudable and far-reaching goal, it is in the realms of fantasy. As suggested by Kayess and French
‘...its Utopian aspirations may prove impossible to operationalise.’\textsuperscript{179} However, it
should be noted that Zola, who was one of the earliest proponents of universalism,


saw it as an additional complementary strategy to that of the minority group or
‘special needs’ approach, rather than as an alternative. One of the major dangers
with a universalist approach in any sphere is that, in seeking to address the needs
of all, that it will fail to address the particular needs of some. A solely universalist
approach may indeed lead to a more inclusive society, institutions and policies,
but, even if all barriers to participation are removed, there will still remain a
significant proportion of people whose impairments are such that they cannot not
be fully included. This is recognized by Bickenbach et al when they note that ‘To
insist on universalism in a disablement classification [the WHO Revised
International Classification of Impairments, Disabilities and Handicaps – ICIDH -2]
is not, however, to suggest that the personal and social burdens of disablement are
unevenly distributed, or to undermine political attempts to draw attention to this
inequality.’\textsuperscript{180} Recognising this reality it seems clear that there is an need for both
- a universalizing of disability policy and a targeted approach which deals with
the specific needs of some who cannot be fully accommodated by universal
 provision – inevitably those with more severe or unusual impairments. It is
unhelpful and unnecessary to conceive of universalism and ‘special
needs’/targeted approaches as opposites, they can in fact be seen as two parallel

\textsuperscript{180} Bickenbach, J.E., Chatterji, S., Badley, E.M. & Ustun, T.B. ‘Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps’ (1999) Vol 48 Social Science and Medicine p1185
strategies with the same aim of inclusion. Universalism must take account of the particular circumstances of specific groups of disabled people and ensure that they are provided for. Its aim is to be fully inclusive, and in order to achieve this, tailored and targeted supports must be provided to some, which are not needed by all. As stated by Imrie ‘... difference is at the heart of universalism, in the sense that the underlying value base is one of toleration, or of providing the socio-institutional frameworks for groups to co-exist. Thus, selective or special programmes are not necessarily contrary to universal principles. Rather, they tend to reflect a commitment to universal equalitarianism... ’181 The challenge then is ensuring that any targeted supports or policies for minority groups, provided within a universalist framework, remain free from stigma and actually achieve their end of inclusion for those they are designed to support or protect. In order to achieve this, such targeted supports will be justice-based as opposed to welfare-based.

The question is, can such a twin track strategy overcome Minow’s ‘difference dilemma’. This is a dilemma whether the overarching framework is universal or particular in intent. However, it is perhaps more likely that stigma will be heightened where there are fewer but more significantly different disabled people availing of targeted supports within an overall universal framework designed to include as large a proportion of the population as possible in mainstream policies. Those who remain outside of the range of what is considered ‘normal’, however wide that range is in a universalist world, would appear to be ripe for stigmatization and marginalization. Minow’s proposal that we take seriously the standpoint of the target group in developing strategies to include them seems to be an important one in this context.

3.7. Conclusion: Rawls, Universalism, Human Rights and the Right to Independent Living

One of the most important features of the Original Position is that the parties do not know what their circumstances in society will be, including their race, gender, natural endowments or wealth. So they know that, they or someone they care about, could have a significant disability at some point in their lives, just as they could be wealthy or poor, talented or not. Knowing this they agree the principles of justice to govern the basic institutions of society and the fair distribution of

social goods. This assumption, that anyone could be disabled, lends itself very readily to a universalist conception of disability and to the idea that disability is part of the spectrum of human variation. For if everyone can be disabled, then it makes sense that the rules governing the basic institutions of society take this into account and ensure that these institutions are open to everyone. It also speaks to the assumption that the parties in the Original Position are self-regarding as it makes sense for them to decide on the principles knowing that they themselves could be disabled and deciding how they personally would want to be treated if they are disabled. The universality of disability and the need to recognize this as reality is also an inherent part of the CRPD, which asserts the need to accept disabled people as part of natural human diversity and humanity. Human Rights by definition are universal, and the CRPD simply applies these rights to the specific situation of people with disabilities. The UDHR begins with the declaration that all human beings are born free and equal and asserts the entitlement of everyone to exercise their rights without discrimination. This is mirrored in the CRPD which asserts that its overall purpose is to promote, protect and ensure the full and equal enjoyment at all human rights by all disabled people. So everyone is included in the principles of justice, in a universalist approach and within the human rights framework.

The further assumption made by Rawls that the parties are rational and capable of exercising the two moral powers can, I believe, be set aside. This is on the basis that the connection traditionally made between capacity and moral personhood can be shown to be unnecessary and dangerous, for individuals, for society and for any theory which claims to be just. Neither is it necessary nor foundational to Rawls’ Principles of Justice. The proposition that capacity varies along a continuum and that it is impacted on by a whole array of factors at different stages of life is self-evidently true. There is no need to distinguish between those with and those without capacity and indeed the drawing of a clear line may not even be possible and certainly is not desirable. Wong’s proposal that everyone be treated as having the potential to develop the two moral powers and that what is needed is ‘enabling conditions’ to support people to do this, seems to surmount this issue. In reality the enabling conditions needed by most people to develop their capacity – or the two moral powers - are already built into the structures of society, albeit that these are not currently fully inclusive of disabled people nor of many other marginalized individuals and groups. For some, other forms of enabling
conditions must be developed by either expanding the inclusiveness and responsive of current structures or by developing specific conditions to facilitate those with particular needs to exercise the moral powers. This addresses the feminist argument that we are all inter-dependent with each other and we are all dependent on the State for many supports, and where these dependencies are conceived as being within the ‘normal’ range, they are taken for granted and not recognized as supports. For some enabling conditions may amount to reasonable accommodation, for others tailored individualized supports may be necessary, but all such supports are required in justice to enable people develop and exercise the two moral powers and be fully included.

A universalist approach to disability clearly asserts that disability is part of human variation and that all environments, policies and institutions should be structured to be inclusive of all. This approach also mandates the provision of targeted or particular measures to achieve inclusion where environments cannot be made fully inclusive for whatever reason. Concomitant to this is a recognition of the universal nature of capacity and the universalist approach would mandate the universalizing of systems to ensure people can develop and exercise their capacity along with the provision of particular supports where these are needed to facilitate people in exercising their capacity. This is mirrored in the CRPD where the right of everyone to enjoy legal capacity on an equal basis with others is recognized along with the right to supports to exercise legal capacity. As discussed elsewhere, legal capacity is intimately linked with the right to independent living, as achieving independent living is not possible in the absence of a recognition of capacity, and the development of capacity is severely limited in the absence of opportunities for independent living. In this sense providing for independent living for people with disabilities can be seen as an essential enabling condition to make it possible for people to develop the two moral powers.

There has been some debate about whether Rawls’ Fair Equality of Opportunity principle allows for positive action measures, however the argument made by Valls in this regard is convincing. His contention that as long as race or gender – or in this case, disability - continue to be sources of inequality these must be taken into account in the basic structures to provide fair equality of opportunity. Measures to counter historical or existing socially created forces that contribute to

inequality must be taken. Where these inequalities arise from prejudice, inaccessible environments or legal rules, then positive actions are not only allowable, they are demanded to ensure fair equality of opportunities. These measures can be targeted at specific groups which have been marginalized, or at individuals who in no sense can be said to deserve their place in the natural lottery which bestows benefits or disadvantages. Valls suggests that this is 'black letter Rawls' and the logic of the argument is persuasive. In fact the Fair Equality of Opportunity and the Difference Principle provide a firm foundation for a substantive equality which is necessary to enable real equality for people with disabilities and where independent living and community participation are achievable. A requirement to enable this to be achieved is universally accessible environments along with targeted measures for groups and individuals to achieve real equality and independent living. The CRPD is also clear about this in asserting universal first and second human rights and the provision of particular or targeted supports to achieve these rights.

At the foundation of Rawls’s theory is the idea of fairness and this can be seen as the elimination of irrational and irrelevant factors from decision-making processes – in effect basic non-discrimination. Clearly this relates directly to the purpose and principles of the CRPD. It also is embedded in the idea of universalism which aims to include all citizens, including people with disabilities.

For the forgoing reasons I propose that in order to realize independent living and community inclusion for pwid, at a basic level the Rawlsian principles of justice are best suited to support a universal approach to disability which aims at inclusion through universal access and specific measures to achieve this.
Chapter 4  Where People with Intellectual Disabilities in Ireland live

4.1. Introduction

Any attempt to enumerate people with disabilities immediately raises the vexed question of definition. What after all is a disabled person? And who decides if one has a disability or not. This question has pre-occupied people with disabilities, legislators and policy makers for many years.

Definition is fundamental and the methodologies used in data collection dictates much about the results emerging. This is clearly illustrated by the following data drawn from the national census\textsuperscript{183} of 2011, the National Disability Survey 2006 and the National Intellectual Disability annual report 2011.

Table 1:  Numbers of people with disabilities - various sources

<table>
<thead>
<tr>
<th>Source</th>
<th>Total people with a disability</th>
<th>People with intellectual disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Census 2011\textsuperscript{184}</td>
<td>595,335</td>
<td>57,709</td>
</tr>
<tr>
<td>National Disability Survey 2006\textsuperscript{185}</td>
<td>325,800</td>
<td>71,600</td>
</tr>
<tr>
<td>National Intellectual Disability Database 2011\textsuperscript{186}</td>
<td></td>
<td>27,324</td>
</tr>
</tbody>
</table>

The Census data is self-reported and in addition to those recorded as having an intellectual disability, in 2011 137,070 were recorded as having difficulties learning, remembering or concentrating. The Census of 2011 is the first time that a separate category of ‘intellectual disability’ was provided for in. The National Disability Survey (NDS) data was collected by personal interviewing and introduced the concept of ‘severity’ of impairment - except in relation to people with intellectual disability and people with emotional, psychological and mental

\textsuperscript{183} All national census data used in this chapter was accessed from the Central Statistics Office (CSO) website between 1/12/2012 and 10/2/2013 at \url{http://cso.ie/en/census/}
\textsuperscript{184} CSO 2011 Census Profile 8 Our Bill of Health - Health, Disability and Carers in Ireland (CD803)
\textsuperscript{185} Central Statistics Office, National Disability Survey 2006, First Results, Dublin, The Stationery Office (October 2008) Table 1.5 p15
\textsuperscript{186} Health Research Board, National Intellectual Disabilities Database Annual Report 2011, Dublin, HRB (2011) Table 2.1 p23
health difficulties. Of the total number reporting an intellectual disability (ID) only 50,400 had a diagnosed ID.\textsuperscript{187} The National Intellectual Disability Database (NIDD) recorded a much smaller number of PWID based on their definition which includes people known to have an ID and who are in receipt of or likely to require specialist ID services.

The definition of disability and the methodology used for collecting the information then, has a major impact on who is seen as having a disability and consequently on the services/supports that are in place or are deemed to be required into the future.

This chapter will detail the number of people with intellectual disabilities in Ireland and their living arrangements. What emerges is a picture of a group of people who remain living with their families until well into their adulthood and when PWID do move out of home, by and large, they move to specialist housing with only a small proportion achieving the core elements of independent living. Why this is the case will be explored elsewhere, but for now it is clear that people who do not live with their families are failing to access mainstream housing, albeit that the numbers in large residential institutions is decreasing.

The sources used in this research are:

- Reports of the 2006 and 2011 Census, compiled by the Central Statistics Office
- National Disability Survey 2006
- Annual Reports of the National Intellectual Disability Committee
- Health Research Board, Irish Psychiatric Units and Hospitals Census 2010

I will firstly outline the most pertinent findings from the 2011 census in relation to PWID, specifically looking at their living arrangements both in private households and in communal establishments. For comparison purposes I will also outline the relevant circumstance both of the general population and of PWD as a group. I will then look at the data produced by the NDS, again focusing on where people live and the relationship between living arrangements, age and level of intellectual disability (ID). The data from by the NIDD reports provides very useful information on the changes in residential provision for PWID over the past

decade and in this part I will highlight the significant movement which has occurred in this period. Finally, a significant number of PWID receive their primary residential service within the mental health system, and I will outline briefly the numbers living in both psychiatric hospital accommodation and in community residences. I will conclude by drawing a picture of the pattern of residential options open to and availed of by PWID in Ireland, which will highlight the challenges to be met in enabling them to achieve Independent Living (IL).

4.2. CSO Census data

From the census data collected in 2011 it becomes clear that an adult with a disability in Ireland is more likely to remain single, more likely be outside of the labour force and less likely to own their own home. This is especially true for PWID who continue to face barriers to access in these major areas of life.

4.2.1. Level of disability in Ireland

An important aspect of the data collection in the 2011 census was that people self-reported having a disability. This meant that the decision about whether to record oneself as having a disability rested with the person themselves or with the person completing the census form. People were asked firstly whether they had any long lasting conditions - such as blindness, intellectual disability, psychological conditions, chronic illness or conditions that substantially limited some basic physical activities. Secondly, people were asked about difficulties they had in basic daily living – such self-care, going out, working or participating in other activities. According to the national census in 2011 there were 4,581,269\textsuperscript{188} people living in the state of whom 595,335\textsuperscript{189} reported having a disability and of this number 57,709\textsuperscript{190} had an intellectual disability. That is, almost 13% of the Irish population in 2011 reported having a disability and 1.2% of the total population of Ireland has an intellectual disability. Among the Irish Traveller population the percentage of people with disability is higher at 17.5\%\textsuperscript{191} and the proportion of PWID is also higher at 3.4\%\textsuperscript{192}.

\textsuperscript{188} CSO 2011 Census Preliminary Report Table 1
\textsuperscript{189} CSO 2011 Census Profile 8 Our Bill of Health – Health, Disability and Carers in Ireland (CD803)
\textsuperscript{190} CSO 2011 Census Profile 8 (CD803)
\textsuperscript{191} CSO 2011 Census Profile 7 Religion, Ethnicity and Irish Travellers - Ethnic and cultural background in Ireland (CD727)
\textsuperscript{192} CSO 2011 Census Profile 7 (CD728)
Table 2 below indicates that the prevalence of disability appears to have increased significantly since the previous census in 2006 when 9.3%\(^{193}\) of the population reported having a disability. This percentage rose to almost 13% in 2011. The latest census reports an increase in the prevalence of disability in every age group which, according to the CSO\(^{194}\), may in part be accounted for by the changes in wording of the disability-related questions – in particular in 2011 a separate category of ‘intellectual disability’ was included while in 2006 the more generic category of difficulty in ‘learning, remembering or concentrating’ may have incorporated this group. There is a consistent rise in levels of disability as people age, with a marked increase as people enter their 60s and again in the 80 years plus age cohort – at which stage almost two thirds of the population group experience some form of disability. As noted the census indicated that there are 57,709 people with an intellectual disability living in Ireland, which represents 9.7%\(^{195}\) of all disabled people. It is not possible to discern whether this is an increase or decrease given that categorisation in this way is new.

Table 2: Disability 2006 - 2011

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total Pop</th>
<th>Number of PWD</th>
<th>% PWD of total pop</th>
<th>Total Pop</th>
<th>Number of PWD</th>
<th>% PWD of total pop</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>590577</td>
<td>17287</td>
<td>2.9</td>
<td>677099</td>
<td>29646</td>
<td>4.4</td>
</tr>
<tr>
<td>10 - 19</td>
<td>564129</td>
<td>30317</td>
<td>5.4</td>
<td>585510</td>
<td>46124</td>
<td>7.9</td>
</tr>
<tr>
<td>20 - 29</td>
<td>715553</td>
<td>31247</td>
<td>4.3</td>
<td>658353</td>
<td>46565</td>
<td>7.1</td>
</tr>
<tr>
<td>30 - 39</td>
<td>671466</td>
<td>38597</td>
<td>5.7</td>
<td>758206</td>
<td>61527</td>
<td>8.1</td>
</tr>
<tr>
<td>40 - 49</td>
<td>576074</td>
<td>47904</td>
<td>8.3</td>
<td>635997</td>
<td>71965</td>
<td>11.3</td>
</tr>
<tr>
<td>50 - 59</td>
<td>472396</td>
<td>59358</td>
<td>12.5</td>
<td>518908</td>
<td>86607</td>
<td>16.7</td>
</tr>
<tr>
<td>60 - 69</td>
<td>325123</td>
<td>57631</td>
<td>17.7</td>
<td>392424</td>
<td>91518</td>
<td>23.3</td>
</tr>
<tr>
<td>70 - 79</td>
<td>211618</td>
<td>55828</td>
<td>26.4</td>
<td>233226</td>
<td>80933</td>
<td>34.7</td>
</tr>
<tr>
<td>80 +</td>
<td>112912</td>
<td>55616</td>
<td>49.2</td>
<td>128529</td>
<td>80450</td>
<td>62.6</td>
</tr>
<tr>
<td>Totals</td>
<td>4239848</td>
<td>393785</td>
<td>9.3</td>
<td>4588252</td>
<td>595335</td>
<td>12.9</td>
</tr>
</tbody>
</table>

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\(^{193}\) CSO Census 2006 Volume 11 Disability, Carers and Voluntary Activities Table 01
^{194} CSO Census 2011, Profile 8 Commentary P8
^{195} CSO 2011 Census Profile 8 (CD803)
The categories of disability used in the census do not correspond easily with those used by the other data collection agencies i.e. mental illness, intellectual disability or physical/sensory disability. For this reason direct comparison between the various sources is not possible. However, census information indicated that 60.4% of PWD reported having more than one disability with particularly high rates of multiple disabilities being recorded in the older age groups.\textsuperscript{196}

**Chart 1: All disabilities and intellectual disabilities by age group 2011\textsuperscript{197}**

As indicated by the above chart, levels of disability rise consistently as the population ages with the highest number of disabled people being in the 60 - 69 age group. Within this however, the picture for intellectual disability is opposite with the numbers being highest among children and young adults and falling consistently thereafter.

4.2.2 Residential circumstances of people with disabilities

The vast majority of disabled people live in private households\textsuperscript{198}, including PWID. However, a significantly smaller proportion of PWD and of PWID live in private

\textsuperscript{196} CSO 2011 Census Profile 8 (CD807)
\textsuperscript{197} CSO 2011 Census Profile 8 (CD806)
\textsuperscript{198} The term 'private household' is defined as ‘... either one person living alone or a group of people
households than the general population. In the general population 97% of people live in private households, this figure drops to 93% for all disabled people and to 84% for PWID. It should be noted that the type of residence was not stated for 8599 PWID while at the same time 8873 PWID were recorded as living in communal establishments.

**a) People living in Private households**

**Table 3:**  Occupancy type of permanent private households

<table>
<thead>
<tr>
<th>Occupancy Type</th>
<th>Total Pop %</th>
<th>Total PWD %</th>
<th>Total PWID %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owner Occupied</td>
<td>75</td>
<td>70</td>
<td>73</td>
</tr>
<tr>
<td>Private rental</td>
<td>13</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Local Authority rental</td>
<td>10</td>
<td>17</td>
<td>16</td>
</tr>
<tr>
<td>Voluntary body rental</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Occupied rent free</td>
<td>N 1606045</td>
<td>N 104080</td>
<td>N 26983</td>
</tr>
</tbody>
</table>

The majority of people live in Ireland live in owner occupied homes and this includes the majority of disabled people, while a significantly greater percentage of disabled people rent from local authorities than the rest of the population. This could indicate that PWD have greater access to social housing, possibly because this system takes greater account of their housing needs, including their disability-related needs. However, it should be noted that in the most recent Housing Needs Assessment completed by the Department of the Environment and local authorities in 2011 only 1,315 households which included a person with a disability were recorded as in housing need i.e. 1.3% of the total. While this

\[(not necessarily related) living at the same address with common housekeeping arrangements - that is, sharing at least one meal a day or sharing a living room or sitting room.' CSO Census 2011 Profile 8: Our Bill of Health, November 2012 Appendix 2 p82

199 CSO 2011 Census Profile 8 (CD823)

200 CSO 2011 Census Profile 8 CD822)

201 CSO 2011 Census Profile 8 (CD826)

202 Housing Agency Housing Needs Assessment 2011 Housing Agency, Dublin (2011) Table 1 p1
represents an increase from previous assessments\textsuperscript{203}, it is notable that in 2011 the HSE reported that there were 4099 PWD living in residential institutions accommodating 10 people or more, all of whom are in need of housing but are clearly not appearing on local authority housing waiting lists.\textsuperscript{204}

These statistics conceals the fact that there are marked differences between the status within the family of disabled people living in private households and that of non-disabled people.

Table 4: Status in family of adults living in private households\textsuperscript{205}

<table>
<thead>
<tr>
<th>Status in Family</th>
<th>Total Pop %</th>
<th>Total PWD %</th>
<th>Total PWID %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head of household</td>
<td>36</td>
<td>35</td>
<td>14</td>
</tr>
<tr>
<td>Spouse</td>
<td>28</td>
<td>23</td>
<td>9</td>
</tr>
<tr>
<td>Child</td>
<td>12</td>
<td>8</td>
<td>33</td>
</tr>
<tr>
<td>Other non-family or relative</td>
<td>24</td>
<td>34</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>N 3289934</td>
<td>N 481336</td>
<td>N 32232</td>
</tr>
</tbody>
</table>

Table 4 above outlines the status within private households of adults in the general population, people with disabilities as a group and of PWID. The numbers given exclude people under the age of 18 years in each group and this number has been deducted from the 'child' category. There are some limitations on this data\textsuperscript{206}, nonetheless it does serve to illustrate important patterns in living arrangements.

\textsuperscript{203} Department of the Environment, Heritage and Local Government Annual Housing Statistics Bulletin 2008 Dublin, The Stationery Office (2008) p103 indicates 480 household which included a disabled person were recorded as needing housing in 2005 (1\% of total) and 1,155 (2\% of total) in 2008.

\textsuperscript{204} Health Services Executive, Time to Move on from Congregated Settings: A strategy for Community Inclusion, Dublin, HSE (June 2011). Table 1 p50

\textsuperscript{205} CSO 2011 Census Profile 8 (CD824)

\textsuperscript{206} The numbers of children under the age of 18 years who were excluded from these figures were those detailed in CSO 2011 Census Profile 8 Our Bill of Health - Health, Disability and Carers in Ireland, ‘Population classified by type of disability and single year of age’ (CD806). The numbers of children were all excluded from the ‘child’ category. The following caveats should be borne in mind a) not all children live with their parents, although the vast majority do b) some children live with non-family or other relatives, including children in foster care and c) some people aged 16 – 17 may be heads of households or spouses of heads of households.
As can be seen 64% of the general adult population living in private households were either the head of the household or a spouse of the head of the household. For PWID this percentage is much lower with only 15% being heads of households or spouses of the head of household. It is also notable that while only 12% of the general population and 8% of disabled adults as a whole were children of the head of the household, 33% of PWID were children of the household head. Finally the difference between the numbers of adults with ID and of PWD as a group, who were living with non-family or other relatives and that of the general population is also notable. In total 44% of adults with ID in private households were living with non-family or other relatives – while 24% of the general population and 34% of all disabled people were living in such arrangements. It is possible to speculate that many adults with ID live with adult brothers or sisters or other relatives, while for the general population many people may be sharing accommodation with friends. The fact is however, that the living arrangements for PWID in private households is significantly different from that of the general population. In terms of percentages much fewer PWID are heads of households or spouses, many more adults with ID live with their parents and many more adults with ID live in the private households of non-family or of other relatives. The census results also indicate that 17% of PWID living in private households live alone, compared to 12% of the general population and 23% of all people with disabilities.\textsuperscript{207}

Access to paid employment dictates much about access to various types of housing and housing finance and as illustrated in Table 5 below this an extremely problematic area for disabled people. While 50% adults in the general population are in paid employment, this drops to 21% for disabled people as a group and to 12% for PWID. In addition the occupations of those outside of paid work differs markedly, in particular 49% of PWID reported that they were unable to work due to disability of illness, as opposed to 23% of disabled people in general and only 4% of the total population. It is notable also that a higher percentage of disabled people were retired that either of the two groupings reflecting the increasing prevalence of disability as people age.

\textsuperscript{207} CSO 2011 Census Profile 8 (CD825)
Table 5: Economic status of people ages 15 years and over

<table>
<thead>
<tr>
<th>Labour force participation</th>
<th>Total Pop %</th>
<th>Total PWD %</th>
<th>Total PWID %</th>
</tr>
</thead>
<tbody>
<tr>
<td>In paid employment</td>
<td>50</td>
<td>21</td>
<td>12</td>
</tr>
<tr>
<td>Unemployed</td>
<td>12</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Student</td>
<td>11</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Looking after family/home</td>
<td>10</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Retired</td>
<td>13</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>Unable to work – permanent sickness or disability</td>
<td>4</td>
<td>23</td>
<td>49</td>
</tr>
<tr>
<td>Others not in labour force</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>N 3608662</td>
<td>N 542277</td>
<td>N 44496</td>
<td></td>
</tr>
</tbody>
</table>

Another key influence on housing is martial status and the statistics again highlight the enormous discrepancy between the general population and disabled people - particularly PWID.

Table 6: Marital status

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Total Pop %</th>
<th>Total PWD %</th>
<th>Total PWID %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>37</td>
<td>31</td>
<td>72</td>
</tr>
<tr>
<td>Married</td>
<td>51</td>
<td>44</td>
<td>16</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>6</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>N 3325643</td>
<td>N 519565</td>
<td>N 39165</td>
</tr>
</tbody>
</table>

For the general population 63% of people were or had been married at some point and for PWD as a group this figure was 69%. For PWID on the other hand

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208 CSO 2011 Census Profile 8 (CD809)
209 CSO 2011 Census Profile 8 (CD808)
the opposite is true with only 28% ever having been married while 72% were single. A key influence in this is Irish legislation which criminalises sexual relationships with PWID\textsuperscript{210} and legal capacity legislation which prohibits people deemed to lack legal capacity from entering into marriage. There are, of course, other factors including stereotyping, poor employment opportunities, lower levels of education and limited opportunities for independent living.

b) People living in Communal Establishments

On census night 2% of the general population were recorded as being resident in communal establishments which included hotels, tourist hostels, prisons, hospitals, shelters, religious establishments and nursing homes. For disabled people generally over 7% were recorded as being in communal establishments and for PWID the figure was 15\%\textsuperscript{211}.

Table 7: Communal Establishments\textsuperscript{212}

<table>
<thead>
<tr>
<th>Type of Communal Establishment</th>
<th>Total Pop %</th>
<th>Total PWD %</th>
<th>Total PWID %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hotel, tourist hostel, guest house</td>
<td>38</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Educational establishment</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Religious community</td>
<td>5</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Nursing/children’s home</td>
<td>26</td>
<td>55</td>
<td>71</td>
</tr>
<tr>
<td>Hospital</td>
<td>17</td>
<td>26</td>
<td>21</td>
</tr>
<tr>
<td>Prison</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Shelter or refuge</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>N 109897</td>
<td>N 44952</td>
<td>N 8873</td>
</tr>
</tbody>
</table>

For both disabled people as a whole and for PWID the majority of those in communal establishments were in nursing/children’s homes and in hospital. For

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\textsuperscript{210} Criminal Law (Sexual Offenses) Act 1993, Section 5
\textsuperscript{211} CSO 2011 Census Profile 8 (CD822)
\textsuperscript{212} CSO 2011 Census Profile 8 (CD822)
the general population the highest percentages were staying in tourist accommodation followed by nursing/children’s homes and hospital. A significantly higher percentage of disabled people in communal establishments were in nursing/children’s home than among the general population. It is also notable that a disproportionately large percentage of PWID were recorded as being in nursing/children’s homes compared to both the general population and disabled people as a whole. It is likely that this figure includes people living in specialist residential accommodation including larger residential institutions.

Table 8: People with intellectual disability in Communal Establishments and age\textsuperscript{213}

<table>
<thead>
<tr>
<th>Type of Communal Establishment</th>
<th>Total</th>
<th>0 – 14</th>
<th>15 – 24</th>
<th>25 – 44</th>
<th>45 – 64</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hotel, tourist hostel, guest house</td>
<td>219</td>
<td>16</td>
<td>37</td>
<td>71</td>
<td>59</td>
<td>36</td>
</tr>
<tr>
<td>Educational establishment</td>
<td>40</td>
<td>5</td>
<td>27</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Religious community</td>
<td>92</td>
<td>1</td>
<td>4</td>
<td>19</td>
<td>27</td>
<td>41</td>
</tr>
<tr>
<td>Nursing/children’s home</td>
<td>6279</td>
<td>78</td>
<td>252</td>
<td>1385</td>
<td>1807</td>
<td>2757</td>
</tr>
<tr>
<td>Hospital</td>
<td>1905</td>
<td>49</td>
<td>37</td>
<td>243</td>
<td>631</td>
<td>945</td>
</tr>
<tr>
<td>Prison</td>
<td>120</td>
<td>0</td>
<td>36</td>
<td>66</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Shelter or refuge</td>
<td>195</td>
<td>6</td>
<td>21</td>
<td>72</td>
<td>75</td>
<td>21</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>5</td>
<td>10</td>
<td>6</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>8873</td>
<td>160</td>
<td>424</td>
<td>1866</td>
<td>2618</td>
<td>3805</td>
</tr>
</tbody>
</table>

From Table 8 it can be seen a total of 6279 PWID live in nursing/children’s homes and that the numbers increases steadily from childhood into old age. While only a small number of children with intellectual disabilities were in nursing/children’s homes, as people entered adulthood this rises sharply and by the time people reach their mid-40’s and mid-60s over 4550 people are in nursing homes.

\textsuperscript{213} CSO 2011 Census Profile 8 (CD822)
4.3. National Disability Survey 2006

The National Disability Survey (NDS) was conducted by the CSO in September/October 2006 after the census of that year and the sample was drawn from those people who reported having a disability in the census. As noted above, the 2006 census did not separately categorize intellectual disability.

The purpose of the NDS was to provide an analysis of the situation of people with disability in Ireland and to provide data for service planning. The NDS First Results, Volume 1, was published in 2008 providing information on prevalence and type of disability, the levels of difficulty experienced by people, the use of and need for disability aids and the age of onset of disability. Volume 2 was published in 2010 providing information on how PWD experience life in nine areas of life including transport, the built environment and social participation.

The definition of disability used introduces the concept of severity as a threshold for deciding whether a person has a disability. This meant that the population surveyed were those people who reported experiencing moderate or more severe levels of difficulty in any of the listed areas of functioning (seeing, hearing, speech, mobility and dexterity, remembering and concentrating, pain or breathing.). For two categories those reporting any difficulty in functioning were classified as being disabled i.e. intellectual/learning difficulties and emotional, psychological and mental health difficulties.

Because of the more restricted definition of disability and the different method of data collection in the census and the NDS (self reporting in the census and personal interviewing in the NDS) the level of disability recorded in each was different. The 2006 census recorded that 9.3% of the population has a disability i.e. 393,800 people, while the NDS recorded that 8.1% of the population has a disability i.e. 325,800.214

The NDS confirms that the prevalence of disability increases with age – 36% of people with a disability were aged 65 years and over.215 The disabilities experienced by people in the older age group are primarily physical and sensory i.e. hearing (54%), seeing (52%), mobility & dexterity (50%) and breathing (42%).216 This raises the issue of the exclusion of details of this segment of the population from the primary planning tool used by the Department of Health and

214 Central Statistics Office, National Disability Survey 2006, First Results, Dublin, The Stationery Office (October 2008)Table 2.2 p21
215 ibid Table 2.5 p23
216 ibid Table 2.7 p24
Children – the National Physical and Sensory Disabilities Database – an issue which the NPSD committee is currently seeking to address.

Interviews were conducted with children and adults living in private households and in communal establishments. For the purposes of the survey ‘private households’ included community group homes for PWD while ‘institutions’ included nursing homes, children’s homes, residential care centers and hospitals. It is interesting to note that those adults living in institutions were not asked about work, while people in private households were asked about work. This is problematic, particularly in relation to PWID living in residential care institutions.

Table 9: NIDD 2011 Adults in residential care centers and community group homes and level of disability

<table>
<thead>
<tr>
<th></th>
<th>Mild %</th>
<th>Moderate/Severe/Profound %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Group Homes</td>
<td>23</td>
<td>77</td>
</tr>
<tr>
<td>Residential Care Centers</td>
<td>9</td>
<td>91</td>
</tr>
</tbody>
</table>

As illustrated in Table 9, the NIDD indicates that a higher percentage of people with moderate, severe or profound (MSP) intellectual disability live in residential centres than in community group homes. Nonetheless all people in this category living in group homes were asked about work, while people in residential care centres were not. This must raise the question about the assumptions made regarding people living in institutions – are people living in institutions seen to be unlikely to be interested in work or have a work history? Does the place in which one lives influence these assumptions even more than the severity of ones disability?

In relation to housing the NDS First Results focuses only on the these two categories i.e. ‘nursing home, hospital and children’s home’ and ‘private households’. No details of the occupancy type of people living in either private households or communal establishments were collected as part of the NDS. The survey indicates, however, that overall 25,600 PWD live in communal

establishments (7.9%) and 300,200 live in private households (92.1%). People living in communal establishments had a higher level of multiple disability than those living in private households – and consequently higher levels of support needs.

There is a marked difference in the age profile of people living in communal establishments and those living in private households. The vast majority of PWID living in private households were aged under 65 (93%), while 67% of the total population of disabled people in private households were in this age group – Table 10 below. This picture changes when looking at people in communal establishments – only 26% of the total population of PWD were under 65 while 67% of those with intellectual disability were less than 65 years. A large majority of the total number of PWD living in communal establishments were in the 65+ age group i.e. 74%, while only 33% of those with ID were over 65 years.

Table 10: Age profile of people living in communal establishments and private households

<table>
<thead>
<tr>
<th>Age Group</th>
<th>All PWD %</th>
<th>PWID %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Private Households</td>
<td>Communal Establishments</td>
</tr>
<tr>
<td>0-64</td>
<td>67</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>93</td>
<td>67</td>
</tr>
<tr>
<td>65–74</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>75 +</td>
<td>19</td>
<td>62</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>23</td>
</tr>
<tr>
<td>N 300,200</td>
<td>N 25,600</td>
<td>N 64,600</td>
</tr>
<tr>
<td></td>
<td>N 7,000</td>
<td></td>
</tr>
</tbody>
</table>

We can conclude from this that it is more likely that a person with an intellectual disability will live in some form of communal establishment at a younger age than people with other types of disability.

One of the areas of life examined in Volume 2 of the NDS was the Social Participation experiences of PWD living in both private households and in communal establishments. The findings highlighted the fact that disabled people

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218 Central Statistics Office, National Disability Survey 2006, First Results, Dublin, The Stationery Office (October 2008) Table 2.4 p28
219 *ibid* p29
220 *ibid* Table 2.17 p31
221 *ibid* Table 2.17 p31
living in private households are much more likely to engage in some form of social activity and to visit family members than people living in communal establishments – 61% of people in private households went to a social event and 72% visited family or friends in the four week period prior to interview. For people in communal establishments these percentages were much lower at 22% attending a social event and 19% visiting family or friends. In addition those living in communal establishments were much more likely than people in private households to depend on carers, disability service providers or friends with a disability for company. These findings reflect those of the HSE report on congregated settings published in 2011 which found low levels of family contact - with one in three residents having no family contact in the preceding six months - and the majority of community participation by residents was as part of a group with other residents. This report also found that the vast majority of residents in these institutions had a moderate, severe or profound intellectual disabilities, had high levels of support needs and a large majority had been in residential care for over 15 years.

4.4. National Intellectual Disability Database
The NIDD was established in 1995, primarily as a tool for planning of services for PWID by the Department of Health and Children, the HSE and non-statutory agencies. Since then the committee has produced a yearly report which outlines the prevalence rates of intellectual disability, current day, residential and multi-disciplinary services people on the database are receiving and estimates of the service needs in these areas over the following 4 – 5 years. The NIDD uses the WHO International Classification of Diseases, Tenth Edition (ICD-10) in its definition of intellectual disability – while the NDS used the WHO International Classification of Functioning (ICF). Registration on the NIDD is voluntary, but the objective of the committee is to obtain information on every person 'known to have an intellectual disability and assessed as being in receipt of, or in need of, an

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223 ibid Graph 8.3 p94
224 Health Services Executive, Time to Move on from Congregated Settings: A strategy for Community Inclusion, Dublin, HSE (June 2011) p58
225 ibid p58
226 ibid p51
227 ibid p54
228 ibid p52
The committee accepts that because of the voluntary nature of registration and the link between service usage and registration, that the statistics presented are likely to be under-representative of people with mild ID, many of whom may not be current users of ID services or may not have a need of such services into the future.

4.4.1. Profile of PWID on NIDD

The most recent NIDD annual report records 27,324 people with intellectual disability registered on the database with 40% of people having a moderate level of ID, 33% mild and 15% being severely intellectually disabled. The level of ID of 8% of those on the database was unverified and it should be noted a large majority (81%) of in this group were children under the age of 10. The largest percentage of people registered on the NIDD were under 20 years of age (36%) and the smallest percentage were 55 years or more (12.6%).

Although categorising people by degree of ID is frequently criticised, it is an indicator of the level of support the person is likely to require. An analysis of figures from 1974 to 2011 included in the 2011 NIDD report points to the consistent rise in the numbers of people with moderate, severe and profound levels of ID aged 35 years and over during this period.

As indicate in Table 11 below over the 2002 – 2011 period there is an increase in the overall numbers of people registered on the NIDD and a change in the proportions of those in the different categories of ID, particularly in the mild and moderate categories. The percentage of people diagnosed with a mild ID fell from 37% of the total in 2002 to 33% in 2011 and those in the moderate category rose from 37% of the total in 2002 to 40% in 2011. The percentages in the severe and profound ranges remained relatively constant.

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230 ibid Table 2.1 p23
231 ibid Table 2.1 p23
232 ibid Table 2.3 p29
Table 11:  Degree of intellectual disability 2002 - 2011

<table>
<thead>
<tr>
<th>Year</th>
<th>Mild %</th>
<th>Moderate %</th>
<th>Severe %</th>
<th>Profound %</th>
<th>Not verified %</th>
<th>Total Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>33</td>
<td>40</td>
<td>15</td>
<td>4</td>
<td>8</td>
<td>27324</td>
</tr>
<tr>
<td>2010</td>
<td>33</td>
<td>40</td>
<td>15</td>
<td>4</td>
<td>8</td>
<td>26484</td>
</tr>
<tr>
<td>2009</td>
<td>33</td>
<td>40</td>
<td>15</td>
<td>4</td>
<td>8</td>
<td>26066</td>
</tr>
<tr>
<td>2008</td>
<td>33</td>
<td>40</td>
<td>15</td>
<td>4</td>
<td>8</td>
<td>26023</td>
</tr>
<tr>
<td>2007</td>
<td>33</td>
<td>38</td>
<td>15</td>
<td>4</td>
<td>10</td>
<td>25613</td>
</tr>
<tr>
<td>2006</td>
<td>33</td>
<td>38</td>
<td>16</td>
<td>4</td>
<td>9</td>
<td>25518</td>
</tr>
<tr>
<td>2005</td>
<td>34</td>
<td>38</td>
<td>16</td>
<td>4</td>
<td>8</td>
<td>24917</td>
</tr>
<tr>
<td>2004</td>
<td>35</td>
<td>38</td>
<td>16</td>
<td>4</td>
<td>7</td>
<td>25416</td>
</tr>
<tr>
<td>2003</td>
<td>37</td>
<td>37</td>
<td>16</td>
<td>4</td>
<td>6</td>
<td>25557</td>
</tr>
<tr>
<td>2002</td>
<td>37</td>
<td>37</td>
<td>16</td>
<td>4</td>
<td>6</td>
<td>25448</td>
</tr>
</tbody>
</table>

The increase in the overall numbers of people registered on the NIDD, the increasing age of people with ID, the increasing percentage of people in the moderate range and the decreasing percentage in the mild range taken together have important implications for the future. Specifically, PWID are living longer, have relatively higher levels of support need - because of the relatively higher degree of ID - and there is an overall increase in the numbers of PWID. All of which indicate that over time the need for services and supports will increase and this clearly has resource implications for the state, for families and for service providers. In terms of independent living and housing it also raises questions about the accessibility of housing stock and housing systems to people with more significant ID, especially as they age, and the configuration of supports to enable people to achieve IL. Will mainstream nursing home or home-based services for the elderly be available or accessible by this population group? Could, for example, the existing ‘Home Care Packages’ or Community Services currently provided by the HSE for older people wishing to remain living in their own home be adapted and made accessible to support elderly people with ID?

233 Drawn from National Intellectual Disabilities Database Annual Reports 2002 to 2011, HRB, Tables Numbers of people registered on the NIDD, by age, gender and degree of intellectual disability
4.4.2. Residential circumstances
When looking at the residential circumstances of PWID the NIDD focuses on the supports available to or required by people on the database. No distinction is made between the ownership or tenancy status of people in the various types of accommodation. This means that it is likely that ‘community group homes’ includes both traditional group homes owned by disability service providers and housing association accommodation rented to groups of PWID. In both forms of housing, support is generally provided by a disability service provider but it is only in the latter that residents hold legal tenancies – in disability service provider-owned group homes residents have no tenancy or ownership rights. A survey by the Irish Council for Social Housing (the national representative body for housing associations) in 2007 indicated that housing associations throughout the state were providing 1149 units for PWID.\(^{234}\) Albeit it that the having legal tenure in one’s home is an important element of IL, this group is not distinguishable from group home residents in the NIDD data.

A large majority of people on the NIDD live at home with parents or other family members i.e. 65.5%. However, although 98% of people under 20 years of age live at home only 39% of adults in the 55 years plus do so.

Table 12: Residential circumstances and age of people with ID 2011\(^{235}\)

<table>
<thead>
<tr>
<th></th>
<th>0 – 19</th>
<th>20 – 34</th>
<th>34 – 54</th>
<th>55 +</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home</td>
<td>9986</td>
<td>4624</td>
<td>3010</td>
<td>596</td>
<td>17916</td>
</tr>
<tr>
<td>Independent Setting</td>
<td>3</td>
<td>226</td>
<td>594</td>
<td>287</td>
<td>1110</td>
</tr>
<tr>
<td>Community Group Home</td>
<td>115</td>
<td>701</td>
<td>2214</td>
<td>1097</td>
<td>4127</td>
</tr>
<tr>
<td>Residential Centre</td>
<td>44</td>
<td>373</td>
<td>1264</td>
<td>1062</td>
<td>2743</td>
</tr>
<tr>
<td>Other full-time service</td>
<td>64</td>
<td>332</td>
<td>562</td>
<td>386</td>
<td>1344</td>
</tr>
<tr>
<td>No fixed abode/no information</td>
<td>6</td>
<td>24</td>
<td>30</td>
<td>24</td>
<td>84</td>
</tr>
<tr>
<td>Total</td>
<td>9918</td>
<td>6280</td>
<td>7674</td>
<td>3452</td>
<td>27324</td>
</tr>
</tbody>
</table>

\(^{234}\) Irish Council for Social Housing *Enhancing Choices for People with Disabilities in the Community: Survey Findings on Social Housing Provision for People with Disabilities in the Voluntary Housing Sector* (September 2007) Policy and Research Series, ICSH, Dublin

Overall 1110 people live in independent settings i.e. 12% of all those not living with family.\textsuperscript{236} The majority of those not living at home with family are living in group homes (44%) or in residential centres (29%) – residential centres accommodate 10 people or more together either in a campus setting or in a single unit. It is notable as well that 1344 (14% of those not living with family) people live in other full-time services which include psychiatric hospitals, intensive placements, nursing homes and mental health community residences.

\textbf{4.4.3. Changes in residential provision}

Table 13 below gives a breakdown of the residential circumstances of all adults registered on the NIDD in 2002 and 2012. In the 10 year period the overall numbers of people availing of some form of residential services increased by 802 - 455 of whom were people living in independent settings.

While 7407 (44%) of people were living at home with family in 2002 this increased to 8230 (47%) by 2011 – an increase of 823 people. This can be interpreted positively or negatively – either families were enabled to continue to support their family member at home for longer or alternatively it represents a failure to meet the greater demands created by the increased numbers of PWID and the greater life expectancy of PWID – there were 905 more PWID aged 55 years and over in 2011 than in 2002. And while the percentage (but not the number) of PWID in the 55 + age group living at home remained relatively static, it is notable that a much larger percentage of people in the 20 – 34 age group lived with family in 2011 (74%) than on 2002 (63%). The same holds true for people in middle adulthood with 39% living at home with family in 2011 as opposed to 34% in 2002. There is also a significant change in the numbers of people accommodated in group homes and residential centres. The numbers living in group homes increased from 3077 to 4012 in the 10 year period i.e. an increase of 30% and the numbers in residential centres decreased from 3278 to 2699 i.e. decrease of 18%. The largest increase in numbers in group homes was among people aged 35 years and over and the decrease in residential centres was only among people ages 34 years and younger – in fact the number of older people living in residential centres increased by 268 during this time.

\textsuperscript{236} Defined as people living in their own home with a maximum of 2 hours residential support daily or no support
Table 13: Residential circumstances and age of adults 2002 and 2011\textsuperscript{237}

<table>
<thead>
<tr>
<th></th>
<th>2002</th>
<th></th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>55 years</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20 – 30</td>
<td>years</td>
</tr>
<tr>
<td>With family</td>
<td>4560</td>
<td>432</td>
<td>652</td>
</tr>
<tr>
<td>Independent setting</td>
<td>161</td>
<td>130</td>
<td>598</td>
</tr>
<tr>
<td>Group Home</td>
<td>883</td>
<td>1686</td>
<td>3077</td>
</tr>
<tr>
<td>Residential centre</td>
<td>850</td>
<td>1634</td>
<td>3278</td>
</tr>
<tr>
<td>Other full-time</td>
<td>362</td>
<td>524</td>
<td>794</td>
</tr>
<tr>
<td>No fixed abode/ No information</td>
<td>434</td>
<td>467</td>
<td>403</td>
</tr>
<tr>
<td>Total</td>
<td>7250</td>
<td>7087</td>
<td>16794</td>
</tr>
</tbody>
</table>

\textsuperscript{237} Drawn from National Intellectual Disabilities Database Annual Report 2002 (Table 3.4, p35) and National Intellectual Disabilities Database Annual Report 2011 (Table 3.2, p37), Dublin, HRB
An analysis of NIDD statistics relating to residential accommodation covering the years 1999 to 2009 conducted by Kelly and McConkey confirms these findings. They found that there has been a slow but significant decrease in the numbers of people living in residential settings and a corresponding increase in people living in community group homes in recent years. This reflects an international and national policy trend which has seen people move from large institutions to community based housing in this period. However, experience from Australia suggests that in the deinstitutionalization process ‘accommodation has often been an afterthought, frequently leading in practice to a reliance on simple housing models such as the group home. Although it is recognised that group homes are an important source of stable accommodation for people with complex support needs, there is the danger that they have become the blueprint, and often the only model, for community-based housing provision.’\(^{238}\) Kelly and McConkey also found that while there had been a decrease in the numbers of people in traditional residential centres (termed congregated settings) there was a corresponding increase in ‘… specialist units as new forms of congregated settings.’\(^{239}\) They noted that the numbers of people accommodated in specialist challenging behaviour units had increased by 265% and those in specialist units for people with multiple disabilities had increased by 30%\(^{240}\).

A closer look at the ‘other full-time placement’ group as illustrated in Chart 2 below highlights this trend. It is clear that the numbers of PWID accommodated in psychiatric hospitals fell consistently over the 2002 to 2011 period. However, during the same time there was a significant increase in intensive placements, particularly for people with challenging behaviour – in effect new forms of congregated settings. Kelly and McConkey also note that in the 1999 – 2009 period 591 people moved from congregated settings to group homes while just 20 people moved to a home setting and 13 to independent settings. During the same period, however, 264 people moved from group homes into congregated settings and they highlight that overall over 100 people per year were admitted to


\(^{240}\) ibid p7
congregated settings, which, they suggest, may be because of the larger number of vacancies there.241

Chart 2: Other forms of Residential Accommodation 2002 - 2011242

The degree of ID which people have will determine much about the level of support they will require in their residential accommodation and daily activities. The majority of this support is provided by families. As indicated in Table 14 below, people with mild intellectual disability are significantly more likely to continue living at home with families than those in the moderate/severe/profound (MSP) category. In 2002 56% of people with mild ID were living with family and in 2011 the figure was 58%. For people in the MSP range however, in 2002 38% were living with family and this increased to 42% in 2011.

242 Drawn from National Intellectual Disabilities Database Annual Reports 2002 to 2011 Tables 3.3 ‘Main Residential Circumstances’ Dublin, HRB
Table 14: Residential Circumstances and Degree of Intellectual Disability 2002 and 2011

<table>
<thead>
<tr>
<th></th>
<th>2002</th>
<th>2011</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mild</td>
<td>Moderate/Severe/Profound</td>
<td>Mild</td>
<td>Moderate/Severe/Profound</td>
</tr>
<tr>
<td>With family</td>
<td>3000</td>
<td>4157</td>
<td>3173</td>
<td>4929</td>
</tr>
<tr>
<td>Independent setting</td>
<td>479</td>
<td>128</td>
<td>852</td>
<td>206</td>
</tr>
<tr>
<td>Group Home</td>
<td>731</td>
<td>2326</td>
<td>906</td>
<td>3086</td>
</tr>
<tr>
<td>Residential centre</td>
<td>268</td>
<td>3001</td>
<td>238</td>
<td>2451</td>
</tr>
<tr>
<td>Other full-time</td>
<td>245</td>
<td>1024</td>
<td>248</td>
<td>1015</td>
</tr>
<tr>
<td>No fixed abode/No information</td>
<td>669</td>
<td>314</td>
<td>13</td>
<td>64</td>
</tr>
<tr>
<td>Total</td>
<td>N 5392</td>
<td>N 10950</td>
<td>N 5430</td>
<td>N 11751</td>
</tr>
</tbody>
</table>

Over the 10 year period there was an increase of over 74% in the numbers of people living in independent settings but the increase was mainly among those with mild ID. This if course is understandable given that the NIDD defines ‘independent setting’ as people living with no more than 2 hours of daily residential support and people in the MSP category are likely to require higher levels of support.

As noted above the numbers of people living in group homes increased while residential centre numbers decreased. However, the change in types of accommodation is not uniform between people in the mild and MSP categories. People in the MSP range of ID remain much more likely to live in residential centres than those in the mild range. However people with MSP ID are also more likely to live in group homes, reflecting the fact that people in this category are significantly more likely overall to not live at home with family.

Looking at service requirements from the present to 2016, the NIDD reports that 2248 people will require full-time residential services, of whom 71.2% have a MSP ID and have, as a consequence, higher levels of support needs. A further 2040
people will require new residential support service such as respite care or part-time care. This latter group includes people living at home or independently/semi-independently at present. 2865 people will require their current residential service to be changed or upgraded and 1654 will require enhanced residential supports.\textsuperscript{243} The database identified 214 people with ID currently living in psychiatric hospitals\textsuperscript{244} and of these 123 had an appropriate alternative residential facility identified for them.\textsuperscript{245}

4.5. Mental health services and people with intellectual disability

As acknowledged by the Health Research Board many PWID are not registered on the NIDD and it is estimated by the Department of Health in its mental health policy document \textit{Vision for Change} that only about one third of people with a mild ID are recorded on the database.\textsuperscript{246} Rates of mental illness among PWID are high compared to the general population with a report from the World Health Organisation putting the prevalence of mental illness among people with severe or profound ID at almost 50\% and at between 20\% and 25\% for people with milder levels of ID.\textsuperscript{247} Many PWID with additional mental health problems are served within the mental health system and are in receipt of psychiatric, multi-disciplinary and residential services therein.

4.5.1. Psychiatric hospitals and community residences

The 2010 census of psychiatric hospitals recorded 2,812 people in hospital on census night – 1,186 of whom had been in hospital for 1 year of more and 692 of whom had been in hospital for 5 years of more. The census also recorded that 154 people in psychiatric hospitals had a diagnosis of intellectual disability, 142 of whom had been in hospital for 1 year – and 127 of these people had been resident

\textsuperscript{244} \textit{ibid} Table 4.14 p72
\textsuperscript{245} \textit{ibid} Table 4.16 p75
\textsuperscript{247} International Association for the Scientific Study of Intellectual Disabilities \textit{Mental health and intellectual disabilities: Addressing the mental health needs of people with intellectual disabilities.} (September 2001) Report by the Mental Health Special Interest Research Group of IASSID to the World Health Organisation. p12 \url{www.iassid.org/pdf/mh-sirg-who-final.pdf} Accessed 12/12/2012
there for 5 years or more. Ninety nine of the people with ID in psychiatric hospitals in the 2010 censuses were residents of St Joseph’s Intellectual Disability Services. Since then the HSE has moved 60 of these people into ten 6-person houses on the grounds of St Ita’s hospital. This move has been somewhat controversial as it appears to replicate many of the features of traditional campus settings - which have been included as part of the policy of closure of congregated settings nationally. The census report tracks the decline in the numbers of long-stay patients (one year or more) in psychiatric hospitals from 1971 to 2010 when numbers fell from 12,860 to 2812. The rate of decrease in numbers of long-stay patients has slowed considerably in recent years and the report suggests that ‘The most recent experience of decline of hospital population from 2006 to 2010 projected on to 2030 ... indicates there will still be over 300 long-stay patients in in-patient care, the majority of them in large public psychiatric hospitals as a consequence of the slowing down of the rate of decline of new long-stay.

A primary source of non-hospital accommodation for former long stay patients and for people with more recent mental illness requiring residential support are community residences. The gradual decrease in the number of long stay patients in psychiatric hospitals since the 1970’s has seen a corresponding increase in the development of these community residences.

Table 15: 24 hour nurse-staffed community residents 2008

<table>
<thead>
<tr>
<th></th>
<th>Number of Residences</th>
<th>Number with &lt; 9 places</th>
<th>Number of residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSE West</td>
<td>34</td>
<td>12</td>
<td>413</td>
</tr>
<tr>
<td>HSE South</td>
<td>33</td>
<td>5</td>
<td>406</td>
</tr>
<tr>
<td>HSE Dublin North East</td>
<td>24</td>
<td>0</td>
<td>307</td>
</tr>
<tr>
<td>HSE Dublin mid Leinster</td>
<td>19</td>
<td>0</td>
<td>245</td>
</tr>
<tr>
<td>Mental Health/ intellectual disability</td>
<td>22</td>
<td>14</td>
<td>213</td>
</tr>
<tr>
<td>Total</td>
<td>132</td>
<td>31</td>
<td>1584</td>
</tr>
</tbody>
</table>

248 Health Research Board Irish Psychiatric Units and Hospitals Census 2010 HRB Statistics Series 12, Dublin, HRB (2011) Table 2.23 p51
249 ibid Table 4.1 p65
250 ibid Table 7.1 p102
251 ibid p106
In 2008 the mental health services provided a total of 132 24-hour nurse-staffed community residences, 22 of which provided accommodation solely to people with ID. Less than a quarter of these community residences accommodate less than 9 people together, and the Mental Health Commission (MHC) notes that ‘it is not unusual for people to share a house with 10 to 32 people.’ In relation to PWID, however, there appears to be a greater effort to keep the residences smaller – over half accommodating less than 9 people.

So although the larger institutional psychiatric hospitals are in decline, the type of alternative community-based accommodation being provided to many people with mental health difficulties (including PWID) appears to reflect some of the features of these institutions – particularly in relation to the numbers of people living together. The MHC highlights this issue in its 2008 report, noting that such residences provide ‘limited opportunity for community integration [and] there is evidence that people are sharing bedrooms, sharing living space with a large number of other people and having little opportunity to be actively involved in a meaningful rehabilitation and recovery plan’. An evaluation of community residences conducted by the Health Research Board and the Mental Health Commission found that the majority of residents were happy with their care and accommodation. However, the evaluation concluded that ‘The climate and culture of the residences reflected more those of a ‘mini-institution’ than of a home-like environment, especially in the high support residences. The medium and low support residences were somewhat more relaxed, but a large number employed constricting rules and regulations, the necessity for which was questionable.’

4.6. Conclusion

Because of the varying definitions and methodologies used by the different data-collection agencies discussed above there is a lack of consistency about the numbers of PWID. It is, nonetheless, possible to get a picture of the circumstances in which people live in Ireland and the trends over recent years. It appears from the 2011 census that 1.3% of the population has an ID, that is there are 57,709

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253 ibid p81
254 ibid p81
255 Mental Health Commission and Mental Health Commission Happy Living Here, An evaluation of community residential mental health services, Dublin, MHC & HRB (January 2007) p10
PWID living in the state. It is worthy of note that there has been an apparent large increase in the numbers of people who define themselves as disabled from the census data. This may have resulted from the changes in wording or new categorization of disability type. However, it is possible to question whether there are links with the economic downturn in the country, an increasing acceptability of disability and a consequent willingness to identify as disabled or indeed with other factors. It is hardly coincidental that the levels of disability and of ID is higher among Travellers – one of the most socially excluded group of people in Ireland.\textsuperscript{256}

Overall PWID are living longer than heretofore and this includes people with more significant levels of ID. This is a welcome development but it does have implications for the amount of resources which will be required to meet the support needs of people as they age, and for their families and service providers.

The data analyzed above paints a picture of the life pathways of PWID which is substantially different from that of non-disabled people. People with ID remain living at home with their families for longer than their non-disabled peers, are much more likely to live in some form of grouped ‘special’ accommodation, are much more likely to remain single, are unlikely to ever be a head of household or own their own home and are significantly more likely to be unemployed.

Over the past 10 years an increasing number of PWID remain living at home with their families across all age groups and degrees of ID. Whether this is by choice or because of a lack of alternative residential options is open to speculation, but it has important implications for the level and the configuration of supports required to enable families to continue to support their disabled family member, especially as parents age themselves. A relatively small, but increasing, number of PWID live independently with minimal levels of support and this is mainly among people with mild ID. Data form the census would appear to indicate that PWID have greater access to social housing than the general population. However, this must be read in conjunction with the relatively small number of PWD assessed by the local authorities as needing housing and the significant number of disabled people accommodated in large residential centres who are clearly not reflected in local authority housing waiting list numbers.

Where people are not living at home with family, their main options then are various forms of communal establishments including predominantly group homes and larger residential centres - and in recent times specialist placements for people with complex needs. People who are older or have higher levels of ID remain more likely to live in the larger residential institutions despite the overall move towards smaller group homes - and it is important to remember that the levels of participation in social activities is greater in these smaller settings. The mental health services provide residential accommodation to a relatively small number of PWID – increasingly in community residences as opposed to psychiatric hospitals. The warning that these community residences bear many of the hallmarks of mini-institutions should be kept in mind.

Residential services, then, are primarily used by people with more significant levels of disability and consequent higher support needs. This combined with the increased life expectancy of people with significant ID is placing greater pressure on residential services, which is reflected in the increasing waiting lists for residential places.

The main conclusion to be drawn from this analysis is that people with intellectual disabilities, in the main, are not accessing mainstream housing options when they move out of the family home. Rather they are moving into what, in effect, are segregated residential services which do not – and perhaps cannot – provide a basis for the achievement of independent living. The almost exclusive location of supports in these segregated services – as opposed to support to individuals to live in their own homes - is perhaps, the single most important reason why this pattern has remained relatively unchanged. Until people have the option of receiving support in their own homes it is difficult to see how the pattern can be broken.
Chapter 5: Independent Living as a human right

5.1. Introduction

The adoption by the UN General Assembly of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 marked the first recognition of the right to independent living and community participation as a fully fledged human right. The evolution of the independent living right can be traced back to the 1970’s as part of a shift from a broadly medical approach to disability through a social model approach to a more universalist approach within international human rights.

In this chapter I will outline the development of the right to Independent Living (IL) within the UN and discuss whether it represents a new human right required to address the situation of disabled people or if it is simply an amalgamation of existing rights or aspects of other rights. I will also discuss the rationale behind the need for such a right within the context of the increasing number of human rights instruments targeted at specific groups of people.

I will outline the implications of the right to independent living and community participation for people with disabilities and for governments. This will include an analysis of Article 19 and its interaction with other CRPD articles and relevant aspects of other human rights instruments, specifically the Universal Declaration of Human Rights (UDHR), the International Convention on Economic Social and Cultural Rights (ICESCR) and the International Convention on Civil and Political Rights (ICCPR).

5.2. Evolution of the right to independent living and community inclusion

Article 19 represents the full maturation of the right to IL, the recognition of which began several decades earlier in international policy. The evolving recognition of the right mirrors the evolution in thinking about disability from the medicalised approach of the early and middle parts of the 20th century, through the adoption of the social model from the 1960’s and 1970’s to the universalist approach in the CRPD.

Early mention of disabled people within United Nations systems emphasized rehabilitation and welfare focusing on people with physical and sensory impairments. The aim of these early policies was to maximize the potential of people to become members of the workforce and to provide welfare measures for
those who could not achieve this. This welfare and rehabilitation approach endured throughout the 1950’s reflecting the pre-dominant medical view of disability. The growth of medical knowledge and the development of increasingly specialized and often segregated services for people with various types of impairments was the hallmark of developments during this time. These services aimed to cure, rehabilitate or manage disability and this was also true for the approach taken in the early UN instruments.

In 1969 the General Assembly adopted the Declaration on Social Progress and Development which is the first declaration that makes specific reference to disability. This declaration referred to the need for social security and rehabilitation and the need to avoid disability-related discrimination.²⁵⁷ The 1971 Declaration on the Rights of Mentally Retarded Persons was the first formal recognition given to the rights of PWID and it reflects a continuing emphasis on welfare and a somewhat conditional according of rights stating that “The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.”²⁵⁸

The idea that PWID should live and be integrated in the community is part of this Declaration along with an emphasis on living with family and only using institutional care when necessary, stating that institutional care should be ‘... provided in surroundings and other circumstances as close as possible to those of normal life.’²⁵⁹ The 1975 Declaration of the Rights of Disabled Persons²⁶⁰, while although still broadly based on a medical/welfare approach, asserts that disabled people have the same fundamental rights as other citizens, including the same civil and political rights.

Despite the somewhat paternalistic and conditional approach of the 1970’s the trend in the early stages was clearly towards a recognition of people’s rights. The UN was sending a clear message that accommodating PWD in large institutions was becoming increasingly unacceptable and that they and their families should be supported to enable them remain living in their communities.

This period saw the birth and the growth of disability rights groups particularly in the UK and the US. These groups of disabled people were, throughout this time,

²⁵⁷ UN General Assembly Declaration on Social Progress and Development (1969) U.N. Doc 2542(XXIV) Article 19(d)
²⁵⁹ ibid para 4
developing the fundamental tenets of the social model of disability and asserting the rights of PWD to live independent lives of their choosing. On both a theoretical and practical level disabled people and their advocates were challenging the medical view of disability and the power of medical and related professionals to determine their lives. This newer understanding of disability is reflected increasingly in the UN Declarations referring to disabled people.

The fact that the UN human rights systems was taking the issue of segregation and rights abuses of PWD seriously was evidenced by development in the 1980’s starting with the International Year of Disabled Persons which asserted ‘...the right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equal to those of other citizens, and have an equal share in improved conditions resulting from socio-economic development.’

In the light of the evolution of the right to live in communities in two previous declarations, this assertion of full equality and participation for disabled people was highly significant. An important statement by Kurt Waldheim, UN Secretary General at the start of the International Year emphasised that ‘A drastic change in our attitude towards disabled persons is the prerequisite for such progress. We have, above all, to remember that problems of physical or mental disability are the problems of society as a whole.’ The need to change attitudes, to take steps to enable PWD to live integrated lives and to realize their human rights are the dominant themes within the UN systems by the early 1980’s. The International Year was followed by the World Programme of Action Concerning Disabled Persons in 1982. The objectives of the World Programme were to promote disability prevention measures, rehabilitation and equalization of opportunity with the overall aim of full participation of disabled people in all spheres of life. Participation in community is an underlying theme of the World Programme and the move towards less reliance on institutions and greater independence is evident.

Although IL is not specifically mentioned in the World Programme the basic tenets of the concept are inherent at this stage and the recommendation concerning environmental assess urges states to provide supports in the community to enable disabled people be as independent as possible. The first

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proposal for a disability rights convention was raised by Italy in 1987, however, it received little support and was not pursued. Sweden made a similar proposal in 1989, again without success. Two years later the Tallinn Guidelines were issued by the Secretary General in relation to implementing the World Programme. These guidelines made strong statements about the self-determination of disabled people, their full citizenship and equality and made mention of the concept of IL: ‘…disabled persons should be offered training in social and self-help skills to prepare them for independent living.’

Throughout the 1980’s there was wide acceptance of the principle of equal participation in society by PWD and of the need to develop community-based services. By the end of the 1980’s the idea of IL was beginning to be recognized within the UN systems reflecting the progress being made by disabled people’s groups in developed countries. Support for the aims of the IL movement and for disability rights continued to grow but it was not until the 1990’s that discrimination against disabled people began to be prohibited by law and the rights of people with disabilities gained legislative recognition at national level.

The adoption of Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles) by the General Assembly in 1991 marked the first recognition of the human rights of people with mental illness at international level. The MI principles were broadly based on the recommendations of a report prepared by Erica-Irene Daes, Special Rapporteur on the Prevention of Discrimination and Protection of Minorities in 1986, which highlighted the frequent and widespread abuse of rights of people with mental illness globally.

The MI Principles were unequivocal in the assertion of the equal applicability of all human rights for people with mental illness and their right to live in the community. The right to receive treatment in the community was outlined and where treatment in a mental health facility was required the principles stressed that this should be provided as close to the person’s home as possible and that people should be allowed to return to the community as soon as possible.

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practicable.

The general comment on the right to adequate housing issued by the CESCR in 1991 advises that disadvantaged groups, including PWD and mental illness, should be accorded ‘some degree of priority consideration in the housing sphere. Both housing law and policy should take fully into account the special housing needs of these groups.’ The importance of this comment is firstly, that it forms part of a mainstream human rights corpus and, secondly, that it recognizes that disabled people may have particular housing needs which are not addressed by mainstream housing law and policy.

A significant step forward was taken in 1993 at the World Conference on Human Rights with the adoption by the General Assembly of the Vienna Declaration and Programme of Action which called for the adoption of Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The Vienna Declaration unreservedly states that all human rights apply equally to PWD and that all have the right to live independently and participate in all aspects of society. The right to IL is fully recognized in this declaration and this was further re-enforced with the Standard Rules. However, the Standard Rules were not compulsory merely carrying a moral and political onus on states to take action to address the situation of disabled people. The overall thrust of the Rules is on equalizing opportunities, promoting independence, eliminating discrimination and opening up access to mainstream society. Because of the lack of legal force, their impact was limited as demonstrated by the 1997 report of the Special Rapporteur which noted that, although the Rules played an important part in guiding states, the fact that they were not obligatory meant that many governments were not supplying the requisite information for monitoring or evaluation. The 2000 report of the Special Rapporteur again referred to the difficulties with monitoring of the Rules and noted they did not address the area of housing and or institutions.

By the 2000’s the right to IL and community inclusion was well recognized within

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the UN human rights systems but the problem posed by the ineffectiveness of the Standard Rules in tackling the widespread rights violations of disabled people increased support for a disability-specific treaty. In 2001 the General Assembly adopted a resolution establishing an ad-hoc committee to develop such a convention when it states ‘...despite different efforts made to increase cooperation and integration and increasing awareness of and sensitivity to disability issues ... these efforts have not been sufficient to promote full and effective participation by and opportunities for persons with disabilities in economic, social, cultural and political life’.

The draft article on IL remained broadly intact up to the ratification of the CRPD in 2006 on the issues of the right to live in the community, to choose where one lives, not to be obliged to live in any particular living arrangement and to have access to support to participate in the community. The original article more pointedly addressed the issue of institutionalization stating that disabled people ‘...are not obliged to live in an institution or in a particular living arrangement.’

Debate about whether to retain the reference to institutions centered around freedom of choice and the feasibility of implementing full deinstitutionalization where resources to develop alternative community-based services are limited. In the end it was agreed to delete the reference to institutions and replace it with the phrase ‘particular living arrangement’ so as to ensure that the focus remained on IL and in recognition of the fact that some people may choose some form of grouped living arrangements. In December 2006 the General Assembly adopted the CRPD which included for the first time the right to IL and community inclusion.

5.3. The CRPD – a new group-specific human rights instrument

It is widely acknowledged that people with disabilities, estimated at more than one billion people or 15% of the world’s population, represent the world’s

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273 Originally Article 15 of the draft convention
largest minority and that as a group they have remained largely beyond the reach of mainstream international human rights law.

All human rights, as developed in the core human rights instruments of the UN are, in theory, applicable to people with disabilities in the same way as they are to all other people, by virtue of their humanity. However, despite this, disabled people have remained marginalized and often mistreated and segregated throughout society. Until relatively recent years they have not been seen as worthy holders of rights throughout the world, but rather as people in need of care or rehabilitation. Their non-inclusion in the foundational UDHR and in the ICCPR and the ICESCR reflects this basic belief – each of which proclaim that human rights apply without discrimination on the basis of ‘... race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.’ Although ‘other status’ is taken to include disabled people, the fact that they were not specifically named is ironic given that the UDHR was drafted in response to the horrors inflicted in Nazi Germany on several minorities, including PWD. The consequences of the non-inclusion of disabled people in the International Bill of Human Rights was that people with disabilities were not considered by national governments or by the UN systems in assessing the state of human rights realization globally or domestically. Quinn and Degener term this the ‘invisibility of people with disabilities.’ In their 2002 analysis of the use of UN human rights instruments in the context of disability, they suggest that the core human rights values, which are important in protecting against abuses of power and in creating space for human development, have a particular importance for disabled people. They suggest that ‘The problem is not the values themselves or the system of basic freedoms that they postulate but the fact that they are either not applied or are applied differently to people with disabilities.’ It is this inability or unwillingness on the part of the international community and of national governments to apply universal human rights to people with disabilities that led eventually to the adoption of the CRPD. Flynn suggests that ‘... the purpose of disability-specific rights is to reinforce the reality that although all human rights

278 ibid p23
apply to people with disabilities, extra support is often needed in order to make these rights accessible for people with disabilities. These rights also require states to acknowledge that the sole existence of a legal principle of non-discrimination may not be sufficient to guarantee that the human rights of people with disabilities will be respected.\(^\text{279}\)

An additional factor was the question as to whether the existing mainstream human rights instruments could in fact properly address the experiences of disabled people. As well as the historic marginalization of PWD which shares much in common with other minority groups, there are issues which are particular to them and to their experiences of, and ability to exercise their, human rights. In particular the issue of access, participation in community, capacity and autonomy are especially relevant to disabled people. The routine denial, whether deliberate or unintended, of people’s capacity to exercise choice in their lives, of their autonomy as persons, of access to public spaces and of the right to participate in communities, are especially pertinent for disabled people. The need of many disabled people to have personal support in order to exercise their rights is also an issue which is specific to their situation. The question of whether existing human rights instruments could adequately deal with these issues was key to the growing consensus in the UN that a disability-specific human rights instrument was needed.

The arguments against a disability-specific convention appear, in the light of the extreme marginalization of disabled people, to be somewhat theoretical. The arguments against any anti-discrimination instruments suggest that they are by definition an unjustifiable interference with the basic human freedoms. Epstein, who adopts an oppositional position in relation to all anti-discrimination law, for example, speaks of the ‘... the bedrock social importance of the principle of individual autonomy and freedom of association. Their negation through modern civil rights law has led to a dangerous form of government coercion that in the end threatens to do more than strangle the operation of labour and employment markets. The modern civil rights laws are a new form of imperialism that threatens the political liberty and intellectual freedom of us all.’\(^\text{280}\) This admittedly extreme


position, however, reflects a not-uncommon view that the market should be allowed to take its course without interference and no individuals or groups should be subject to preferential treatment simply because they do not fit the needs of the market. Any market interference of this type is an indefensible encroachment on the freedom and autonomy of employers and service providers, who should be free to employ, provide services to and associate with whom they wish. This argument rings hollow however, in the light of evidence of the exclusion of several groups resulting from prejudice and historic and current structural disadvantages - including people with disabilities. In view of the uncontested facts of mistreatment, exclusion and marginalization of many groups from mainstream society, the development of international human rights instruments can only be seen as a necessary and positive thing.

5.3.1. New rights in the CRPD?
The CRPD can be seen as an applied version of human rights, specifying what human rights mean in the situation of one particular group. The suggestion that this actually means developing new rights for disabled citizens has been denied from the very start of the treaty negotiation process. However, despite these protests it is arguable that in fact the CRPD does include new rights – rights so fundamental that there was no need to detail them in the pre-existing human rights instruments. Megret proposes that not only does the CRPD contain new rights, but that it also formulates existing rights in innovative ways which have never appeared in human rights instruments before. In particular he suggests that the CRPD ‘... makes the achievement of autonomy for persons with disabilities one of its primary goals. It holds up autonomy, therefore, as something akin to an entitlement.’ The recognition in the preamble to the CRPD of ‘... the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices’ highlights the importance of this issue to disabled people. Autonomy can be defined as the capacity ‘... to be one’s own person, to be directed by considerations, desires, conditions, and characteristics

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283 ibid pp512-513
that are not simply imposed externally upon one, but are part of what can somehow be considered one’s authentic self. Autonomy is an inherent part of several CRPD articles including those relating to accessibility, IL, freedom of movement and personal mobility. For disabled people, whose autonomy is often curtailed in law and by cultural practices or policies, this speaks directly to their experiences. Megret compares this to the inclusion of a right to maternity leave and pregnancy-related health care in the Convention on the Elimination of Discrimination Against Women, experiences which are specific to women.

Whether the right to IL is actually a new right derived from the lived experiences of disabled people has also been the subject of debate. Although this right appears in no other international human rights conventions it has been increasingly present in numerous UN policy documents and legal instruments. The right to participate in community and to live independently are rights which are routinely denied to disabled people across the globe on the basis that they have an impairment alone – this right may also be denied to others but the regularly and systematic nature of its denial is particularly pertinent in the case of PWD. For example research by Mansell et al highlighted the fact that in the 27 member states of the EU plus Turkey almost 1.2 million PWD were living in residential institutions – and segregated institutional living represents the direct opposite of living independently and participating in community life. Although Article 19 of the CRPD was specifically linked to the ICESCR right to liberty of movement and choice of residence in the treaty negotiations, this right in itself was not adequate to address the wholesale institutionalization and denial of the right to live and participate in community. Parker and Clements argue that ‘Although the right to independent living and community participation is not specifically referred to in any of the existing United Nations core human rights treaties, the last 15 years has witnessed an increasingly assured recognition within the UN human rights agencies


They suggest that Article 19 ‘... has not created a new right to community inclusion and participation. Rather, it is intended to provide a clarification of the obligations on states to ensure disabled people’s full and equal enjoyment of this “existing” right.’

The debate about whether the CRPD confers new rights to disabled people or simply applies pre-existing rights to them is important because the CRPD only applies to disabled people. If, for example, any other individuals or groups who are not disabled are denied the right to live independently or participate in community, how can this be identified and remedied since this right applies only to those who are disabled. It is not hard to envisage a situation where the right to choose where and with whom to live and not be obliged to live in any particular living arrangement could be denied to people who are not disabled. There is no doubt that this right is highly appropriate and necessary for disabled people, but it may also be applicable for others and it is perhaps the next step to extend this right to all people. Megret argues that in fact the CRPD could serve as a template for a more holistic conception of human rights by overcoming the traditional theoretical dichotomies such as that between the private and public spheres and between civil and political and socio-economic rights. Article 16, for example, explicitly provides for the right of disabled people to be free from exploitation, violence and abuses ‘... both within and outside the home ...’ thus recognizing that disabled people are especially vulnerable to abuse in the private as well as in the public sphere. Prohibiting abuse or exploitation in the public sphere alone would simply be insufficient in addressing the experiences of PWD. He suggests that such innovations in the CRPD in the application of human rights to the experiences of one particular group can be used as a template for other group-specific human rights instruments.

He suggests that ‘It is not simply the case that disabilities are a “special issue”, requiring special and sui generis arrangements. ... the Disabilities Convention, in forcing us to think about the rights of some provides a unique opportunity to rethink how we conceive of the human rights of all, and could, as such, be a very fruitful way of charting the future of human rights.’ In this sense then, the CRPD can be of benefit not only to disabled people, but also to everyone, if it seen and used as a

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289 Ibid p509
way of considering the particular human rights experiences of groups and of identifying what ‘new’ rights – or applied existing universal rights - can then be explicated for everyone.

5.3.2. The debate about group-specific human rights instruments

Whether groups need instruments which specifically address their experiences is debatable. Megret explores this question in relation to disabled people and the CRPD in particular. Pointing to the apparent tension between human rights ‘.. as fundamentally making a point about the sameness and unity of human beings. ... Group-specific treaties conversely ... can be seen as at least partly making a point about difference and pluralism. Difference and pluralism are obviously in tension with the ideas of equality and universality. Pointing to the pluralisation of human rights which has seen the UN develop conventions for women, children, racial groups and migrant workers, he suggests that such instruments are needed ‘...not only to adapt the existing language of rights, but because there is a dimension of the experience of specific groups that is inherent to them and which almost requires the creation of new rights. The common experience of disabled people would support this thesis, especially in relation to such issues as access to mainstream services, denial of legal capacity and denial of freedom to choose their place of residence – and while these are issue which may also be true for other groups, they are especially relevant for disabled people. So in order to bring such issues under the ambit of human rights law a convention directly addressing them was necessary, for without this, these factors which act to prohibit disabled people from exercising their human rights would remain in place.

It is, however, important to consider whether a disability-specific convention, or indeed other group-specific conventions, contributes to creating divisions between marginalized groups and between marginalized groups and the rest of the population. Do they, in effect, highlight the differences between such groups and the norm in society, and by focusing on the differences inadvertently contribute to their ‘otherness’ perhaps re-enforcing a belief that these differences matter in ways that can be either beneficial or detrimental. This is the ‘difference dilemma’ described by Martha Minow: ‘when does treating people differently


292 ibid P496

emphasise their difference and stigmatise or hinder them on that basis? and when does treating people the same become insensitive to their difference and likely to stigmatise or hinder them on that basis? It can be argued that demanding different treatment marks them out as different from the norm. Such different treatment often has resource implications which must be met from the public purse, and inevitably budgets are limited and must be used to meet many different demands. This potentially singles out disabled people as targets either for resentment because of the increased costs, or as objects of charity who are deserving of such public support. The CRPD acknowledges this danger and calls for what is in effect a widening of what is considered to be the norm in society and respect for the difference of disability. It outlines as one of its principles 'Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity'. This dilemma is also applicable to all other groups who are seeking to have their difference recognized as legitimate and not used as a reason for the denial of rights or for mistreatment. It appears to be an inherent danger of any minority group approach and groups must strike a careful balance between highlighting their differences and highlighting their sameness.

While the UN has developed human rights instruments to address race, women, children and people with disabilities, there are many other groups who experience human rights disadvantages whose situation remain unaddressed, including sexual minorities and older people. This begs the question as to which groups will or should have a convention focused on their specific experiences and on what basis will this be decided. And at what stage will the list be deemed to be complete?

An additional problem with group-specific human rights instruments is that they seem to be poorly equipped to deal with the situation of people with several different stigmatised identities such as disabled women. In real life people's identities are made up of several elements and people may be discriminated against for any number of reasons. The question is how helpful is it to focus on the reasons why people are being discriminated against, as opposed to the actual acts of discrimination – whether systemically or individually perpetrated. As

noted above levels of disability are higher among Irish Travellers than the rest of the population. No doubt disabled Travellers experience discrimination in many aspects of life and it may well be the case that women or girls who are disabled fare worse. For disabled women who are members of the Irish Traveller community, which of the group-specific instruments is most appropriate? Should they pursue their rights through the CRPD, the Convention on the Elimination of All Forms of Discrimination against Women or the Convention on the Elimination of All Forms of Racial Discrimination – all of which could be applicable? And how helpful is it to fragment people’s experiences in this way? Surely the fact that a specific group of people or individuals experience discrimination should be sufficient grounds for action, without the need to identify the single or myriad reasons. Yet this seems to be demanded by the current UN human rights structures. As Fredman suggests, group-specific legislation is problematic in respect of intersectional discrimination. She points out that ‘Such a demarcation [between groups] is highly problematic, in that it necessitates bright line distinctions between different grounds of discrimination. … [it is] based on an assumption that groups are mutually exclusive, defined according to objective characteristics, and operating in opposition to one another. Differences between groups are highlighted; differences within groups are rendered invisible...’

Identifying the trait or traits which are the basis for the discriminatory treatment, may deflect attention from the actual act of discrimination. Anti-discrimination legislation and the implementation systems for such legislation insist that people belong to a particular suspect group before the question of whether or not they have been discriminated against can even be considered. This fails to recognize that people can belong to several groups – or indeed to none of the suspect groups – and still experience unfair discrimination. In addition the effectiveness of this method of dealing with discrimination for people with disabilities has proved to be especially problematic as is evidenced by experience in the American courts dealing with cases under the anti-discrimination mandate of the Americans with Disabilities Act (ADA). To pursue a case under the ADA plaintiffs must firstly establish that they qualify as ‘disabled’ – unlike members of other protected groups who do not have to prove that they qualify as a woman or as a Black person. What qualifies as a disability has been interpreted in a very restrictive manner by the courts, thus effectively excluding many disabled people from the

ADA’s protections. As highlighted by Bagenstos, in a series of ADA employment-related cases297 ‘...the employers denied opportunities to the plaintiffs based on their physical impairments notwithstanding the fact that the plaintiffs were able to control the effects of their impairments through corrective measures. Yet ... the Court said that the plaintiffs’ use of such corrective measures could remove them from the protection of the ADA and thus deprive them of the right to show that they were in fact qualified for the positions at issue and that their employers acted on the basis of prejudice or stereotypes.298’ Where disabled plaintiffs could not prove that they were sufficiently disabled under the Act they were placed beyond its protective reach, despite the fact that in some cases299 they had immediately observable impairments which were used as a basis for different treatment which had negative effects upon them.

In order to get beyond this difficulty, which may appear to be inherent in group-specific human rights instruments and legislation, the need is to adopt a concept of equality which embraces non-discrimination on an individual level along with measures which fully recognize that addressing inequalities necessarily involves addressing societal structures which cause inequality. Fredman300 proposes what she terms ‘fourth generation’ equality measures which include both a commitment to universal equality and a positive duty to proactively identify structural inequalities – this will be discussed further below. Arnardottir suggests that the by placing a positive obligation on states to reasonably accommodate people with disabilities on an individual basis (Article 5.3) along with the stipulation that affirmative action measures are legitimate and do not constitute discrimination (Article 5.4) that the CRPD incorporate a more multidimensional approach to equality for PWD.301 She also suggests that the CRPD ‘... places great emphasis on the issue of multidimensional equality’302 both by the inclusion of specific articles referring to the situations of disabled women and children and the reference in the preamble to ‘... the difficult conditions faced by persons with

302 ibid p63
disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status."\textsuperscript{303} However, despite the inclusion of quite an extensive list of possible identities which could be the basis of discrimination, the list is not exhaustive of all possible reasons for unfair discrimination and it is only the intersectional discrimination faced by disabled women and children which are directly addressed in separate articles. On the other hand if, as is widely acknowledged, disabled people were largely invisible in human rights law it seems that a convention aimed at their particular experiences is an essential element in bringing light onto their rights experiences. It is one of the main purposes of the CRPD to directly address the rights infringements which are part of the everyday reality of disabled people. Why then single out women and children for particular attention in this convention and not other groups? Why not focus solely on disabled people regardless of any other identity? There is a danger that the inclusion of any named groups in the CRPD and the exclusion (or rather non-naming or inclusion under the ambiguous ‘other status’ heading) of others indicates that rights-infringements on the basis of these other identities do not carry the same weight. People with disabilities have themselves been the subject of this type of second-class treatment by their inclusion as part of the ‘other status’ group in each of the three treaties of the International Bill of Rights. It is arguable that this is one factor which contributed to the very invisibility of people with disabilities in human rights law in the first place.

5.3.3. Monitoring mechanisms and fragmentation

The fragmentation of human rights instruments is, perhaps, compounded by the treaty and convention monitoring mechanisms operated by the UN. The CRPD, in accordance with Article 34, is monitored by the Committee on the Rights of Persons with Disabilities. This is very much in line with monitoring mechanisms for other treaties and the UN now has ten separate treaty monitoring bodies. In addition the Human Rights Council has, since 2007, operated the Universal Periodic Review (UPR). The UPR, which monitors the human rights records of all UN member States at 4 yearly intervals, was created by the General Assembly to improve human rights situations on the ground throughout the UN member States.

and to promote the universality, interdependence, indivisibility and interrelatedness of all human rights. The General Assembly resolution establishing the UPR states that it ‘... shall complement and not duplicate the work of treaty bodies.’ The UPR working groups draw on reports from States under review, from national stakeholders - including national human rights bodies, academic institutions and non-government organisations – and from reports of the UN treaty monitoring bodies and other UN human rights entities. This mechanism then is in addition to the work of the other treaty monitoring bodies and regardless of its effectiveness or otherwise, represents an additional layer of monitoring.

If, as declared in the Vienna Declaration ‘All human rights are universal, indivisible and interdependent and interrelated’ then the logic and the effectiveness of monitoring each of the treaties separately must be questionable. Debate about reforming the UN treaty monitoring structures has tended to focus by and large on the administrative inefficiencies of the current system, identifying such problems as poor resourcing, duplication of reporting cycles and contradictory jurisprudence from the various bodies. Overall it is well acknowledged that the system ‘...has become increasingly complex, opaque and cumbersome.’ Administrative issues besetting the increasingly large treaty monitoring mechanisms obviously require urgent attention, but the additional element of the fragmentation of human rights along treaty lines is equally important. As noted by Louise Arbour, UN High Commissioner for Human Rights in 2006 ‘...individuals and groups do not enjoy their human rights or experience violations along treaty lines ...’ Her proposal for a single monitoring body incorporating all of the treaties did not, however, receive significant support and was not pursued. The most recent recommendations for rationalizing treaty monitoring mechanisms were presented by the current High Commissioner for Human Rights in 2012. His report noted the persistent high level of non-compliance with reporting

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305 United Nations General Assembly Resolution 60/251 3 April 2006 Para 5(e)
requirements by State parties, inadequate resourcing of the treaty monitoring bodies, lack of coherence between the work of the various treaty bodies and significant backlogs by treaty bodies in dealing with State reports.

The High Commissioner proposed, rather than a single treaty monitoring body, that changes be introduced to increase efficiency. These changes include a comprehensive reporting calendar which would require States to report to no more than two of the treaty bodies annually, the establishment of simplified reporting procedures, the establishment of standing national reporting and coordination mechanisms, increased coordination and consistency among the treaty bodies and the allocation of greater resources at UN level to monitoring.

However to date the problem remains. Some form of integrated or coordinated monitoring of all of the treaties would aid cross-fertilisation of rights between the various groups protected by the categorical instruments and help ensure that rights specified to particular groups (such as the IL right) would be equally applicable to all.

5.4. Article 19: Living Independently and being included in the Community

Individual autonomy is at the heart of the right to IL. Autonomy can be understood as the freedom of the individual to direct his own actions without interference from others. Clearly people may, and frequently do, make decisions which take account of the needs and wishes of others. Nonetheless the autonomous person is still self-determining if he willingly takes other’s needs or wishes into account, and is not coerced into taking a particular course of action.

For Quinn and Degener autonomy ‘... entails opening up a free or uncoerced space for voluntary action based on a person’s conscience and freely made life choices, while preserving comparable liberty for others.’ The choice, as outlined in Article 19 of the CRPD, of where and with whom to live and not to be obliged to live in any particular living arrangement clearly requires that PWD have autonomy of

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309 UN High Commissioner for Human Rights Strengthening the UN Human Rights Treaty Body System (June 2012) New York noted that 16% of State parties report to the various treaty monitoring bodies on time p21
310 UN High Commissioner for Human Rights Strengthening the UN Human Rights Treaty Body System (June 2012) New York noted a cumulative backlog of 281 State part reports pending consideration as of 21 March 2012
choice in the same way as all other citizens. However, for PWID the ideal of autonomy has been constrained by assumptions about people’s capacity to make self-determined decisions or choices. Assumptions about the inability of PWID to make autonomous choices has often led to a denial of the conditions necessary for people to learn to make such decisions. As Quinn and Degener suggest ‘…society seems over-inclined in many instances to conflate disability – especially intellectual disability – with a lack of capacity for moral freedom. This presumption often rests of sheer prejudice.’\(^{312}\) The centrality of autonomy is acknowledged in the CRPD, which recognises ‘…the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.’\(^{313}\) The denial of autonomy or self-determination is one of the hallmarks of society’s treatment of PWID, and the fact that the CRPD headlines autonomy in this way is a clear acknowledgment of this.

Community inclusion can be defined as the right of disabled people to participate in all aspects of society. The right to participate in the community, demands firstly, that systems, structures and the physical environment be accessible and secondly, that people have the supports they need to participate. Both of these aspects are addressed in Article 19 and indeed in the CRPD overall. The general principles recognise the importance of full and effective participation in society and of accessibility in enabling disabled people exercise their human rights. The CRPD also recognises that for many PWD having accessible infrastructure, systems and communication will not, however, be sufficient to realise rights and that many will require additional supports to be fully participating and be self-determining in their decisions. Article 19 incorporates the right to personal assistance and to general community supports and Article 4 General Obligations mandates state parties ‘To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities.’\(^{314}\)

5.4.1 The nature of state obligations
Before looking in detail at the content and implications of Article 19 it is important to identify the obligations on state parties in the realisation of human

\(^{312}\) ibid p16
rights. And in this it is most useful to look at the general comments of the UN Committee on Economic Social and Cultural Rights (CESCR) and of those of the UN Human Rights Committee (HRC), which serve as authoritative interpretations for state parties in implementing rights. In particular the General Comment on Non-Discrimination and that on the Nature of State Parties Obligations are instructive here.

Civil and political rights are subject to immediate implementation. This means that states must immediately ensure that everyone can exercise all civil and political rights. In terms of the right to IL the most important rights engaged here are the right to self-determination and the non-discrimination right as outlined in Articles 1 and 2 of the ICCPR. So states must respect and protect these rights for all people, including people with disabilities.

Socio-economic rights outlined in the ICESCR, are, in general, subject to progressive realization, in particular where there are significant resource implications in the realisation of these rights. While recognizing that the realization of many socio-economic rights may take time and ‘... may be achieved progressively, steps towards that goal must be taken within a reasonably short time after the Covenant’s entry into force for the States concerned. Such steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations.’ In effect this means that states must have specific, targeted and time-defined plans for the achievement of socio-economic rights. In terms of the right to IL this includes plans for the provision of support for people with disabilities, adequate housing and accessibility. States are also obliged to ensure that in progressively realizing socio-economic rights that no group is discriminated against in how this is achieved.

In addition to the obligation to progressively realize socio-economic rights states must meet a minimum core obligation in relation to each of these right. The CESC states that ‘... a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, prima facie,

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failing to discharge its obligations under the Covenant.” In concluding this chapter I will attempt to attempt to define what these minimum core obligations are in relation to the right to IL.

5.4.2. The significance of Article 19

Article 19 of the CRPD states:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 19 is ground-breaking for disabled people on many levels. Firstly it is first time that the right to IL has been specified in an international human rights instrument. Secondly, the inclusion of personal assistance as a key part of IL has been enshrined in human rights law. And thirdly, it directly addresses the issue of institutionalisation of people with disabilities across the globe.

Article 19 spells out what can now be seen as an international standard for independent living and community inclusion for people with disabilities. It embodies the universalist approach to disability which aims at inclusion and mandates both universal accessibility and specialist supports to facilitate inclusiveness. It asserts the universal right to choice of residence and to living in the community along with the right to specialist supports to facilitate access to the right. It defines what substantive equality means in this context i.e. to make independent living and community inclusion truly equal, particular provision must be made in the form of mainstream and specialist supports including

personal assistance.

Article 19 includes a combination of civil and political rights (freedom of choice and access to community facilities) and of socio-economic rights (access to personal and residential supports to enable participation and avoid isolation). As civil and political rights are subject to immediate implementation and taken in the context of the cross-cutting non-discrimination right of Article 4 (and that in other mainstream human rights instruments) this would suggest that states must ensure that people have choice in where and with whom they live with immediate effect. French proposes that ‘while parties are to pursue the right to adequate housing and the right to adequate social services progressively, they must do so in a way that immediately complies with the right of persons with disability to live in and be a part of the community. It is therefore not open to parties to claim …. that institutional accommodation and support services fully realize the rights of persons with disability to adequate housing and support services. The CRPD is clear that institutional accommodation and support services are an explicit violation of human rights, and one that parties have an immediate responsibility to prevent and remedy.’

However, systems change take time and so transforming housing and support systems which are discriminatory will be a long-term project for most states and will be subject to progressive realization. The CRPD dictates that any policies or systems which impact on people’s choice of living arrangements or their ability to participate in the community must not discriminate against disabled people either directly or indirectly. Of significance in this context is the concept of reasonable accommodation included in the CRPD. Reasonable accommodation is defined in Article 2 as any ‘...necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms’ and the denial of reasonable accommodation is one form of disability-based discrimination. There is some debate about the effectiveness of reasonable accommodation as a means of bringing about systems change but it remains a key tool in including disabled people in the mainstream while avoiding or deferring the sometimes considerable

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costs of providing universal access. Lawson suggests that reasonable accommodation plays a bridging role in human rights law and may be regarded as ‘... an integral element of non-discrimination ... Its function is to ensure that rights of all ... become available, in a meaningful sense to disabled people.’\(^{319}\) Where housing or support systems discriminate against disabled people, reasonable accommodation must be made in the case of particular individuals. Measures such as ensuring that people are fully consulted on their housing need, have access to relevant information in accessible formats and assessment systems which take full account of all disability-related housing and support needs also constitute reasonable accommodation and hold the potential to lever wider system change over time. The inclusion of the ‘disproportionate burden’ clause in the definition ensures that any accommodations will not be overly demanding on public resources while the progressive realization obligation ensures that plans for system-wide change happen along side changes for individuals. Accommodations provided in individual cases also provide good practice examples which can be replicated and the reasonable accommodation obligation can foster creativity and flexibility about how to include people when resources are limited.

The divide between rights in the private and public spheres in traditional human rights instruments is surmounted in the CRPD and is one of its important innovations. Megret suggests that the CRPD, in delving into the private sphere, recognises that it is here that many disabled people are especially vulnerable to abuses and that ‘[a] treaty that focused exclusively on the obligations owed directly by the state to persons with disabilities without forcing the state to also become involved in preventing negative encroachments occurring in the private sphere would miss an important dimension of the experience of persons with disabilities.’\(^{320}\)

**a) Personal assistance and supports**

Inherent in Article 19 is the recognition that support will be required in the private sphere of the home in order for people with disabilities to realize their right to IL and community inclusion in the public sphere. For many disabled

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people this personal support is an essential element, and the right to residential support and to personal assistance in the private sphere is key. The Independent Living Movement has asserted that importance of personal assistants in enabling people live the lives of their choice for many years. Early thinking on the role of personal assistants within the Independent Living Movement envisaged the disabled person as employing or directing the activities of the personal assistant so that support is provided in a way which responds directly to the requirements of the disabled person, as defined by the disabled person. More recently there is an increasing recognition that for some people with intellectual disability being in the role of director or employer of personal assistants may not be possible or desirable. For a person with significantly impaired intellectual capacity the support required will be of a different nature and will often have to be directed by someone other than the disabled person themselves. This is acknowledged in the definition offered by Adolf Ratzka of the Independent Living Institute which states that the key elements of personal assistants are ‘...funding of services follows the person and not the service provider, [and] users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations.’321 (emphasis added) This emphasis on responsive and individualized support based on the person’s wishes and needs is inherent in Article 19, which makes no reference to how personal assistance is to be provided. By definition personal assistance is provided to the person in a personalized, flexible and individualized way, which maximizes the person’s degree of self-determination. Where people live in large groups, such as residential institutions, personal assistance or this nature cannot be provided regardless of how well-intentioned staff may be – staff remain under the direction of the institution and attend to the needs of several individuals. The inclusion of personal assistance is key to the issue of institutionalization as well to independent living. Where State structures direct people with ID to institutions or other grouped provision because these are the only locations where support is available, this represents a violation of Article 19.

b) Institutionalisation and independent living

Article 19 is important in bringing attention to and providing direction about what is required to realize the right to IL. The issue of institutionalisation of PWD

is dealt with by the Committee on the Rights of Persons with Disabilities under Article 14, the right to liberty and security of person. However, for people who live in institutions, either because of the lack of community-based alternatives or because they are unable to live without support, clearly the right to IL is being violated. In fact it is being increasingly recognized that institutionalisation, by definition, is an infringement of people’s rights in international law. Parker and Clements reflect this view stating that ‘Independent living identifies a fundamental objection to institutionalisation and with it a recognition that the unjustified segregation of disabled people in institutions is in itself a human rights violation. However good the environment and quality of care, placement in an institution is likely to represent a grave interference with an individual’s human rights, in particular the right to private and family life.’\(^{322}\) In 1999 the US Supreme court recognized that institutionalization is a form of unjustified discrimination against people with disabilities and that it violates Title II of the ADA, which mandates the provision of services in the most integrated settings possible. In his judgment Ginsberg J stated that ‘Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments. First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.’\(^{323}\) The court goes on to highlight the trap in which people with disabilities who require support are caught – where support or treatment are only available in an institutional setting people must relinquish their participation in the community in order to get access to this support, while non-disabled people who require services of various sorts do not have to make the same sacrifice. The CRPD brings this understanding into international human rights law. This understanding was already evolving in policy and within other UN human rights structures as evidenced by the 2005 report of the Special Rapporteur for the Right to Health: ‘Decisions to isolate or segregate persons with mental disabilities, including through unnecessary institutionalization, are inherently discriminatory and contrary to the right of community integration


\(^{323}\) Olmstead v L.C 527 U.S. 581 [1999]
enshrined in international standards. Segregation and isolation in itself can also entrench stigma surrounding mental disability. Even though the CRPD is relatively new there is already evidence that it can be a useful tool in establishing IL as the standard in the international courts. Specifically Article 19 and the conception of institutionalization as being de facto discrimination have been cited in recent cases before the European Court of Human Rights concerning people with disabilities, particularly in these cases where institutionslisation was associated with a stripping of legal capacity. In addition to direct institutionalization, systems which link individualized support provision to specific geographic areas, as is common in the both the UK and Ireland, limits people’s choices about where and with whom to live, hence the importance of the portability of personal assistance or supports as included in Ratzka’s definition. It is widely acknowledged that institutional living produces poorer outcomes for people and is not necessarily any more cost effective than community-based alternatives.

Although the final CRPD article makes no direct reference to the issue of institutionalization, it is evident from the negotiation debates and from the content of the article itself that this is central to its aim. If state governments take the challenge of Article 19, major changes in the provision of support to disabled people will be required. These changes will be legislative, structural and practice-based.

Where state systems are structured in such a way as to limit people’s choices in ways which do not apply to other citizens, these systems must be altered. Institutional accommodation or other ‘special needs’ housing for disabled people, while they may be the choice of some people, these cannot be the only choices. In addition, any assertion that people choose to live in institutions or other congregate arrangements must also demonstrate that people have been given real choice and are not obliged to make this choice because of a lack of supports in the

325 See Kedzior v Poland App. No. 45026/07, (ECHR, 16 October 2012) and Stanev v Bulgaria App. No. 36760/06, (ECHR, 17 January 2012)
community. It also means that regular housing and support systems available to the rest of the population must be fully open to disabled people.

5.5. Article 19 and other CRPD articles

Article 19 must be read in conjunction with all of the other article of the CRPD and it plays a central role in the realization of the aims of the CRPD overall. It can be seen as one of the core drivers of the CRPD in that IL cannot be realized without the realization of several other rights and likewise many of the other rights cannot be realized in the absence of the realisation of IL. All human rights are indivisible, interdependent and inter-related and this is true for Article 19. In particular it intersects with the Article 12 (Equal recognition before the law), Article 9 (Accessibility) and Article 28 (Adequate standard of living and social protection) in addition to being underwritten by the general principles and obligations and the equality and non-discrimination articles.

5.5.1 Article 12 – Equal Recognition before the law

Article 12 on Legal Capacity (LC) is at the heart of the CRPD and it has been suggested that it is in fact emblematic of the ‘paradigm shift’ which places people with disabilities as ‘subjects’ rather than ‘objects’.\textsuperscript{328} Article 12 identifies the right of people with disability to recognition as persons before the law and to enjoy legal capacity on an equal basis with all other citizens. It also provides that supports must be available to people who require them, in the exercise of their legal capacity. In relation to housing specific reference is made to the right of people to inherit property and to access mortgage finance. This article is crucial as it asserts the right of people to make all manner of decisions on their own behalf, it provides for legal protection in effect for people to exercise self-determination in how they live their lives. It bestows full legal personhood on disabled people, who are frequently denied this status, when decisions are made for or about them by others, albeit it often construed as being in their best interests.

The ability to make personal decisions is of paramount importance in realizing the right to IL. As Quinn states ‘\textit{Without legal capacity to make life choices (big and

small), to have choices equal to others and respected by others, and indeed to make one’s own mistakes, it is hard to see how the promise of living an independent life and being included in the community can be made good.\textsuperscript{329} There is a circular relationship between IL and legal capacity and in reality one is not possible without the other. People with disability, like everyone else, must learn the skills needed to live self-determining lives in the community, and to learn these skills they must be accorded the right to make their own decisions. It is through experience that all people learn and this includes learning from mistakes. People who do not have a disability are, in the normal course of events, allowed the freedom to learn, to make mistakes and to acquire IL skills. Disabled people on the other hand – especially people with impaired mental capacity – are routinely denied the freedom to make their own decisions and to learn from experience of living in the community. Where people are segregated from the community in institutions of one form or another their opportunities to learn how to live in community are severely restricted and so they may never acquire IL skills. In order to exercise the right to IL and community participation people must be recognized as having legal capacity, at the same time development of capacity requires that people are enabled to live independently and participate in the community. As Hammarberg points out the realization of Articles 12 and 19 is interconnected especially when considered in the context of institutionalisation ‘Challenging institutionalisation is thus interwoven with challenging the legitimacy of guardianship and developing alternative models for supported decision-making by the individual. Similarly, progress in implementing the right to live independently in the community will strengthen individual’s exercise of legal capacity. Thus, the implementation of Articles 12 and 19 of the CRPD go hand in hand, and progress in one area positively affects the other area.’\textsuperscript{330} People regularly make decisions in inter-dependence with others. People regularly take advise from others and consider the interests of others in their decision-making processes and many people make and repeat poor decisions. Where a person does not have a disability this goes unquestioned, while disabled people often have to prove their capacity to make any given decision, so it can be

\textsuperscript{329} Statement by Professor Gerard Quinn, Director, CDLP, to the Oireachtas Joint Committee on Justice, Defence and Equality. Re: Hearing on the Mental Capacity Bill, February 29, 2012. p3

argued that the standards set for independent decision-making is actually higher for disabled people than for non-disabled people. Without a full recognition of legal capacity (and the availability of supports where necessary) people’s ability to enter into legal tenancies, open bank accounts, inherit or purchase property means that their access to mainstream housing is severely constrained. Recognition of legal capacity, as identified in Article 12, provides the route for people to acquire IL skills and develop their capacity and it enables people to undertake the many legal or quasi-legal exchanges needed to access housing in the community in the same way as all other members of the community. To quote Quinn Article 12 ‘involves putting in place the essential ingredients for enabling capacity to evolve. This requires a place of one’s own – stamped with one’s own personality even if that is something as simple as a treasured photo. It is this ‘materialization of identity’ that links Article 12 with Article 19. It isn’t just that expanding legal capacity allows one make choices about where to live and with whom. It is that having this choice itself helps augment legal capacity.’

A universal approach of LC is strongly supported by Article 12 although it does not preclude a functional approach which could include substitute decision-making. Article 1 of the CRPD makes explicit that all of the rights contained therein are applicable to all people with disabilities regardless of type or degree of impairment, this is equally the case in relation to LC. Quinn suggests that even though there will be cases where decision are made ‘for’ rather than ‘with’ some disabled people “… we have to ensure that the paradigm shift means that even in this category it is now necessary on foot of Article 12.3. to take additional steps … To me we should never give up on this possibility [that a glimpse of the person’s ‘will and preferences’ can be found] – no matter how remote. Secondly, and with respect to those whose social connectedness has been severed due to institutionalization it seems to me to be the correct response to try to create social conditions in the hope of kindling some kernel or preferences.’

Part 4 of Article 12 details the safeguard needed to ensure that the supports provided are free from conflict of interest, avoid abuses, are tailored to individual need and are focused at all times on the ‘rights, will and preference’ of the

individual. It is this aspect of Article 12 which gives rise to the concern that substitute decision-making could be justified. Dhanda suggests that ‘The text of Article 12 does not prohibit substituted decision-making and there is language which could even be used to justify substitution. Under the circumstances, it could well be argued that the Article would be a stranglehold of the past on the Convention. However, such a contention can be made only if the universal reach of the capacity formulation is diluted or ignored and the article is read divorced from the process of advocacy and negotiation.’ The safeguards needed to protect and support the exercise of LC for all disabled people must be conceptualized in the overall context of the CRPD and its universal reach i.e. the right to LC applies to everyone regardless of type or degree of impairment, the supports required are part of this right regardless of type or degree of impairment and the safeguards on the provision of supports apply to all regardless of type or degree of impairment.

Article 12, then, should be understood and interpreted in the context of the whole of the CRPD and its spirit and intent. Such a reading would support a universal approach to legal capacity. This would see a changed role for national courts to that of protecting people’s legal capacity and ensuring that the supports necessary to exercise legal capacity are in place. As stated by Bach and Kerzner ‘The question can no longer be: Does a person have the mental capacity to exercise their legal capacity? In other words, mental capacity can no longer serve as a proxy for legal capacity. Rather, the question is: What types of supports are required for the person to exercise his or her legal capacity? This is a profound shift in the law of legal capacity. ... From questions about how to determine mental capacity, the CRPD directs a shift to asking about how people can best exercise their legal capacity. It directs that we ask about who gets what supports and accommodations to enjoy, exercise and maximize their legal capacity, when, where and how.’

### 5.5.2 Article 9 and 4 – Accessibility and universal design

Accessibility to the physical and social environment is one of the cornerstones of IL and community inclusion. And while attention is often focused on accessible transport and buildings, it is equally important that access to social, educational,

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occupational, health and cultural life is ensured. The purpose of Article 9 is to open up access to all areas of life so that people can live independently and participate fully in the community. If access to any area is hindered then people cannot participate effectively, thus limiting their ability to realize the right to IL and community inclusion. The CRPD at Article 4(f) obliges states to promote research and development of universally designed (UD) goods, services, equipment and facilities thus ensuring that universal access is not confined to just the physical environment. The need for universalizing policies for people with disabilities so that they are inclusive of and accessible to the whole population, was identified by Irving Zola in 1989 who suggested that 'What we need are more universal policies that recognize that the entire population is "at risk" for the concomitants of chronic illness and disability. ... without such a perspective we will further create and perpetuate a segregated, separate but unequal society ...'335 Applying the principles of UD to all services and facilities as well as to the physical environment would ensure that all life activities are accessible to all citizens on an equal basis.

Story et al, who detailed the seven principles of UD highlight the fact that '[a]n understanding of human diversity is critical to designing effectively. Successful application of universal design principles requires an understanding of how abilities vary with age, disability, the environment, or the circumstances.'336 Outlining that UD can take account of physical, cognitive and sensory differences, which form part of the human condition they detail the seven principles of UD as:

1. Equitable use
2. Flexibility in use
3. Simple and intuitive use
4. Perceptible information
5. Tolerance for error
6. Low physical effort
7. Size and space for approach and use.337

The benefits of using UD principles in terms of social inclusion and accessibility, not just for people with disabilities, but for everyone, cannot be underestimated.

337 ibid PP 34-35
If all environments were based on the UD principles then there would be much less of a requirement for parallel specialist services, which are often expensive and stigmatized. The social integration of disabled people would be greatly enhanced along with their ability to realize the right to live independently in the community.

While there may be a cost in applying the UD principles, these must be considered in the context of costs which can be avoided by ensuring access for all, including the costs of operating specialist systems such as in health care, transport or housing. In 2005 the National Disability Authority (NDA) reviewed the regulatory systems governing accessibility in the build environment in Australia, Canada, USA and England and Wales. They concluded that ‘Studies in all jurisdictions indicate that the earlier in the planning process discussion of access issues is introduced, the more effective the process will be in achieving access and the lower the cost of that access will be.’

There will, however, inevitable be some costs associated with adapting the existing environment and in this context reasonable accommodation is significant. According to the US Department of Justice ‘Reasonable accommodation is usually far less expensive than many people think. In most cases, an appropriate reasonable accommodation can be made without difficulty and at little or no cost. A recent study commissioned by Sears indicates that of the 436 reasonable accommodations provided by the company between 1978 and 1992, 69% cost nothing, 28% cost less than $1,000, and only 3% cost more than $1,000.’

Using the UD principles in the design of physical objects and infrastructure, although presenting challenges, is easier to envisage than it is to apply to the design of systems and policies. However, Bickenbach and Cieza suggest that at least the first two principles, of equity of use and flexibility of use, can be beneficially used in designing universal policy and law. They conclude that ‘UD principles ... are directly applicable to social policy and law, and ... in two major social policy areas, health and welfare, that applications of these principles is feasible and, in some restricted examples has actually been implemented in these policy areas.’ They conclude that further research is needed to ascertain how

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339 Department of Justice, USA Myths and Facts about the Americans with Disabilities Act www.ada.gov/archive/mythfact.htm Accessed 17/6/12
these principles can be applied in other policy or legal systems, and this includes areas such as housing which is at the heart of IL and community inclusion. In this regard French proposes several measures which could be useful in ensuring the realisation of the right to adequate housing, including accessibility of housing for disabled people. He highlights the fact that accessibility in housing for people with disabilities includes not just the physical building, but also information about housing, provision to ensure people can build and maintain social contact, availability of support services and regulation and policies which do not hinder access. 341

5.5.3. Article 28 – Adequate Standard of Living and Social Protection

The right to an adequate standard of living and social protection in the CRPD mirror those of the ICESCR Articles 11 (adequate standard of living) and 9 (social security). This right also forms part of the UDHR where Article 25 states ‘Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.’

In addition to the general obligation of ensuring the right of PWD to have an adequate standard of living without discrimination, Article 28 importantly specifies their right of access to social protection and public housing programmes. Quinn suggests that ‘[e]ffectively, Article 28 places a floor of social provision beneath persons with disabilities which co-mingles the principle of non-discrimination (immediately effective) with more programmatic elements (to be progressively achieved)’ 342

An ‘adequate’ standard of living demands standards and at national level these can be gleaned from systems such as legally enforceable building regulations 343 and health and safety regulations. At international level the issue of standards of adequacy is more problematic as cultural, social and economic factors influence what is considered to be adequate in widely varying ways. However, as discussed

343 In the case of Ireland those especially relevant to people with disabilities include Building Regulations Part M – Access for People with Disabilities and the Disability Access Certificate
below, it is helpful to look to the General Comments of the CESCR, particularly those on adequate housing and social security, to ascertain what the international community deems to be adequate.

Article 19 requires states to ensure that housing and social supports are structured in ways which enable IL and community inclusion. Article 28 requires states to ensure adequate standard of living including adequate housing and social support. French suggests, the combination of the two means that while states may seek to progressively realize the right to an adequate standard of living they must do so in a manner which immediately realizes the right to IL and community inclusion, the civil and political elements of which are subject to immediate implementation.344

5.6. The Independent Living right in mainstream human rights instruments

In this section I will attempt to identify those aspects of the core UN human rights treaties which are most relevant to the right to IL. Locating the core elements of the right within the broad human rights framework is important, in legitimizing what could be claimed is a new right.

Article 19 incorporates the twin concepts of freedom of choice and community participation, both of which are integral parts of generic human rights law. The juxtaposition of the two acknowledges the interdependent nature of people and that it is in our relationships with others that our personality forms and develops. As stated by Quinn and Doyle Article 19 ‘... sees independence as tied to community and civic engagement. That is to say, it sees something that applies to all of us – how our independence depends on our interdependence – and makes this plain in the specific context of disability.’345 In this way one of the key feminist criticisms of the orthodox social model is addressed i.e. Article 19 recognises our interdependent relationships with others as a valued state and as a key contributor to our personal development. As Kittay points out ‘In acknowledging dependency we respect the fact that as individuals our dependency relations are constitutive of who

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we are and that, as a society, we are inextricably dependent on one another.\textsuperscript{346} To achieve full personal development people must have access to and be enabled to participate in community in addition to freedom of choice. The importance of community in the formation of personality is recognized in the UDHR where it is stated that it is only in community that ‘... the free and full development of his personality is possible.’\textsuperscript{347}

Article 19, like several other of the CRPD articles, intertwines both traditional civil and political rights and socio-economic rights. The indivisibility and interdependence of the two types of rights is generally proclaimed as a foundational principle of international human rights, and is especially pertinent in the case of disabled people. As Alston points out ‘It is quite possible to accord full civil and political rights to persons with disabilities, while effectively disenfranchising and silencing them through the maintenance of policies ... which ignore the particular situations and needs of persons with disabilities. Unless the economic and social rights dimension is also addressed the enjoyment of civil and political rights can easily become largely illusory.’\textsuperscript{348} The CRPD, in combining the two types of rights in Article 19 and several other of its articles, specifically addresses this reality.

All human rights apply to all people by virtue of our common humanity. Despite the fact that disabled people are not specifically named in the three core human rights instruments it is widely accepted that they form part of ‘other status’ category. In addition the ICESCR general comments make it clear that disability is included as a group to whom rights apply equally.\textsuperscript{349}

The right to self-determination is explicitly included in Article 1 of both the ICCPR and the ICESCR. Autonomy or self-determination, although not overtly named in the UDHR, are foundational in that all of the rights are, in effect, designed to protect individual autonomy.

In the context of the IL right, UDHR Articles 12 and 13 are perhaps the most pertinent – Article 12 protects against interference with privacy, family, home and correspondence, and Article 13 guarantees freedom of movement and residence.

\textsuperscript{346} Kittay, E.F. ‘When Caring Is Just and Justice Is Caring: Justice and Mental Retardation’(2001) Vol 13, No. 3 Public Culture, p570
\textsuperscript{347} United Nations, Universal Declaration of Human Rights (1948) UN Doc A/810 Article 29(1)
Other aspects of the UDHR which are related to IL include the right to own property (Article 17), equal access to public services (Article 21) right to social security (Article 22) and the right to an adequate standard of living – including housing (Article 25). These rights are reiterated in both the ICCPR and the ICESCR. The ICCPR at Article 17 protects against arbitrary interference with privacy, home, family and correspondence and Article 25 establishes the right to ‘... have access, on equal terms, to public services in his country.’ Also significant in terms of civil and political rights as they relate to IL is ICCPR Articles 12 (liberty of movement and freedom to choose one’s residence) and it was specifically to this article that the IL right was linked in the CRPD negotiations. In terms of housing this means that people with disabilities should have equal access to all of the same housing choices as everyone else, subject only to the same restrictions in choice as everyone else – and that any restrictions in housing choices arising from the presence of a disability must be eliminated. Importantly for disabled people, restrictions often arise from their need for support and from the need for access. Where housing choices are limited by the availability or location of supports or by inaccessible housing, the right to liberty of movement and choice of residence in ICCPR are in effect denied. Article 9 of the ICCPR, which asserts the right to liberty and security of person, is also relevant in light of the widespread institutionalisation of people with disabilities across the world, as institutionalisation represents the polar opposite of IL. Where disabled people, especially people with intellectual disability or mental illness are placed in institutional care because of a lack of alternative community-based supports this has a direct impact on their right to IL and community participation. Where state systems are designed or have the effect of directing people with disabilities into residential institutions, this surely constitutes a violation of the right to liberty and security of person. It is particularly insidious where people’s access to the justice system in order to challenge this violation, is restricted or non-existent because of a denial of legal capacity or social or legislative practices which serve to deny access to justice.

5.6.1. Non-Discrimination

One of the general principles of the CRPD is that of non-discrimination and it defines disability-based discrimination as ‘... any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or
nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation."\textsuperscript{350}

The principle of non-discrimination is emphasised in each of the instruments of the International Bill of Human Rights and their supporting general comments as it is in the Vienna Declaration which states 'Special attention needs to be paid to ensuring non-discrimination, and the equal enjoyment of all human rights and fundamental freedoms by disabled persons, including their active participation in all aspects of society.'\textsuperscript{351} A fundamental implication of the non-discrimination principle is that segregation on the basis of any personal characteristics is prohibited because segregation is inherently discriminatory. The CESC\textsuperscript{32} R General Comment on Non-Discrimination states that 'States parties must adopt an active approach to eliminating systemic discrimination and segregation in practice.'\textsuperscript{352} Non-discrimination in the application of the right to adequate housing entails an obligation on the state to ensure that any plans for, or actual provision of, housing must be undertaken on the basis of equality of treatment. As a key aspect of the IL right for people with disabilities, this obliges states parties first and foremost to ensure that people have access to all mainstream housing options on the same basis as everyone else and that there is nothing therein which hinders access and therefore, constitutes discrimination. Where personal support is only available in particular housing types or locations, this in effect prohibits many disabled people from accessing the full range of housing options available to the rest of the population. The need then is to disentangle the two and ensure that disabled people who have a housing need can access housing in the same way as non-disabled citizens and that their support need is considered in parallel with this. This does not mean that housing need should be considered in isolation from support needs, rather that access to the full range of housing options must not be conditional on the availability of support.

In interpreting the application of socio-economic rights to disabled people the General Comment on Persons with Disabilities is highly significant and can be seen as a pre-cursor to the CRPD. In terms of the core elements of IL and

\textsuperscript{350} UN Convention of the Rights of Persons with Disabilities Article 2
\textsuperscript{352} United Nations, CESC\textsuperscript{32} R, Non-discrimination in economic, social and cultural rights, General Comment No. 20 (2009) U.N. Doc. E/C.12/GC/20 para 39
community participation the General Comment places great emphasis on state obligations to promote the independence of disabled people and to ensure their access to the community. It provides a definition of disability-based discrimination which includes denial of reasonable accommodation as discrimination.\footnote{United Nations, CESC Persons with disabilities General Comment No. 5: (1994) U.N. Doc. E/1995/22. para 15} It also notes that disability-based discrimination has been especially severe in the areas of education, transport, employment, housing, cultural life and access to public places and services and outlines that for disabled people, in order for housing to be adequate, it must be accessible. Importantly in achieving substantive equality for people with disabilities the committee stresses the obligation of government to take affirmative actions stating that ‘The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities.’\footnote{United Nations, CESC, Non-discrimination in economic, social and cultural rights, General Comment No. 20 (2009) U.N. Doc. E/C.12/GC/20 para 12} This recognises that systemic discrimination is a particular problem for disabled people, that discriminatory practices, policies and laws contribute to the disadvantaging of people with disabilities and to the denial of rights. Systemic discrimination is defined in the General Comment on Non-Discrimination as ‘... legal rules, policies, practices or predominant cultural attitudes in either the public or private sector which create relative disadvantages for some groups, and privileges for other groups.’\footnote{ibid Para 9} There can be no doubt that systemic discrimination adversely affects disabled people in their pursuit of the right to IL and the challenge laid down by the CRPD is for states to identify where laws, policies, practices and cultural attitudes impede this right and then to work for change at every level. Finally the General Comment acknowledges the importance of ensuring that human rights norms are applicable in both the public and private sphere. For disabled people to achieve the aims of IL what happens in the private sphere is at least as important as what happens in the public domain. If someone requires assistance or support to go about the ordinary activities of daily life, then the denial of such assistance or its provision in inappropriate or abusive ways in the private sphere means that in effect, people's right to participate in community or to IL are violated.
Of relevance to the right to IL is the right to social security, delineated in the ICESCR at Article 13 and it is within this article that a right to social support is located for the general population and for disabled people – this is discussed further below. The General Comment outlines that PWD should have access to an adequate standard of living and that this should be made available in a dignified manner and importantly that it should reflect the costs of disability-related needs.\textsuperscript{356} The General Comment on People with Disabilities emphasises the need to promote the independence of disabled people and to ensure their access to the community and to accessible housing. In addition to ensuring non-discrimination in access to mainstream facilities and service, governments must also develop plans for the progressive realization of the right to adequate housing and these plans must ensure that disabled people are treated at least as fairly as others. However, indirect discrimination can occur when the same rules are applied to everyone without taking account of relevant differences between groups of people. It is arguable in this context that such plans should actually treat PWD more favourably to compensate for their history of widespread institutionalisation and denial of rights. This approach, which would give effect to a substantive equality for disabled people, is legitimated by CESCR General Comment on Non-Discrimination which states that governments may adopt special measures to attenuate conditions that perpetuate discrimination and that such measures may have to be permanent in nature.\textsuperscript{357} The HRC General Comment on Non-Discrimination also supports such an approach to realising substantive equality stating that ‘… the principle of equality sometimes requires States parties to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination prohibited by the Covenant …. Such action may involve granting for a time, to the part of the population concerned, certain preferential treatment in specific matters as compared with the rest of the population. However, as long as such action is needed to correct discrimination in fact, it is a case of legitimate differentiation under the Covenant.’\textsuperscript{358} Because of the disproportionately higher rate of institutionalization of disabled people compared with the rest of the population there is a strong case to made that governments are obliged to take positive measures to compensate for this in their policies and

\textsuperscript{358} UN Human Rights Committee Non-Discrimination, General Comment No. 1 (1989) Para 10
5.6.2. The Right to Adequate Housing

Having access to a home of one’s own is pivotal in the realisation of the right to IL and community participation – where one lives and the conditions of the home itself determines much about ones ability to access community and about personal well-being and personal development. Miloon Kothari, former UN Special Rapporteur on the Right to Adequate Housing expresses the essence of the right to adequate housing as ‘The human right to adequate housing is the right of every woman, man, youth and child to gain and sustain a safe and secure home and community in which to live in peace and dignity.’359 The ICESCR, in common with the UDHR, specifies the right to an adequate standard of living, including adequate housing in Article 11. In a General Comment adopted by the Committee of Economic, Social and Cultural Rights the key elements of what constitutes ‘adequate’ housing are outlined as follows:

1. Legal security of tenure
2. Availability of services, materials, facilities and infrastructure
3. Affordability
4. Habitability
5. Accessibility
6. Location
7. Cultural adequacy.360

What precisely the minimum core obligations of the right to adequate housing are has been subject to much debate. General Comment No. 4 states that ‘… the right to housing should not be interpreted in a narrow or restrictive sense which equates it with, for example, the shelter provided by merely having a roof over one’s head or views shelter exclusively as a commodity. Rather it should be seen as the right to live somewhere in security, peace and dignity.’361 This minimum threshold approach in relation to housing, Kenna suggests, ‘… would involve a guarantee that everyone enjoyed a right to adequate shelter and a minimum level of housing services, without

359 Kothari, M. Statement by Special Rapporteur on Adequate Housing on World Habitat Day, Geneva, 1 October 2007
361 ibid para 7
Leckie suggests that ‘Of all elements of the right to housing, it is perhaps the right to security of tenure that forms the most indispensable core element of the norm. When security of tenure ... is threatened or simply non-existent, the full enjoyment of housing rights is highly unlikely.’ In the Irish context we know that people with intellectual disabilities living in residential centres or group homes owned by disability service providers and people with mental illness living on community residences operated by the mental health services do not have any legal security of tenure. This immediately raises the question about the State’s compliance with its minimum core obligations to implement the right to adequate housing for this population group.

The content of the state’s minimum core obligations in relation to adequate housing would, therefore, seem to include security of tenure, adequate shelter, a safe environment and access to basic services. The realisation of the right to adequate housing, like all socio-economic rights, is conditional on resource availability. Clearly not all governments will be in a position to provide adequate housing as defined in the General Comment even if they wished to do so. The progressive realization obligation requires that states, regardless of resources, put in place plans to realize these rights which are deliberate, concrete and targeted and that such plans do not discriminate against any individuals or groups. This means that states must also ensure that they have concrete plans in place to deliver on the totality of the right within its available resources. This will, according to the general comment, almost invariably involve the development of a national housing strategy.

In this context, the publication of the National Housing Strategy for People with Disabilities by the Irish Government in 2011 and the establishment of the National Group for the Implementation of the Congregated Settings Report are hopeful developments. However, the entanglement of housing and support for disabled people, especially PWID and people with mental illness, in Ireland is at the heart of the problem and in effect it leads in many instances to segregated provision.

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5.6.3. The Right to Social Security

The General Comment on Social Security identifies the state’s core obligations as:

(a) To ensure access to a social security scheme that provides a minimum essential level of benefits to all individuals and families that will enable them to acquire at least essential health care, basic shelter and housing, water and sanitation, foodstuffs, and the most basic forms of education. ....

(b) To ensure the right of access to social security systems or schemes on a non-discriminatory basis, especially for disadvantaged and marginalized individuals and groups

(c) To respect existing social security schemes and protect them from unreasonable interference

(d) To adopt and implement a national social security strategy and plan of action

(e) To take targeted steps to implement social security schemes, particularly those that protect disadvantaged and marginalized individuals and groups

(f) To monitor the extent of the realization of the right to social security.365

The General Comment stresses that this right encompasses the right to access benefits to secure protection from, among other things, a lack of income caused by sickness, disability, unemployment or old age. It emphasizes the responsibility of states to provide ‘...adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost, or received a reduction in, their income, have been denied employment opportunities or have a permanent disability.’366

Article 28 of the CRPD, which is subject to the same standard as mainstream human rights, also clearly declares, not only that people should not be discriminated against directly, indirectly or by the denial of reasonable accommodation, but also that people should have access to all mainstream housing and social protection programmes and services.

The minimum core obligations in relation to social security remain consistent, regardless of resources or cultural differences. In relation to social security the minimum core obligations include ensuring that people have access to a minimum level of benefits to enable them acquire essential health care and basic shelter and housing without discrimination and the obligation to take targeted steps to protect marginalized people.

366 ibid Para 20
5.7. Conclusion: Proposed Minimum Core Obligations Arising from the Right to Independent Living

States are duty bound to satisfy at least a minimum core obligation in relation to all socioeconomic rights. From the foregoing analysis and drawing on the minimum core obligations of the right to adequate housing, the non-discrimination right and the right to social security as well as the obligations arising from Article 19 itself, the following are suggested as the minimum core of the right to IL and community inclusion:

1. Legislation which prohibits discrimination in the provision of goods and public services and accessible mechanisms for pursuit of complaints
2. Legislation recognizing the universal legal capacity of people with disabilities and provision of supports to enable people exercise their legal capacity
3. Ensure that all disabled people achieve security of tenure in the same way as all other citizens. In this context the legal tenure of people living in residential centres should be given priority.
4. Closure of all institutions, progressive development of community-based alternatives and the development and monitoring of standards for in-home care and support services
5. Individualisation and portability of personal support funding mechanisms, including but not limited to the option of direct payments to individuals, and their protection from unreasonable interference
6. Disentangle funding for, and provision of, housing and support services and ensure that housing and support assessment and allocation processes take account of the full range of disability-related needs
7. Ensure adequate income protection for people with disabilities in line with that available to the rest of the population, but which takes account of disability-related needs
8. Ensure all public services do not inadvertently discriminate against or exclude disabled people and that they are responsive to the needs of people with disabilities.
9. Advocacy support for people with disabilities, in particular people with intellectual disability and mental illness. Access to justice remains a problem and it would seem that where few people with intellectual disability are aware of, much less access, the justice system that this should form part of the minimum core required of states.
10. National progressive plans for the achievement of accessible transport, housing and public facilities

Achieving IL for people with disabilities, however, will require more than legislative and structural change. It requires a decisive political commitment and leadership endorsing and actively supporting the right of all disabled people to live independently and participate in their communities. It also requires a cultural change which recognises disabled people as fully equal citizens who have rights, but equally importantly have duties to the community.
Chapter 6: Independent Living and the European Convention on Human Rights

6.1. Introduction

The European Convention for the Protection of Human Rights and Fundamental (ECHR) does not include an explicitly stated right to Independent Living. Nonetheless within its articles and protocols it may hold the potential to assist in the realisation of some of the core aspects of this right – in particular by way of Article 5 and Article 8. Article 19 of the CRPD specifically states that people with disabilities have the right to choose where and with whom they live and to have the supports needed to achieve this. While the CRPD right to IL and community inclusion has not appeared in this formulation in previous international human rights instruments, its core elements can be located therein. It is important therefore, to locate the core aspects of the IL Right within the ECHR.

Article 5 of the ECHR deals with the right to liberty and security of person. Its importance in relation to IL is that it can be seen as directly addressing the issue of institutionalisation which represents the opposite of IL and, for many people with disabilities across Europe, this is a widespread phenomenon. Article 8 centres on the right to private and family life, which clearly is of direct relevance to the idea of IL.

The Council of Europe (COE) was established in 1949 against the background of the Second World War based on the fundamental values of Human Rights, Democracy and the Rule of Law. The following year saw the signing of the European Convention for the Protection of Human Rights and Fundamental Freedoms. The role of the European Court (the Court) is to adjudicate on alleged violation of Convention rights and to deliver judgments binding on the States involved. The Court’s case law is not ‘soft law’ as is the case with other international human rights instruments, but rather it is directly enforceable in national courts. Citizens of all COE member state – especially those which have incorporated the ECHR into domestic law – may call on the jurisprudence of the Court in challenging their treatment alleging violation of ECHR rights at domestic level. Citizens also have the opportunity to bring their case before the European Court.

Court for consideration if all domestic remedies have been exhausted. In this respect the Court has a unique and important role for individual citizens, but also for member states and legislation and policy therein as they impact on human rights. Reflecting its origins, the ECHR has been interpreted as a traditional civil and political rights treaty and as such does not readily lend itself to consideration of economic, social and cultural rights. However, this distinction between civil and political rights on one hand and socio-economic rights on the other is somewhat nebulous. The Court itself acknowledged this in 1979 in the Airey v Ireland case when it held that ‘Whilst the Convention sets forth what are essentially civil and political rights, many of them have implications of a social or economic nature. The Court therefore considers, like the Commission, that the mere fact that an interpretation of the Convention may extend into the sphere of social and economic rights should not be a decisive factor against such an interpretation; there is no water-tight division separating that sphere from the field covered by the Convention.’\footnote{Airey v Ireland App. No 6289/73 (ECtHR, 9 October 1979 para 26} However, the Court does recognize that realizing most traditional socio-economic rights will involve the expenditure or redistribution of resources and has consequently been reluctant to proceed too far into the socio economic field, allowing States a wide margin of appreciation in this area.

### 6.2. Article 5: Liberty and security of person

The European Court has repeatedly reiterated the importance of the right to liberty and security of person and the obligations of States to firstly, not interfere directly with this right and secondly, to protect citizens from interference with it by others. Article 5 states ‘Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law ...’\footnote{Council of Europe, European Convention on Human Rights (1950) Article 5 1} The cases where deprivation of liberty is allowable include legal detention of a convicted person, non-compliance with court orders, reasonable suspicion of the committal of an offense, detention of a minor for educational or legal purposes, to prevent the spread of infectious disease and in order to prevent illegal entry into the country. Those people who can be legally detained include, therefore, people convicted of a crime, people suspected of having committed a crime, children, and ‘... persons of unsound mind,'
alcoholics or drug addicts, or vagrants.\textsuperscript{370}’ Article 5 goes on to specify that all detained people should be informed promptly of the reason for their detention, should be promptly brought before a court and brought for trial within a reasonable time, that detained people have the right to appeal the lawfulness of their detention and, where the detention is found not to be legal, shall be entitled to compensation. The object and purpose of Article 5 of the Convention is to ensure that no one is arbitrarily deprived of their liberty. In considering how Article 5 has been interpreted by the Court in relation to people with disability it is necessary to determine firstly, what it means to be ‘of unsound mind’ and secondly what it means to be deprived of ones liberty.

6.2.1. ‘Of unsound mind’

The ECHR was signed in Rome in 1950 and came into effect in September 1953. The Court recognises that the term ‘of unsound mind’ is an outdated term, the meaning of which has changed considerably since that time. In the landmark Winterwerp judgment the Court noted that it is “...a term whose meaning is continually evolving as research in psychiatry progresses, an increasing flexibility in treatment is developing and society’s attitude towards mental illness changes, in particular so that a greater understanding of the problems of mental patients is becoming more wide-spread”.\textsuperscript{371} The judgment in this case outlined a three part standard which must be met in deciding whether a person is ‘of unsound mind’ and warrants compulsory confinement as a result. This standard, which has become the benchmark used by the Court in later cases, relies heavily on medical expertise in determining unsoundness of mind. The Court stated that:

1. There must be reliable objective medical evidence of the existence of a true mental disorder
2. The medical disorder must be of such a kind or degree warranting compulsory confinement and
3. The validity of continued confinement depends on the persistence of such a disorder.\textsuperscript{372}

\textsuperscript{370} ibid Article 5 1 (e)
\textsuperscript{371} Winterwerp v the Netherlands App. No. 6301/73 (ECtHR, 24 October 1979) para 37
\textsuperscript{372} ibid para 39
The insistence on having objective medical evidence places an onus on national authorities to ensure that independent medical personnel are involved in determining the existence of a mental disorder, its nature and the need for compulsory confinement or otherwise. The Court pointed out that the purpose of Article 5 is ‘...to ensure that no one should be dispossessed of his liberty in an arbitrary fashion’ and that ‘...obviously cannot be taken as permitting the detention of a person simply because his views or behaviour deviate from the norms prevailing in a particular society.’ The presence of independent objective medical personnel should act as a safeguard in ensuring that people with mental disabilities are protected against arbitrary detention or detention based on unusual or unconventional beliefs or behaviours.

The establishment of a standard or test which can be used in determining whether a person is of unsound mind and requires confinement is, in many ways, helpful. However, the test is heavily reliant on medical evidence which poses two major challenges. Firstly, the over reliance on medical evidence runs directly contrary to developments in the area of disability rights. The social model of disability assert that disability arises primarily from social, attitudinal and environmental barriers to participation in society. Another view, which is related to the emerging universalist conceptualisation of disability, is that societal norms in terms of behaviour and performance are built around a very narrowly defined idea of what constitutes ‘normal’ or acceptable standards – and that these are primarily male, white, able bodied and heterosexual. The challenge for society then in seeking to include all citizens is to broaden the parameters of the ‘normal’. Using medical expertise as the primary tool in diagnosis and treatment of a person with mental disability ignores the many other personal, environmental and social factors which impact on people with disabilities and which determine much about what constitutes a disability and how these are experienced by individuals.

A second difficulty with the Winterwerp test is that doctors can make mistakes or may differ in their diagnosis and prescribed treatment with potentially serious consequences for people. This is, in fact, implicit in the Courts recognition that what it means to be ‘of unsound mind’ is evolving with progress in psychiatric research and societal attitudes. The Court recognized this difficulty as early as 1997, especially in relation to mental illness, in its judgment in the case of Johnson.

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373 ibid para 37  
374 ibid para 37
Johnson v United Kingdom\textsuperscript{375} where it was noted that ‘It must also be observed that in the field of mental illness the assessment as to whether the disappearance of the symptoms of the illness is confirmation of complete recovery is not an exact science. Whether or not recovery from an episode of mental illness, which justified a patient’s confinement, is complete and definitive or merely apparent cannot in all cases be measured with absolute certainty.’\textsuperscript{376}

The consequences of misdiagnoses was especially serious in the Storck\textsuperscript{377} case where the applicant spent almost twenty years of her life in psychiatric institutions having been variously described as displaying signs of autism and of suffering from schizophrenia. These diagnoses were later contradicted by other medical experts who attested to the fact that Ms Storck had never suffered from a mental illness and that her challenging behaviour resulted from family conflict. The applicant was treated for many years with anti-psychotic medication which was contra-indicated for people with her particular physical condition. As Bartlett et al point out ‘...it is difficult to see that a highly discretionary system [of severity of medical diagnosis] offers appropriate protections to civil rights.’\textsuperscript{378}

**6.2.2. Deprivation of Liberty.**

In defining what exactly constitutes a deprivation of liberty the Court has relied on the 1980 judgment in the case of Guzzardi,\textsuperscript{379} a member of the Italian mafia who was confined to the island of Asinaria under ‘special supervision’ allowable under Italian law. This followed a period on remand awaiting trial where he was acquitted of a serious crime.

Mr. Guzzardi claimed that during this period of ‘special supervision’ he was in fact illegally deprived of his liberty, as he was not on remand and should have been free to leave the island. On the island Mr. Guzzardi was limited in where he could go and who could visit him, he required permission to leave the island for given periods of time, communication via telephone was supervised and he was liable to be arrested if he failed to comply with any of the set conditions. In ascertaining whether Mr. Guzzardi had been deprived of his liberty the Court held that ‘In order

\textsuperscript{375} Johnson v United Kingdom App. No. 119/1996/738/937 (ECtHR, 24 October 1997)
\textsuperscript{376} ibid Para 61
\textsuperscript{377} Storck v Germany App. No. 61603/00 (ECtHR, 16 June 2005)
\textsuperscript{379} Guzzardi v Italy App. No. 7367/76 (ECtHR, 6 November 1980)
to determine whether someone has been "deprived of his liberty" within the meaning of Article 5, the starting point must be his concrete situation and account must be taken of a whole range of criteria such as the type, duration, effects and manner of implementation of the measure in question. 380

The criteria which need to be considered cumulatively include:

1. The physical size of the place of confinement and the use which the person can make of it.
2. The ability of the person to maintain social contact with the outside world and within the place of confinement – can he visit places outside of the place of confinement or have visitors come to him.
3. Whether the person can leave the place of confinement of his own free will
4. The level of supervision by staff
5. Degree and level to which the person can communicate via letters or phone calls with the outside world
6. The consequences for the person if he does not return to the place of confinement or comply with any other restrictions.

Taken in combination the Court decided that, on balance, Mr Guzzardi had been deprived of his liberty under the meaning of Article 5-1. It is important to note that institutional provision for people with disabilities across Europe varies from large centers accommodating more than 100 people to much smaller residential centers accommodating 4 to 10 people as a group. The numbers of people and the conditions of life may vary between institutions, however, the key question to be addressed is whether people with intellectual disability or mental illness in residential care are being deprived of their liberty by the standards established in this case.

What constitutes a deprivation of liberty is not clear cut and a ruling must be made in each individual case taking account of the particular circumstances. The Court recognized this ambiguity commenting in Guzzradi that ‘The difference between deprivation of and restriction upon liberty is …. merely one of degree or intensity, and not one of nature or substance’. 381 The issue of the distinction between deprivation of liberty and restriction on liberty was dealt with in relation

380 ibid para 92 and 93
381 ibid para 93
to *Ashingdane v United Kingdom*\(^{382}\), *HL v United Kingdom*\(^{383}\) among others.

Mr. Ashingdane\(^{384}\) was convicted of a criminal offence in the UK in 1970 and, following the submission of medical evidence, the Court made a hospital order and an order restricting his discharge without limit of time. He was detained in Broadmoor Hospital from 1971 to 1979 - a ‘special hospital’ for people in need of treatment under conditions of special security because of their dangerous, violent or criminal tendencies. He had been diagnosed as suffering from paranoid schizophrenia and his continued detention in Broadmoor was reviewed regularly by the Mental Health Tribunal during this period. In 1979 the Mental Health Tribunal recommended his transfer to Oakwood Psychiatric Hospital, on the basis that his condition had sufficiently improved and that Oakwood could provide the continuous supervision Mr Ashingdane required. However, his transfer to Oakwood was delayed by 18 months because of industrial relations issues at the hospital. Mr Ashingdane claimed that he had been illegally deprived of his liberty during this time under Article 5 of the ECHR. The Court, as advised in the *Guzzardi* case, directed its attention to the differences between the regimes in both institutions. Broadmoor is a secure facility in a remote location with a high perimeter wall, locked gates and doors and barred windows. Patients were escorted between blocks and during his period there Mr Ashingdane had two escorted visits away from the hospital to meet with family. Oakwood operated a very different regime – it is located in an urban area and is easily accessible by public transport and it accommodates both voluntary and involuntary patients. Although Mr Ashingdane was initially held in Oakwood in a locked ward, he was later placed in an open ward and was subject to decreasing levels of supervision within the hospital grounds. From 1984 onward he was allowed to leave the hospital grounds unescorted on certain days, on the proviso that he return at night, and to visit family overnight.

The Court concluded that, although the regime in Broadmoor was much more restrictive, that this did not alter the fact that he still remained a detained person in Oakwood. This was on the basis that his liberty (not just his freedom of movement) was circumscribed in Oakwood in fact and in law – this was true even though he was, in the latter part of his time in Oakwood, allowed to leave the hospital unaccompanied overnight. *Whilst these differences (between the two*

\(^{382}\) *Ashingdane v United Kingdom* App. No. 8225/78 (ECtHR, 25 May 1985)

\(^{383}\) *HL v United Kingdom* App. No. 45508/99 (ECtHR, 5 October 2004)

\(^{384}\) *Ashingdane v United Kingdom* App. No. 8225/78 (ECtHR, 25 May 1985)
institutions) were of vital concern for Mr. Ashingdane and for the quality of his life in detention, they were not such as to change the character of his deprivation of liberty as a mental patient.\textsuperscript{385} The Court concluded that Mr Ashingdane had been lawfully deprived of his liberty in both institutions under the meaning of Article 5-1.

The key points taken into account by the Court in determining if a person has been deprived of their liberty under the meaning of Article 5 are, therefore, the level and degree of supervision to which the person is subject and whether they can leave of their own free will at any stage. This point was reiterated in both the \textit{HM v Switzerland}\textsuperscript{386} and \textit{HL v United Kingdom}\textsuperscript{387} cases. In \textit{HM}, the applicant, a pensioner who had dementia, was placed by the authorities in a nursing home under the Swiss Civil Code and the ‘Deprivation of Liberty on Grounds of Welfare Assistance’ Act. She had been living with her son, and following the failure of community based welfare services to gain access to their apartment, HM’s health declined significantly. Following her placement in the nursing home, HM agreed to stay but reiterated that she wished to return to live with her son. Within the home HM had complete freedom of movement, was not held in a secure ward, could make telephone calls and have personal contact with people outside of the home. However, she was not free to leave, and would have been brought back by the authorities if she had done so. The majority decision of the Court was that HM’s detention fell within the meaning of ‘lawful detention of a person of unsound mind’ under Article 5 on the basis that it was necessary for her health and well-being, and noted that ‘...a person’s own interests may also warrant a deprivation of liberty’.\textsuperscript{388}

However, a famous dissenting judgment by Judge Loucaides in this case provided a different interpretation which has become the basis for future Court judgments in deprivation of liberty cases as it pertains to ‘persons of unsound mind’. Judge Loucaides disputed the conclusion of the majority that the deprivation of liberty to which HM was subject was lawful because it was in her own best interests. He stated that the motivation for depriving a person of their liberty could not be taken as the determinitive factor – if a person is detained on the basis that it serves their interests this does not alter the fact that they have been deprived of their liberty: ‘\textit{In my opinion the question whether a measure amounts to a}

\textsuperscript{385} \textit{ibid} para 47
\textsuperscript{386} \textit{HM v Switzerland} App. No. 39187/98 (ECtHR, 26 February 2002)
\textsuperscript{387} \textit{HL v United Kingdom} App. No. 45508/99 (ECtHR, 5 October 2004)
\textsuperscript{388} \textit{HM v Switzerland} App. No. 39187/98 (ECtHR, 26 February 2002) para 36
deprivation of liberty does not depend on whether it is intended to serve or actually serves the interests of the person concerned’. The fact that the nursing home operated a relatively free regime and HM was not restricted in her social contacts nor was held in a locked ward or the fact that she agreed to stay once in the nursing home, were not the determinative points. None of these points ‘... in any way change the reality and severity of the restrictive regime in which the applicant was placed’. He compared the situation of HM to that of prisoners legally detained ‘Detainees in prisons and other places of detention, which amount to typical cases of deprivation of liberty for the purposes of Article 5 of the Convention, may be allowed to move freely within defined areas and have social contact with the outside world through telephone calls, correspondence and visits .... Yet, so long as they (like the applicant) are not permitted to leave the place where they are detained and go anywhere they like and at any time they want they are certainly “deprived of their liberty”. In effect if people cannot leave, whether they are legally detained or not, they are in fact detained.

Article 14 of the CRPD is reflective of Article 5 of the ECHR but adds the significant addition that ‘... the existence of a disability shall in no case justify a deprivation of liberty.’ Keys suggests that there is a conflict between these two provisions and, in particular, that Article 5.1(e) which permits removal of liberty on the basis of unsound mind is in contravention of CRPD Article 14 1(b).

Many people with disabilities living in institutions are not legally detained but may be doing so because of a lack of community-based alternatives or because the provision of required supports is only available in institutional settings. This is a much more insidious phenomenon as there is no legal basis upon which people in this situation can, therefore, challenge their ‘detention’. The COE Committee for the Prevention of Torture in 2011 reported that the supposedly voluntary residents in St Joseph’s Intellectual Disability Services, Dublin ‘... were de facto detained: they lived in a closed unit and were not allowed to leave the institution without prior permission.’

While work is progressing towards improving conditions in this particular service, there remain over 4000 people with ID living in congregated settings accommodating 10 or more people throughout the Irish

389 ibid Dissenting Judge Loucaides p17
390 ibid Dissenting Judge Loucaides p16
391 ibid Dissenting Judge Loucaides p16
392 Keys, M. Article 12 of the CRPD and the ECHR (2012) forthcoming
393 Council of Europe, Committee for the Prevention of Torture and Inhuman or Degrading Treatment Report to the Irish Government, Strasbourg CPT/Inf (2011) 3, 10 February 2011 para 152
state\textsuperscript{394} whose situation is not dissimilar to that of the residents of St Joseph’s. So the question is whether the conditions of people living in these congregated settings meet the standard of ‘restriction of liberty’ as defined by the European Court, whether or not they have been legally detained.

6.2.3. Consent

The issue of informed consent to treatment or other interventions is highly significant and highly contentious for disabled people, especially where the person’s legal capacity has been brought into question. Judge Loucaides addressed this issue in \textit{HM} suggesting that the applicant had been illegally deprived of her liberty because she had not consented to her placement, was not free to leave the nursing home of her own volition, and, if she had left she would have been brought back. The fact that HM eventually agreed to stay in the nursing home after her placement there also did not alter the fact that she had been deprived of her liberty. In this he cited the judgement in the \textit{De Wilde, Ooms and Versyp} case “... the right to liberty is too important in a 'democratic society' within the meaning of the Convention for a person to lose the benefit of the protection of the Convention for the single reason that he gives himself up to be taken into detention. Detention might violate Article 5 even although the person concerned might have agreed to it.”\textsuperscript{395}

The issue of voluntary submission to unlawful detention has arisen in several cases in relation PWD and the case law clearly states that even if a person agrees to their detention, where this is unlawful it constitutes a violation of Article 5.\textsuperscript{396} Where a person is ‘of unsound mind’ the issue becomes more complex – can a person with an intellectual disability or a severe mental illness give valid consent to any form of treatment, including detention in an institution, where the relevant authorities deem such treatment necessary? The Court has emphasized that consent is a key question in relation to deprivation of liberty. The issue was dealt with at length in the \textit{Storck v Germany} case.\textsuperscript{397} Ms Strock was placed in a private psychiatric clinic by her father and, although she did not object to the placement at the beginning, at no stage was her consent to the placement sought.

\textsuperscript{394} Health Services Executive, \textit{Time to Move on from Congregated Settings: A strategy for Community Inclusion}, Dublin, HSE (June 2011) p50

\textsuperscript{395} \textit{De Wilde, Ooms and Versyp v Belgium} App. No. 2832/66; 2835/66; 2899/66 (ECtHR, 18 June 1971) Para 65

\textsuperscript{396} See \textit{Storck v Germany} App. No. 61603/00 (ECtHR, 16 June 2005)

\textsuperscript{397} ibid
Throughout her period in the institution Ms Strock repeatedly expressed her opposition to the placement and had attempted on several occasions to run away. On one occasion she was returned to the clinic by the police. The Court held that the applicant had been deprived of her liberty on the basis established in the Guzzradi and HM cases i.e. while at the clinic Ms Storck was under the continuous control of clinic personnel, was not free to leave and when she attempted to escape she was brought back by police and she was unable to maintain contact with the outside world. In addition the Court drew attention to issue of consent in depriving a person of their liberty, ‘A person can only be considered to have been deprived of his liberty if, as an additional subjective element, he has not validly consented to the confinement in question’\textsuperscript{398}. The Court noted that as the applicant was not placed under guardianship and was over 18 years of age, as such she was considered to have the capacity to consent or not to her admission and treatment. The fact that Ms Strock came to the clinic voluntarily was rejected by the Court as a basis for assuming consent on the part of the clinic, reiterating the importance of protecting the right to liberty even where a person has voluntarily given it up. Even if the initial admission was voluntary, the Court held that it could find no basis for the assumption that the applicant had consented to her continued detention in the clinic.

The complexities of the consent issue where people have cognitive impairments was also dealt with in the case of HL v United Kingdom.\textsuperscript{399} HL, a man with autism, was admitted to a psychiatric treatment facility following an episode of violent and self-harming behaviour. He remained there for some months. HL’s carers, with whom he lived, were not allowed to visit him in the treatment centre. They asked to be allowed to take him home but these repeated requests were denied. HL was admitted as an ‘informal’ patient because he was compliant with the admission procedures and did not attempt to leave. However, medical personnel dealing with him stated that they would have sought his committal under the Mental Health Act 1983 had he attempted to leave as they believed he was in need of in-patient treatment. The government in this case argued that the admission and detention of HL was necessary in his best interests – and that this was mandated by the British common law ‘doctrines of necessity’ as provided for in Part 2 of the 1983 Act. This argument was rejected by the Court, which concluded that HL had been deprived of his liberty under the meaning of Article 5-1 i.e.

\footnotesize\textsuperscript{398} \textit{ibid} para 73
\footnotesize\textsuperscript{399} HL v United Kingdom App. No. 45508/99 (ECtHR, 5 October 2004)
despite the fact that he was in an unlocked ward, he remained under the supervision and control of hospital staff and was not free to leave. The Court reiterated the importance of the right to liberty even if voluntarily given up by the individual ‘... especially when it is not disputed that that person is legally incapable of consenting to, or disagreeing with, the proposed action.’ Where admission to an institution is involuntary the issue of consent also arises. In the recent Stanev case the Court found a violation of Article 5.1 because the applicant, who had been deemed partially legally incapable by the national court, was placed in a social care home without consultation with him and without his consent despite the fact that he was capable of expressing an opinion on this course of action.

Where a person with an intellectual disability or mental illness is placed in institutional care, therefore, their consent must be sought even if such a placement is thought to be in their best interests.

6.2.4. Review procedures

Article 5-4 guarantees to people deprived of their liberty the right to have the legality of their detention reviewed speedily by a Court. The Court has emphasized the importance of ensuring access to such proceedings for people ‘of unsound mind’ who have been detained including the right to be active participants in any proceedings concerning them. In Winterwerp the Court stressed that ‘It is essential that the person concerned should have access to a Court and the opportunity to be heard either in person or ... through some form of representation’ going on to point out that ‘mental illness may entail restricting or modifying the manner of exercise of such a right but it cannot justify impairing the very essence of the right.’ The Court suggested that special procedural safeguards may be required in seeking to protect the interests of people with mental disabilities. The fact that in this case the applicant was not present at (either personally or by a representative) nor informed of any of the proceedings violated his rights under Article 5-4. The same was true in the case of Shtukaturov v Russia where the applicant, who had a mental illness, had been taken into guardianship without his knowledge. The fact that Mr Shtukaturov was not

400 The lack of administrative and judicial safeguards identified in this judgment were addressed by the Mental Capacity Act 2005 and the Mental Health Act 2009
402 Stanev v Bulgaria App. No. 36760/06, (ECHR, 17 January 2012) para 132
403 Winterwerp v the Netherlands App. No. 6301/73 (ECHR, 24 October 1979) para 60
404 Shtukaturov v Russia App. No. 44009/05 (ECHR, 27 March 2008)
informed of, nor given the opportunity to participate in the guardianship proceedings, was criticized by the Court, particularly as the outcome of the court deliberation had such serious implications for the applicant.

Procedures to review the lawfulness of detention must be conducted by a court, not an administrative body. In the case of DeWilde, Ooms and Versyp v Belgium\textsuperscript{405} the Court pointed out that 'Where the decision depriving a person of his liberty is one taken by an administrative body, there is no doubt that Article 5 (4) obliges the Contracting States to make available to the person detained a right of recourse to a court; but there is nothing to indicate that the same applies when the decision is made by a court at the close of judicial proceedings.'\textsuperscript{406} Although a ‘court’ in the context of Article 5-4 does not have to have the same level of guarantees as is required under Article 6 for criminal or civil litigation, it must nonetheless, as stated in the DeWilde, Ooms and Versyp judgment, be independent of the executive and of the parties to the case. In addition ‘...they [review procedures] must have a judicial character and provide guarantees appropriate to the kind of deprivation of liberty in question ..... the Court has held that independence is one of the most important constitutive elements of the notion of a “court”......In the Court’s opinion, it would be inconceivable that Article 5 § 4 of the Convention, relating, inter alia, to such a sensitive issue as the deprivation of liberty of “persons of unsound mind” within the meaning of Article 5 § 1 (e), should not equally envisage, as a fundamental requisite, the impartiality of that court.'\textsuperscript{407} The need for review procedures to have a judicial character was identified in 1981 in X v United Kingdom where the Mental Health Review Tribunal was found to lack the competence to decide the lawfulness of detentions.\textsuperscript{408} In the case of HL v United Kingdom the need to have in place review procedures for informal or voluntary patients was recognized – especially where people do not have the capacity to consent to admission to an institution. This is particularly important where many PWID or serious mental illnesses may enter an institution on a voluntary basis at the behest of family members or a doctor. Many people in this situation simply have nowhere else to go. Many do not in reality have the ability to source alternative care or housing and as a result are forced to consent to remaining even if they are unhappy with their situation.

\textsuperscript{405}DeWilde, Ooms and Versyp v Belgium App. No. 2832/66; 2835/66; 2899/66 (ECtHR, 18 June 1971)
\textsuperscript{406}ibid para 76
\textsuperscript{407}D.N. v Switzerland App. No. 27154/95 (ECtHR, 29 March 2001)para 41-42
\textsuperscript{408}X v United Kingdom App. No. 7215/75 (ECtHR, 5 November 1981) para 61
6.2.5. Positive obligations and Private institutions

A very significant precedent emerging from the Storck case is that of the state’s responsibility for the protection of the rights of citizens in private institutions. The State had argued that as the applicant had been held in a private institution it was not implicated in the alleged violation of her rights. The Court found to the contrary by virtue of the facts that, firstly, the police had been involved in returning the applicant to the institution when she absconded, secondly, because her confinement to the private clinic was not authorized by any state body and thirdly, there was no state system in place at the time overseeing the lawfulness and conditions under which people were confined and treated in private facilities. The Court emphasized that ‘...the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective’\(^410\). In addressing this issue the Court also raised the question of positive obligations under Article 5 akin to those under Article 8. The Court enquired as to whether the state had positive obligations to not only refrain from infringing on people’s rights, but also to protect people from such interference by private parties. The conclusion of the Court was that under Article 5-1 the state has a positive obligation to protect the liberty of its citizens and that it should put in place ‘...measures providing effective protection of vulnerable persons, including reasonable steps to prevent a deprivation of liberty of which the authorities have or ought to have knowledge’\(^411\) and further in relation to people with mental illnesses that ‘...the state cannot completely absolve itself of responsibility by delegating its obligations in this sphere [psychiatric treatment] to private bodies or individuals’\(^412\). The Court concluded that the state has a duty to effectively supervise private institutions including by licensing and regular competent supervision.

6.3. Article 8 - Right to Private Life and positive obligations

Article 8 concerns the right to respect for private and family life and in the context of independent living is the aspect of the ECHR with most potential to reap benefits in this regard. A limited number of Article 8 cases concerning people with disabilities have come before the Court – and these not with great success. Recently three cases referring to institutions have come before the Court alleging

\(^409\) Storck v Germany App. No. 61603/00 (ECtHR, 16 June 2005)
\(^410\) ibid para 92
\(^411\) ibid para 101
\(^412\) ibid para 102
violations of Article 8 which will be dealt with later.

The Court has drawn broad definitional lines around the concept of a ‘private life’ under Article 8 recognising that the division between private and public life varies according to the circumstances of each case. The key elements of the Court’s definition are:

1. Private life includes the right to relationships with others.

2. An individual’s ‘private life’ is not restricted solely to activities within the home or private sphere.

3. Private life encompasses not only respect for an individual’s physical welfare but also for psychological welfare and for unhindered personal development. An important element of this aspect of private life is mental health.

Clearly people with disabilities also have these Article 8 rights – including those with significant cognitive impairments or mental illness. In the Storck case the Court asserted in relation to enforced treatment that ‘...even a minor interference with the physical integrity of an individual must be regarded as an interference with the right to respect for private life under Article 8 if it is carried out against the individual's will.’

Because the applicant had not consented to taking prescribed medication there had been an infringement of Article 8. As noted above Ms Storck’s detention occurred in a private psychiatric facility and the State had argued that this released them from any responsibility for her treatment. The Court found otherwise in relation to Article 5 and in relation to Article 8. The Court pointed out that there is settled case law relating to Article 8 which establishes the ‘positive obligations’ on States to ‘..take reasonable and appropriate measures to secure and protect individuals’ rights to respect for their private life’ and that this includes the duty to effectively supervise and control private psychiatric facilities. Therefore, there had been an interference with the applicant’s right to a private life and such interference was not lawful under Article 8-2, which describes the conditions under which such interferences may lawfully occur.

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413 Niemietz v Germany App. No. 13710/88 (ECtHR, 16 December 1992) para 29
414 ibid para 29
416 Bensaid v United Kingdom App. No. 44599/98 (ECtHR, 6 February 2001) para 47
417 Storck v Germany App. No. 61603/00 (ECtHR, 16 June 2005) para 142
418 Storck v Germany App. No. 61603/00 (ECtHR, 16 June 2005) para 148
An important element of Article 8 rights is the obligation on States to act positively to ensure respect for these rights. The concept of a States ‘positive obligations’ in relation to Article 8 was first outlined by the Court in the *Airey v Ireland* case in 1979. In this case the Court stated that ‘...the substance of her complaint is not that the State has acted but that it has failed to act. However, although the object of Article 8 is essentially that of protecting the individual against arbitrary interference by the public authorities, it does not merely compel the State to abstain from such interference: in addition to this primarily negative undertaking, there may be positive obligations inherent in an effective respect for private or family life’. On its face this would appear to hold considerable potential for the realization of these rights for disable people by placing on the State the obligation to act positively. If, for example, an individual is being hindered in the development of relationships with others by virtue of State inaction this should raise a concern under Article 8. However, the Court has ruled in the *Botta v Italy* case that the extent of a State’s positive obligations is conditional in three ways:

1. The need to strike a fair balance between the interests of the community and the interests of the individual
2. The wide ‘margin of appreciation’ allowed to States in striking this balance
3. The existence of an immediate and direct link between the action sought by the individual and the persons private life.

### 6.3.1. The direct link and positive obligations

The need for applicants to demonstrate a direct link between the actions sought and their right to private life has been stipulated by the Court. To date this has proven to be unattainable, because of the limits on State’s positive obligations, as outlined, and the reluctance of the Court to stray into areas of policy especially where this has budgetary implications for national governments.

The application of Article 8 to physical access to public spaces was dealt with in the case of *Botta v Italy* and in *Zehnalova and Zehnal v Czech Republic*, the latter of which was judged inadmissible. While on holidays in 1990 Mr. Botta discovered that the resort did not have facilities to enable him access the beach or

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419 *Airey v Ireland* App. No 6289/73 (ECtHR, 9 October 1979) para 32
422 *Zehnalova and Zehnal v Czech Republic* App. No. 38621/97 (ECtHR, 14 May 2002)
the sea. There were no ramps, toilets or washrooms accessible to people with physical disabilities. Under Italian law people with disabilities are guaranteed access to private buildings and establishments and are entitled to the removal of architectural obstructions. In June 1989 the minister of Public Works adopted a decree requiring all future contracts for the development and operation of private beaches to include a clause obliging beaches to install at least one changing cubicle and one toilet designed for people with disabilities and to construct a ramp for access to the beach and the sea. The applicant asserted that the State had failed to enforce this legislation.

Mr Botta alleged that he was unable to enjoy a normal social life, participate in the community and exercise his rights – not because of interference by the State but because of its failure to observe its positive obligations to implement its domestic law regarding private beaches – and that this breached his rights under Article 8. The Court stated that ‘While the essential object of Article 8 is to protect the individual against arbitrary interference by the public authorities, it does not merely compel the State to abstain from such interference: in addition to this negative undertaking, there may be positive obligations inherent in effective respect for private or family life’ (emphasis added) and that such obligations may involve the adoption of specific measures to ensure respect for people’s private or family life. However, in determining if such positive obligations exist there must be a balancing between the general interests of the population and the interests of the individual and within this the State has a ‘margin of appreciation’. In this case the Court held that ‘...the right asserted by Mr. Botta, namely the right to gain access to the beach and the sea at a place distant from his normal place of residence during his holidays, concerns interpersonal relations of such broad and indeterminate scope that there can be no conceivable direct link between the measures the State was urged to take in order to make good the omissions of the private bathing establishments and the applicant’s private life’. Because of the perceived absence of a direct link between the actions sought and the applicants private life the Court ruled that there had been no breach of Article 8. It is interesting to note that a dissenting opinion was expressed by Judge Loucaides on this case to the European Commission of Human Rights to the effect that the failure of the Italian government to enforce its own national legislation requiring beach establishments to ensure access to their facilities for disabled people represented, in his view, a

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violation of the applicants right to private life contrary to Article 8. The fact that the Italian government in enacting this legislation must have taken account of the needs and resources of the community was key to this conclusion along with the judges belief that ‘...the positive obligations of the State for an effective protection of the private life or personality of an individual entail the duty to secure to everyone certain minimum rights and facilities to enable the free development of his or her personality in the context of the conditions of social life.....Things that are essential for the enjoyment of life in a modern society and are intended to be enjoyed through public use ... should be made accessible to every individual to develop freely his personality or to meet the essential needs of his personality.’425

Despite the fact that this case was unsuccessful it did leave open the potential for others to pursue this line of argument with the Court if a more direct link between the measure sought and an individuals private life could be established. An attempt to prove this link was made by the applicants Zehnalova and Zehnal426 in 2002. Ms Zehnalova, who is physically disabled, alleged a failure on the part of the Czech Republic to fulfil its positive obligations under Article 8 by not adopting and monitoring compliance with domestic building regulations ensuring the accessibility of public buildings in their home town. The applicants asserted that the lack of access to public buildings which housed facilities providing for their everyday needs hindered their rights to a private life. The Court reiterated that Article 8 may entail positive obligations on states to respect people’s private lives and noted that ‘...a fair balance has to be struck between the competing interests of the individual and the community as a whole, and in both contexts the State enjoys a certain margin of appreciation.’427 The Court, however, ruled the case inadmissible on the basis that the applicant ‘...has not demonstrated the existence of a special link between the lack of access to the buildings in question and the particular needs of her private life. In view of the large number of buildings complained of, doubts remain as to whether the first applicant needs to use them on a daily basis and whether there is a direct and immediate link between the measures the State is being urged to take and the applicants’ private life.’428

Convincing the Court of the existence of a direct link along with the margin of

426 Zehnalova and Zehnal v Czech Republic App. No. 38621/97 (ECtHR, 14 May 2002)
427 ibid p11
428 ibid p12
appreciation allowable to states in fulfilling their positive obligations in relation to Article 8 proved to be an insurmountable obstacle in the case of Sentges v The Netherlands\(^{429}\) in 2003. In this case the applicant had a severe physical disability and required assistance from others for all basic functions. He applied to his health insurance company for a robotic arm, which would enable him to be more independent in a wide variety of activities ranging from operating a computer to picking up items to shopping. The request was refused by the health insurers despite being recommended by a rehabilitation specialist. Mr Sentges argued that respect for private life encompasses quality of life, including personal autonomy and the right to develop relationships with others. His complete dependence resulted in a loss of personal autonomy and the ability to develop relationships independent of his parents or carers. The provision of this particular assistive devise would enable him to develop relationships and exercise his right to a private life. There was, therefore, a direct and immediate link between the measure sought and the Mr Sentges’s right to a private life. His complaint related, not to an interference by the State with his rights, but rather to a lack of action on the State’s part and a failure to meet its positive obligations. The Court agreed that in this case a direct link did exist but referred to the need to balance the interests of the individual and the community as a whole and, significantly, to the wide margin of appreciation afforded to States in deciding how to meet its positive obligations and to ensure compliance with the Convention. The Court then went on to State that ‘This margin of appreciation is even wider when, as in the present case, the issues involve an assessment of the priorities in the context of the allocation of limited State resources’\(^{430}\). The Court noted that the State had provided the applicant with standard health care and with other assistive devises and commented that it (the Court) ‘...by no means wishes to underestimate the difficulties encountered by the applicant and appreciates the very real improvement which a robotic arm would entail for his personal autonomy and his ability to establish and develop relationships with other human beings of his choice. Nevertheless the Court is of the opinion that in the circumstances of the present case it cannot be said that the respondent State exceeded the margin of appreciation afforded to it.’\(^{431}\) On this basis the case was judged inadmissible. This disappointing judgment appears to point to the reality that even where there is a

\(^{429}\) Sentges v The Netherlands App. No. 27677/02 (ECtHR, 8 July 2003)

\(^{430}\) ibid p7

\(^{431}\) ibid p7
direct connection between the measure sought and the person’s ability to exercise their right a private and family life this will only be supported by the Court if the costs of implementing the measure are believed not to be significant i.e. the rights of people with disability – or indeed other citizens – to private or family life under Article 8 will only be considered within the context of national budgets and the competing demands placed on these budgets.

6.3.2 Home as an element of private life
A key element of private and family life is having a home – without a home exercising ones right to private or family life is difficult to envisage. This issue was dealt with by the Court under Article 8 in the case of Marzari v Italy.\textsuperscript{432} In this case the applicant, who had various physical disabilities, stopped paying rent on his apartment requesting that the local housing authority adapt the apartment to his specific disability related needs. The housing authority subsequently issued eviction proceedings, which were eventually carried out five years later following several failed negotiations and stays of execution. Thereafter the local authority appointed a commission consisting of six medical doctors to review six apartments it had identified to assess their suitability to the needs of the applicant. One suitable apartment was identified and was allocated to the applicant but he refused the offer. Mr. Marazi’s claim was that the local authority had not discharged its positive obligations under Article 8 by failing to allocate him accommodation adequate to his disability. The Court noted that ‘…although Article 8 does not guarantee the right to have one’s housing problem solved by the authorities, a refusal of the authorities to provide assistance in this respect to an individual suffering from a severe disease might in certain circumstances raise an issue under Article 8 of the Convention because of the impact of such refusal on the private life of the individual’\textsuperscript{433}. The Court found that the local authority had interfered with the applicant’s private life by evicting him but that this was lawful under Article 8-2, in that it had a legitimate purpose in protecting the rights of others. It was further found that, although Article 8 may impose positive obligations on States, this did not include an obligation to provide a specific apartment to the applicant. The Court ruled that the local authority has discharged its positive obligations towards Mr. Marzari by firstly, delaying his eviction on several occasions, secondly, appointing a commission to identify

\textsuperscript{432} Marzari v Italy App. No. 36448/97 (ECtHR, 4 May 1999)
\textsuperscript{433} ibid p8
suitable accommodation for the applicant and thirdly, by allocating an apartment to him. For these reasons the case was judged inadmissible.

6.3.3. Institutionalisation, legal capacity and the right to private life

Life in an institution is generally characterized by high levels of regulation and supervision, isolation from community and large numbers of people living together. For many disabled people it is a reality that many institutions throughout Europe accommodate very large numbers of people together\(^{434}\) and that conditions in these homes are generally very poor.\(^{435}\) In Stanev v Bulgaria\(^ {436}\) the Court found that the conditions in the social care home in which the applicant was detained amounted to inhuman and degrading treatment of such a scale that it violated the Article 3 of the ECHR. In particular the Court pointed to the poor quality and quantity of food, inadequate heating, dilapidated and unhygienic bathroom and toilet facilities and the fact that the applicant and other residents did not have their own clothes. The lack of resources claimed by the government as a reason for these conditions was rejected by the Court.

As evidenced by the reports referenced above, people in institutions for disabled people generally have no choice about where and with whom to live, have severely limited access to the community and have only have access to personal supports as part of a group. In the case of DD v Lithuania\(^ {437}\) the Human Rights Monitoring Institute argued that institutionalisation of disabled people represents discrimination in violation of Article 14 of the ECHR.\(^ {438}\) The Institute, in its response to the Lithuanian government observations to the Court, cited the US Supreme Court Olmstead judgement which found that institutionalisation of people with disabilities constitutes discrimination, severely limits people's access to everyday life activities and perpetuates negative stereotyping of disabled

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\(^{436}\) Stanev v Bulgaria App. No. 36760/06, (ECtHR, 17 January 2012) para 209-213

\(^{437}\) DD v Lithuania App. No. 13469/06 (ECtHR)

\(^{438}\) Human Rights Monitoring Institute re: DD v Lithuania App. No. 13469/06 (ECtHR) Applicant’s response to the Government’s observations dated 17 March 2008 para 409-417
They argued that DD’s confinement in the Kėdainiai Social Care Home following the stripping of her legal capacity was discriminatory. They further argued that ‘... where institutionalisation is the default or only option for persons with psychosocial disabilities and where there are few or no services or support to people who wish and are able to live independently, the State fails its obligations under Article 8.’ A lack of alternative community-based supports for disabled people in Lithuania – as in many other parts of Europe - means, in effect, that frequently people have little option but to reside in institutions and as a result live their lives under conditions which are in direct opposition to the ideals of IL as expressed in CRPD Article 19. This latter argument was not considered by the Court which found that because DD had maintained contact with friends and relatives this aspect of her application was inadmissible. However, in the Stanev judgement in the same year this issue was tentatively addressed and recognised.

In its third party intervention to the Court in Stanev, Interights argued that faced with a choice between homelessness and life in a social care home many disabled people in central and Eastern Europe are forced to opt for the latter because of a lack of alternatives, but that this can not be taken to mean that they have consented to their placements. Acknowledging that Mr Stanev required both accommodation and social support the Court stated that ‘... the objective need for accommodation and social assistance must not automatically lead to the imposition of measures involving deprivation of liberty.’

The refusal by the Court to deal with alleged violations of Article 8 where people have been institutionalized is disappointing. In Stanev and more recently in Kedzior v Poland the Court held that there was no requirement to deal with alleged Article 8 violations as the issues had been addressed in relation to other Articles. Two dissenting judgments in Stanev disagreed with this position with Judges Tulkens, Spielmann and Laffranque jointly stating that life in the social care home had ‘... effectively barred him from taking part in community life and from developing relations with persons of his choosing. The authorities had not attempted to find alternative therapeutic solutions in the community or to take measures that

439 Olmstead v L.C 527 U.S. 581 [1999]
440 Human Rights Monitoring Institute re DD v Lithuania App. No. 13469/06 (ECtHR) Applicant’s response to the Government’s observations dated 17 March 2008 para 355
441 Interights re: Stanev v Bulgaria App. No. 36760/06, (ECtHR) January 2010 para114
443 Kedzior v Poland App. No. 45026/07, (ECtHR, 16 October 2012)
were less restrictive of his personal liberty ..." and that these issues required separate examination under Article 8. The exclusion of these Article 8 claims has been subject to criticism and Lewis suggests that the rationale behind it may be a lack of common agreement on policy in this area among the COE member states and fear of opening the floodgates to large scale policy change with significant resource implications at national level. Suggesting that the Court has been the subject of much criticism for straying into areas of national policy he posits that ‘... perhaps the Grand Chamber was willing to offer the State a wide “margin of appreciation” and was reluctant to provide broad policy guidance in an area where there is not yet clear common ground amongst the member States (let alone among the judges) on an issue they consider to be a social or moral one, notwithstanding the existence of the UN Convention on the Rights of Persons with Disabilities.’ It is, of course, legitimate for the Court to be concerned about overstepping its boundaries into areas of national policy, but there is evidence of an emerging consensus across Europe that these large institutions are no longer the best option for disabled people. The COE Revised Social Charter, which has been signed and ratified by the majority of member states, at Article 15 states that disabled people have a right to independence, social integration and participation in the life of the community. In addition all of the COE member states have signed the CRPD and the majority have ratified it. So although progress in recognizing institutionalisation as a violation of Article 8, and as discriminatory, is comparatively slow the growing consensus within the COE and the adoption of international human rights instruments including the CRPD indicates that a move towards deinstitutionalization is taking place – and the Court can have an important role to play in nudging states along this road.

6.3.4. Legal capacity

In each of the cases dealing with people with disabilities living in large social care homes (including Stanev, DD and Kedzior) the applicants had been fully or

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444 Stanev v Bulgaria App. No. 36760/06, (ECtHR, 17 January 2012) Joint partly dissenting opinion of Judges Tulkens, Spielmann and Laffranque
445 See Munro, N. Mental Health and Mental Capacity Law blog, ‘Strasbourg goose laying golden eggs’ http://mentalhealthandcapacitylaw.wordpress.com/2012/10/19/strasbourg‐goose‐laying‐golden‐eggs/#more‐139 Accessed 15/12/2012
447 ibid p5
448 The Revised European Social Charter has been signed by 45 of the COE member states and ratified by 32 member states
partially deprived of their legal capacity and had consequently been admitted to institutional care. There is clearly a link between legal capacity and institutionalisation, a fact which was explicitly acknowledged by the Court in the Stanev case. A deprivation of legal capacity increases the vulnerability of people to institutionalisation and deprives them of the opportunity to have their wishes regarding where and with whom to live heard or respected in law. This issue is crucial for PWID and people and mental illnesses as a ruling of full legal incapacity effectively takes away individual control and decision-making powers and turns people into ‘non persons’. As Thomas Hammarberg, COE Commissioner for Human Rights, states ‘Curtailing the overall ability of individuals to make choices or have them respected naturally compromises opportunities to make more specific choices about where to live and how one’s life will look in relation to the community. At the same time, exclusion from life within the community increases the risk of legal capacity being denied. Little opportunity exists in the strictly controlled lifestyle, and lack of choice, inherent to institutional life, for an individual to voice his or her will.’ Keys suggests that the right to respect for private life has recognition of legal capacity at its core and this question was addressed in the Shtukaturov case. In this case the Court emphasised that ‘...the existence of a mental disorder, even a serious one, cannot be the sole reason to justify full incapacitation. By analogy with the cases concerning deprivation of liberty, in order to justify full incapacitation the mental disorder must be “of a kind or degree” warranting such a measure’. The judgment further stated that legislation, which automatically deprives a person taken into guardianship of all legal capacity was deficient under Article 8 - ‘The law permitted the deprivation of an individual’s legal capacity if that person “could not understand the meaning of his actions or control them”. However, the law did not explain what kind of “actions” the applicant should understand or control, or how complex these actions should be. ... The law was clearly deficient in this respect; it failed to protect mentally ill people from arbitrary interference with their right to private life.’ An important aspect of this judgment in the context of enhancing the rights of people with disabilities, was the

449 In Stanev v Bulgaria App. No. 36760/06, (ECHR, 17 January 2012) para 154 the Court stated ‘It seems clear to the Court that if the applicant had not been deprived of legal capacity on account of his mental disorder, he would not have been deprived of his liberty.’
451 Keys, M. Article 12 of the CRPD and the ECHR (2012) forthcoming
452 Shtukaturov v Russia App. No. 44009/05 (ECHR, 27 March 2008)para 94
453 ibid para 79
reference made to the COE Recommendation No. R(99)4 ‘Principles concerning the legal protection of incapable adults’, adopted in 1999. The Court noted that Russian guardianship legislation was not in conformity with these principles by failing to provide a tailor-made response to the applicant’s legal capacity.454 The COE Disability Action Plan refers to the need for States ‘to provide appropriate assistance to those people who experience difficulty in exercising their legal capacity and ensure that it is commensurate with the required level of support’.455 Despite the rulings of the Court and broader COE policy many member States still retain legislation which does not allow for a functional or universalist approach to legal capacity and operate within a system which means that individuals may be deprived of their right to make any decisions which have any legal implications. This includes the option of taking independent legal action in pursuit of the Convention rights and decisions about where and with whom to live.

In an important dissenting judgment in Stanev, in response to the failure of the Court to consider Article 8 concerns, Judge Kalaydjieva contended that restrictions on legal capacity represent an interference with the right to private life and that ‘... the lack of respect for the applicant’s recognized personal autonomy violated Mr. Stanev’s right to personal life and dignity as guaranteed by Article 8 and failed to meet contemporary standards for ensuring the necessary respect for the wishes and preferences he was capable of expressing.’456 The fact that Mr. Stanev had been partially stripped of his legal capacity meant that he could only take legal proceedings to challenge his legal incapacity - and therefore his placement in the social care home - with the permission of his guardian. If a person is legally denied the capacity to make decisions, they are effectively barred from challenging this in court because they do not have the capacity to take any decisions with legal implications, including the decision to take legal proceedings. They are caught in a catch 22 situation – they can only make decisions about how and where to live if their legal capacity is recognized and they cannot assert their rights if their legal capacity to go to court is not recognized by the courts. Lewis suggests that ‘... guardianship and institutionalization conspire not only to invalidate a person’s will and preferences, but .. [also] .. segregate people from our societies, exclude them from the political sphere and erase them from our legal

454 ibid para 95
455 Council of Europe, Committee of Ministers, Action Plan to promote the rights and full participation of people with disabilities in society Recommendation Rec (2006)5, 23 February 1999, para3.12.3.vi
456 Stanev v Bulgaria App. No. 36760/06, (ECtHR, 17 January 2012) Partly dissenting opinion of Judge Kalaydjieva
Article 12 of the CRPD asserts the right to full legal capacity for all disabled people and the right to support to exercise legal capacity. Hammarberg states that ‘Since the Court continues to recognise mental disorder as a possible justification for limiting legal capacity, the European human rights system has not yet fully incorporated the paradigm shift envisioned in the CRPD …’ Clearly there is some way to go to bring the jurisprudence of the European Court into line with CRPD Article 12, but there is room for hope. The more recent judgments from the Court would suggest that the case law is gradually moving in the direction of recognizing and supporting the legal capacity of disabled people, particularly in the Shtukaturov and Stanev cases, and is acknowledging the connection between legal capacity and institutionalisation.

6.4. Limitations of the Court

The process of litigating rights in the European Court is a long and arduous and many hurdles must be crossed by potential applicants, especially those with intellectual disability or mental illness. Applicants must first exhaust all domestic legal procedures before lodging a complaint with the Court – this in itself is time consuming requiring a high level of commitment and resources. The rules of the court do not allow for collective complaints to be heard which means that there must be an individual applicant (or applicants) who is willing and able to take a case. For PWID or mental illness this is a significant deterrent, as most people in this situation do not have the support or resources to undertake proceedings and many lack the capacity to do so. Other problem of accessing justice through the Court identified by Lewis include ‘low levels of knowledge about rights and remedies, little access to the outside world by people living in institutions, distrust of the legal system, and lack of human rights knowledge and/or enthusiasm by lawyers.’ O’Cinnide also points to the catch-22 cycle whereby, in the absence of successful cases the chances of success are unclear, which acts as a disincentive

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to potential new cases. An analysis of cases involving applicants with mental illnesses concerning psychiatric commitment conducted by Niveau and Materi in 2004 highlighted the very limited number of cases of this nature coming before the Court and the uneven distribution of cases among CEO member states. The authors suggest that ‘...accessibility to the ECHR depends on both the degree of democracy of the country where the case is situated (the ability of an individual to access the local and supranational legal system), and on the degree of support offered to the individual by a person or organization specializing in the field of psychiatric commitment’.\(^{461}\) It can be assumed that the availability of support to take legal action must also be a major factor for PWID and people with mental illnesses whose complaints do not concern commitment. The availability and accessibility of such support varies greatly between member states and within states. Lewis concludes that ‘The gulf of mental disability cases reaching Strasbourg is evidence of the fundamental and systemic problem of access to justice by people with mental disabilities, coupled with stigmatization at every level in society including within the health and justice systems.’\(^{462}\)

Another, and perhaps less obvious shortcoming of the Court is what O’Cinneide\(^{463}\) terms the ‘marginalization of disability’ within mainstream national and international human rights instruments, including the ECHR. This is reflected in the fact that the ECHR makes no reference to people with disability in relation to any of its rights - other than in Article 5 where being of ‘unsound mind’ can be a basis for deprivation of liberty. The failure to include disability in Article 14 as a basis for the prohibition of discrimination is particularly marked – although it is generally taken to be included under the generic term ‘other status’. O’Cinneide suggests that ‘These [mainstream] rights instruments conceptualise the individual in essentially liberal terms as an autonomous being capable of operating in isolation from the state: civil and political rights are designed to protect this individual from unjustified state interference, and the state is only placed under a positive obligation to assist this independent individual in certain very specific contexts.’\(^{464}\) These mainstream instruments fail to take account of the fact that many PWD require


\(^{464}\) *ibid* p165
additional support or accommodations to access their rights and are dependent on the state for this. For O’Cinneide these supports, which are essential for people with disabilities, are generally viewed as the exception by general human rights instruments and therefore not generally applicable, or only available in very specific circumstances. The CRPD moves this analysis forward. It recognizes that, despite the fact that many people require on-going state support to access their human rights, that this does not impinge on the fact that they are holders of rights, and consequently places an obligation on the state to ensure that all citizens have the supports needed to access their rights. From the point of view of the disabled citizen this means that they are ‘...seen as entitled to claim the essential support that will enable them to live a dignified life and to maximize their autonomy as a matter of positive rights.’

The generally conservative nature of Court decisions also limits its potential in assisting change at national level in the direction of IL. De Schutter’s offers an analysis of the reasons behind the Courts reluctance to place far-reaching positive obligations on States, particularly in relation to the right to private life. He suggests that the barriers to a broader interpretation of States positive obligations by the Court are institutional, rather that due to a lack of an understanding of how Article 8 relates to disabled people and their rights to private life. These constraints are:

1. The ‘all or nothing’ approach which exemplifies the judicial function of the Court. A ruling of the existence of a positive obligation, especially in relation to physical access issues, opens respondent States to the possibility of having to spend large amounts of national resources to meet this obligation. It does not leave open the possibility of the progressive realization of rights.

2. The need for the Court to ensure that in addressing the needs of one applicant the interests of other citizens are not damaged in the process. The Court must be mindful of the implications of its decisions for everyone where an individual applicant seeks to have his/her rights realized but the State does not have the resources to solve the same problem for everyone else in similar situations.

3. The open ended nature of the concept of ‘respect for private life’ and the

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465 *ibid* p166
potential scope of the positive obligations it could impose on member States.

‘We know, perhaps, where the obligation begins: we hardly know where it ends’\(^{467}\).

Each of these points also touch on the democratic mandate of the Court – does it have a right to impose priorities on member States in relation to the expenditure of national resources? Is this not properly the role of national governments elected by their citizens?

6.5. The Potential of the Court

6.5.1 Article 8 Positive Obligations

On its face Article 8 appears to hold most potential for the realization of a right to Independent Living especially if taken in conjunction with the revised Article 14. The revised Article, under amending protocol 12, now prohibits discrimination in the enjoyment of all rights ‘set forth by law’, whereas protection against discrimination was only provided in relation to Convention rights heretofore. As noted above the three key issues from the point of view of the Court in relation to positive obligations to ensure respect for private life of PWD under Article 8 are a) the need to strike a fair balance between the interests of the individual and those of the community as a whole, b) the existence of a direct link between the measure sought and the individual’s private life and c) the margin of appreciation allowed to States in implementing such positive obligations in the context of national budgets. The case law to date in this area does not appear to provide much scope for optimism particularly in the light of the Sentges case where, even though the Court acknowledged the existence of a direct link and the significant potential benefit to the applicant, the ‘margin of appreciation’ allowed to the respondent state was given greater credence by the Court. The restrictive and conservative interpretation by the Court of the scope of Article 8 positive obligations may, however, mask the potential of this article to encompass the core elements of a right to Independent Living. Bartlett, for example, sees the potential for arguing that institutionalization is a violation of the right to respect for private life suggesting that ‘Institutions commonly violate this right cumulatively by way of overcrowding, invasive treatment, lack of activities etc. ...The applicant could argue that it is only community based services which provide services in the least

\(^{467}\) ibid p43
restrictive setting, with the least possible invasion of privacy rights."\textsuperscript{468} Dissenting judgments in the Stanev and Koua Poirrez v France\textsuperscript{469} cases have expressed a broader view of the scope of the positive obligations of Article 8. Judge Mularoni dissenting in Koua stated 'The Court has held that these States must in the first place respect the private and family life of anyone within their jurisdiction, but also remove the obstacles and restrictions which hinder the free development of the personality, and assume broader and broader positive obligations.'\textsuperscript{470} Parker and Clements suggest that the CRPD may help in this regard. They suggest that the Court’s emphasis on personal autonomy and on the need to provide clear justification for interference with a person’s chosen lifestyle hold potential for a more expansive interpretation of Article 8 rights for people with disabilities. Further they note that ‘Article 8 has the potential ... to extend to situations of passive institutionalization, where the care regime is constructed in such a way as to make institutionalization the default option: for example where there are few or no services or supports available to people who wish to live in their own homes.’\textsuperscript{471} Arguments in this regard made in The Human Rights Monitoring Institute in DD did not convince the Court, nonetheless it is line of argument worth pursuing given the increasing attention being paid by the Court to the CRPD and in the light of the Olmstead judgment in the US.

The use of the ‘direct link’ concept by the Court in Botta represents what De Schutter\textsuperscript{472} terms an attempt to ‘domesticate’ the notion of positive obligations – one means of setting boundaries around States positive obligations. He proposes a number of strategies that could assist in the identification of clear boundaries for positive obligations and for the provision of reasonable accommodations. These include firstly, requiring States to comply with and enforce their own domestic law to protect individual autonomy. A requirement to adhere to domestic legislation and an acknowledgment of States progress in this was a key factor in the Zehnalova and Zehnal case where the Court noted that the State was attempting to improve accessibility to public buildings. Secondly, assessing the extent of Article 8 positive obligations in the context of other international human

\textsuperscript{469} Koua Poirrez v France App. No. 40892/98 (ECtHR, 30 September 2003)
\textsuperscript{470} ibid Dissenting Judgment
rights instruments to which member States have signed up – as he suggests ‘How could a State possibly argue that it would be unreasonable to expect it to adopt a particular measure, if the State has already undertaken to adopt that measure by agreeing to other international agreements.’

Thirdly, focusing on the need to ensure that States’ decision-making processes take account of the impact of proposed actions or policies on vulnerable groups i.e. taking account of the perspective of disabled people and other marginalized groups in all policy formulation.

In seeking to identify directions forward in the implementation of a right to private life in relation to people with disabilities and to address the above listed concerns of the Court, making positive obligations concrete and finite offers one possibility. DeSchutter draws a distinction between the Botta and Zehnalova and Zehnal cases on one hand and the Marzari and Sentges cases on the other. In the former cases the measures required to address the barriers to access would have involved general environmental changes and potentially imposing a ‘disproportionate burden’ on the State. In the latter cases the remedies required would have been relatively minor individualised measures – the direct link with individual’s private lives being much more evident in the Marzari and Sentges cases. Judge Loucaides also proposes the drawing of this distinction: ‘In cases where the complaint relates to general problems of indeterminate scope which would cover everything and anything in abstracto which could or could not be of direct significance for the life of a particular disabled person, the position of the jurisprudence is in my opinion correct. But one could not exclude an obligation on the part of the State to solve specific problems of a disabled person which are essential for the enjoyment of life in a modern society and are within the financial capacity of the State’.

According to O’Cinnide a number recent cases in the UK and Ireland which applied the jurisprudence of the Court illustrate that the ECHR may be capable of being interpreted so as to require the State to ‘...to give effect to Article 8 bundle of rights, if the resource allocation in question is distinct, clearly delineated and required in a specific case’.

473 ibid p 48
6.5.2. Article 14 non-discrimination right

Article 14 cannot be invoked independently. Combining Article 8 rights with the Article 14 obligation not to discriminate – including a focus on indirect discrimination – appears to offer a potentially fruitful route. This was pursued in the *Thlimmenos v Greece* case which concerned a refusal by the State to allow a Jehovah’s Witness to access the profession of chartered accountant because of a criminal conviction – gained because of his refusal on religious grounds to serve in the armed forces. The Court outlined the dimensions of the term ‘discrimination’ stating that the right not to be discriminated against ‘... is violated when States treat differently persons in analogous situations without providing an objective and reasonable justification. ... The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States, without an objective and reasonable justification fail, to treat differently persons whose situations are significantly different.’ De Schutter suggests that although the court did not use the term ‘reasonable accommodation’, the concept is nonetheless implicit in this judgment. The Court, in finding a violation of Article 14, highlighted the way in which the rules governing access to the profession of chartered accountant in Greece had an adverse, although unintended, impact on people of the Jehovah’s Witness faith and that this constituted indirect discrimination. For disabled people living in institutions the Article 14 prohibition on indirect discrimination appears to offer potential. In particular the disproportionate impact on the right to private and family life of policies biased towards institutional rather than community based residential provision and the disproportionate number of people with disabilities living in state funded residential care facilities compared with the general population resulting from government policy decisions. The recent Grand Chamber judgment in the *DH v Czech Republic* may also provide some guidance in relation to the prohibition of discrimination. In this case the Court found that psychological testing of Roma children and the consequent disproportionate numbers of Roma children referred to special schools for children with intellectual disability amounted to indirect discrimination. The Court recognized

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476 *Thlimmenos v Greece* App. No. 34369/97 (ECtHR, 6 April 2000)
477 *ibid* para 44
479 *DH and Others v The Czech Republic* App. No. 57325/00 (ECtHR, 13 November 2007)
that this was not an intentional outcome or policy on the part of the Czech government, nonetheless its adverse impact on Roma children as a group was discriminatory.

Clearly for many people with disabilities simply being treated in the same way as non-disabled people will not result in equality. Disabled people will often require different treatment because of their different circumstances in order to exercise their rights i.e. they will require reasonable accommodation and they will require support. Indeed the requirement to treat people in different circumstances differently in order to achieve equality has previously been recognized by the Court in relation to Article 3. In the case of *Price v the UK*\(^\text{480}\) the State’s failure to treat the applicant, who was being held in custody, differently in order to take account of her disability-related needs -resulting in significant physical and psychological suffering on her part - amounted to inhuman and degrading treatment and constituted a violation of Article 3. Judge Greve, in a separate but concurring opinion in this case, referred specifically to this need for different treatment: ‘The applicant’s disabilities are not hidden or easily overlooked. It requires no special qualification, only a minimum of ordinary human empathy, to appreciate her situation and to understand that to avoid unnecessary hardship – that is, hardship not implicit in the imprisonment of an able-bodied person – she has to be treated differently from other people because her situation is significantly different.’\(^\text{481}\)

It is clear from this and other judgments that the Court considers a failure to treat different people differently and to take account of their specific needs, represents a violation of the individual’s rights while in State care – how far this may be extended into non-state sectors and in relation to other rights remains unclear.

### 6.6. The European Court and Irish Law\(^\text{482}\)

The European Court occupies a unique position in international law as it affords citizens the opportunity to challenge national law and its judgements are legally binding on the State involved in the proceedings. As part of the Good Friday Agreement signed in 1998 the Irish government agreed to incorporate the ECHR into Irish legislation leading to the passing of the European Convention of Human Rights Act in 2003. The ECHR Act provides for three significant measures which

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\(^{480}\) *Price v United Kingdom* App. No. 33394/96 (ECtHR, 10 July 2001)

\(^{481}\) *ibid* Separate opinion of Judge Greve

\(^{482}\) See Chapter on Irish legislation for greater detail
offer potential in the domestication of European Court jurisprudence into Irish law and practice as follows:

1. The interpretative obligation which requires the courts to interpret and apply the law in a manner compatible with the ECHR. The courts are required to take judicial notice of declarations, decisions and opinions of the European Court, the European Commission of Human Rights and the Council of Europe.

2. The obligations on all 'organs of the State' to perform their functions in manner compatible with the ECHR.

3. The facility for the High Court and the Supreme Court to make a declaration that a statutory provision or rule of law is incompatible with the State's obligations under the ECHR. Where such a Declaration has been made by either court the Taoiseach is obliged to lay it before the Dail within 21 days in order for the necessary legislative changes to be considered. However, pending such changes the Act allows for the 'continuing operation or enforcement of the statutory provision or rule of law in respect of which it is made'.

Opinion varies as to the likelihood of any significant legislative changes resulting from the incorporation of the ECHR Act into Irish law. There would appear to be a reluctance on the part of the State and its agencies to fully embrace the Act reflected in its decisions to appeal each of the three cases where Declarations of Incompatibility have been granted.

The potential benefits of incorporation of the ECHR into Irish law include:

1. The Act brings the jurisprudence of the European Court into the Irish courts offering a wider and deeper interpretation and application of ECHR rights than would have previously been the case. It makes available the accumulated knowledge and wisdom of the European Court to our judicial system.

2. Enabling Irish citizens to challenge the convention-compatibility of laws, rules or policies in the national courts means that such cases should no longer have to be pursued as far as Strasburg. It would seem unlikely that an Irish 'organ of the State' would allow a measure deemed to be incompatible with the ECHR by the Irish courts to proceed as far as the European Court.

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483 European Convention on Human Rights Act 2003 Section 2(1)
484 European Convention on Human Rights Act 2003 Section 3(1)
485 European Convention on Human Rights Act 2003 Section 5(1)
486 European Convention on Human Rights Act 2003 Section 5 (2)(a)
3. The incorporation of the Act should directly impact on the process of law reform. As it ‘beds down’ the ECHR should become a touch stone in the development of all new legislation so that all new law should consider the rights protected by the ECHR from the outset.

6.7. Conclusion - A Right to Independent Living?

At the heart of the right to Independent Living are choice and control, personal autonomy, equality of access, the right to participate and the right to support to exercise rights. These are also fundamental values of the ECHR.

The case law of the Court in relation to disabled people reflects the medical model–social model dichotomy. On one hand the Court relies heavily on medical evidence in determining whether an applicant is ‘of unsound mind’, arising primarily from the Winterwerp criteria. On the other hand recent decisions, especially in Stanev and in Shtukaturov, recognises the need to protect disabled people from the enormous negative consequences of being deprived of legal capacity and the importance of ensuring that a need for social support does not lead to automatic deprivation of liberty. It is now time to acknowledge that for many PWD institutional care is provided, not, solely because of their need for care or support, but rather because of state policies and prejudicial societal attitudes to disability. It is valid to question whether the Winterwerp criteria should also include an obligation on States to examine alternative community based arrangements before placing a person in an institution – instead of institutional care being the default position in providing care/support for disabled people, the first option should be community based provision.

In its jurisprudence in relation to Article 5 the Court has identified that a person may be considered to his been deprived of his liberty even though he did not resist his detention or did not have the capacity to give consent, even where he is not held in a locked ward but nonetheless is not free to leave and where his behaviour and activities are under the supervision and control of staff. Where these conditions exist they represent a deprivation of liberty under Article 5. Many PWID or people with mental illness remain in institutional settings because of a lack of available alternatives. This must raise the question of whether people in this situation in Ireland or other European countries are deprived of their liberty in violation of their Article 5 rights.

The Court has recognized the vulnerable position in which such people live and has stressed the importance of exercising a high level of attention to the
protection of their convention rights as a result vis ‘...the position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with.’\textsuperscript{488} Mary Keys suggests that institutional care including group homes, large residential institutions and psychiatric hospitals, hinder people from living independent lives and that they are ‘... potentially inhuman and degrading’.\textsuperscript{489} Article 5 jurisprudence would suggest, at the very least people must consent to their placement at such institutions. However, consent, where there are no other realistic alternatives, can be said to be somewhat hollow.

Article 8 jurisprudence provides a broad definition of ‘private life’ as encompassing personal relationships, physical and psychological well-being and a right to unhindered personal development. However, the Court decisions in relation to Article 8 have been hindered by a narrow interpretation of the ‘direct link’ needed between the measure sought and the applicants private life. In addition the Court has yet to consider whether institutionalisation represents an infringement of the right to private life. But there is still room for progress to be made in these two areas.

The power of the Court lies in its authority to compel States to amend legislation, policies or practices which violate people’s human rights. It could plausibly be argued that systems which are biased towards placing disabled people in institutional care, as opposed to enabling people to live independently in the community, represents a violation of people’s right to private or family life. In conjunction with this it is reasonable to argue that a biased system which places a disproportionate number of people with disabilities in institutions of one sort or another, compared to other groups in the population, is indirect discrimination under Article 14. The proposal by De Schutter that a distinction be drawn between ‘reasonable accommodation’ and ‘indirect discrimination’ offers potential: this would involve arguing the need for reasonable accommodation where a direct link exists between the measure sought and the applicants private life and setting limits to what ‘reasonable accommodation’ entails for this specific individual i.e. not involving wholesale costly changes by the respondent State. It the light of the CRPD all these lines of argument are considerably strengthened.

\textsuperscript{488} Herczegfalvy v Austria App. No. 10533/83 (ECtHR, 24 September 1992) para 82

There can be no doubt that legal and policy developments internationally over the past 10 years have seen significant progress in the recognition of the rights of PWD, although clearly there is still much to be achieved in this regard. Within the United Nations human rights structures a right to Independent Living has gradually emerged over the past number of years culminating in the CRPD. The significance of the CRPD cannot be underestimated in the development of the recognition of a right to Independent Living internationally. Parker and Clements suggest that ‘It is strongly arguable that a European consensus already exists concerning the qualified right of disabled people to live independently. The case for such a right will become incontestable with the widespread ratification of the Disability Rights Convention. The recognition of such a right brings with it a presumption that Independent Living will be the default option for disabled people; a positive obligation on the State to promote their social inclusion and an interpretative principle, that domestic legislation will be given a meaning that advances the possibility of Independent Living and challenges policies that are weighted to produce an institutional outcome.’

There can be no doubt that the direction of change is towards Independent Living, what remains to be seen is the pace at which such change comes about and what the European Court can contribute to the momentum. The impact of the CRPD on the Court is already becoming evident – in the recent Glor v Switzerland, Stanev and DD cases the Court demonstrated that it will take the CRPD into account in coming to decisions. In Glor the judgment referred specifically to the CRPD as the basis for the existence of an international consensus on the need to protect disabled people from discrimination. Oliver Lewis of the Mental Disability Advocacy Centre, which acted for the applicant noted that ‘The Glor judgment has paved the way for litigation which encourages a synthesis of European human rights jurisprudence with the principles and provisions of the UN Convention on the Rights of Persons with Disabilities...’

At policy level within the COE there has been considerable progress in the development of a right to Independent Living. In the COE policy framework the right to Independent Living is specifically detailed in Article 15 of the Revised

491 Glor v Switzerland App. No. 13444/04 (ECtHR, 30 April 2009)
European Social Charter – ‘The right of persons with disabilities to independence, social integration and participation in the life of the community’. The overall thrust of the COE Disability policy as expressed in its Disability Action Plan 2006 – 2015 is that of promoting the independence and participation of people with disabilities in society. The Plan has as one of its fundamental principles that member States will work to ‘...enhance independence, freedom of choice and quality of life of people with disabilities...’493. Although policy documents from the COE are not legally enforceable in the same way as Court decisions, they contribute to the recognition of international norms and standards and as such are a significant influence of the Court.

What then is the likelihood of a right to independent living being recognized by the Court in the future? An examination of international and regional policies in relation to disabled people clearly indicate that there is broad agreement on the emergence of such a right, despite the fact that practices on the ground in many European countries are far from realizing this right. And it is precisely this developing consensus that holds the greatest potential for people with intellectual disability and mental illness to live lives of their choosing in places of their choosing and having the supports needed to do this. There is still a long way to go but the thrust of policy formation over the past 10 – 15 years supports the momentum in the direction of community-based provision. The passage of the CRPD is very significant, firstly, in setting international standards for the realization of human rights for disabled citizens, secondly, explicitly naming a right to independent living for people with disabilities, thirdly, unambiguously outlining the right of disabled people to the supports needed to enable access to rights and fourthly, and perhaps most importantly, moving disability to the centre of human rights law. It is difficult to see how the Court will be able to operate in a way which is contrary to the developing international and European consensus and the CRPD in particular – in fact, as noted, the Court has already indicated its willingness to take account of the CRPD in the recent cases.

493 Council of Europe, Committee of Ministers, Action Plan to promote the rights and full participation of people with disabilities in society Recommendation Rec (2006)5, 23 February 1999, para 1.2.1
Chapter 7: Disability legislation in the European Union

7.1. Introduction

The European Union of today emerged from the aftermath of the Second World War and a determination to prevent further violent conflicts in Europe by forging industrial and economic ties between the founding member states. Its foundations, therefore, were largely economic and political in intent, and this was reflected in the original treaty, The Treaty of Rome, signed in 1957 by six states creating the European Economic Community. The focus at this stage was on the removal of trade barriers and the creation of a common market.

A series of further treaties since then has increased the membership of the European Union (EU) and has expanded its reach into areas of policy and legislation beyond that of economic and political co-operation.

In the context of disability and anti-discrimination law more generally, the passage of the Treaty of Amsterdam in 1997 and more recently the Lisbon Treaty in 2007 can be seen the most significant developments enabling the Union to begin developing policies aimed at protecting marginalized groups from unfair treatment in employment and in the social sphere.

Article 13 of the Amsterdam Treaty established the legal basis from which anti-discrimination legislation could be developed and the Union set about the task of developing such legislation relatively quickly after the Treaty came into law.

The adoption by the EU in 2000 of the Charter of Fundamental Rights (the Charter) was one of a series of important steps taken to enshrine human rights within the member states. The Charter also made the significant contribution of outlawing discrimination against people with disabilities (PWD) and other groups – the first time disabled people were specifically protected in this way in international human rights instruments either in the United Nations or the Council of Europe.

The signing of the Lisbon treaty and particularly the amendment to Article 6 of the treaty marked what Groussot and Pech term a ‘quantitative and qualitative jump’ in terms of the status value of human rights within the EU. The amended

Article 6 of the Lisbon Treaty provides for the incorporation of the Charter into EU law, giving it the same value as the Treaties, and for accession by the EU to the European Convention on Human Rights (ECHR).

In 2000 the EU adopted Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation – The Framework Employment Directive (FED). The FED prohibits discriminatory treatment of people on the basis of religion or belief, disability, age or sexual orientation in relation to employment and vocational training. Prior to the Amsterdam Treaty the only area where anti-discrimination law had been developed by the EU was in relation to equal treatment between men and women. The EU explicitly espoused broader social justice goals in the Amsterdam Treaty, and, regardless of the motivation for neglecting to protect people from discrimination on bases other than gender prior to this time, the movement thereafter has been extremely significant for people with disability.

In 2008 the European Commission proposed a draft Directive on Equal Treatment in Areas Other than Employment (draft ETD) to provide protection from discrimination on the basis of religion or belief, disability, age and sexual orientation. And although the draft directive appears at this stage unlikely to be passed, its intent and content are worth noting.

The EU formally ratified the CRPD in 2010 and, as the first international human rights treaty to which the Union has acceded, the full implications of it within EU law are still uncharted waters. It is possible to anticipate that it will enhance the status of disabled people within EU law and Ferri suggests that its ‘... remarkable content, and its underlying rationale, could potentially have a positive influence on the overall conception of human rights within the EU ... [and] ... may well have a profound impact not only on EU (secondary) law but also on European constitutional standards of human rights.’

The purpose of this chapter is to explore how the rights of disabled people are protected and promoted within EU law. The first section will look at the concept of equality espoused in the various EU statues and how these conceptions impact on the rights of people with disabilities. The second section will outline the EU

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Treaties and how or if these have progressed disability rights looking in particular at the Treaty of Amsterdam and the Lisbon Treaty. This will include the place of the Charter and the ECHR in EU law resulting from the passage of the Lisbon Treaty. The following section will examine the implications of the ratification of the CRPD by the EU. This will be followed by an examination of FED and the draft ETD. The areas of how ‘disability’ is defined in the various instruments, how ‘discrimination’ is defined, the concept of reasonable accommodation and the developments in the area of accessibility will be explored.

7.2. Models of Equality in EU law

Before looking at the detail of EU legislation in respect of people with disabilities it is useful to consider the values and the concepts of equality underlying such law.

7.2.1 Individual Justice/Formal Equality

The formal equality model is reflected in the individual justice model as described variously by Fredman, McCrudden, DeSchutter and by Bell and Waddington among others. The individual justice model is, in effect, a formal guarantee of equal treatment outlawing differences in treatment on the basis of irrelevant traits of the individual. The European Court of Justice (ECJ) outlined the parameters of equal treatment under this model as follows:

‘...the principle of equal treatment is breached when two categories of persons whose factual and legal circumstances disclose no essential difference are treated differently or where situations which are different are treated in an identical manner’

McCrudden suggests that this approach ‘...concentrates on cleansing the process of decision making, and is not concerned with the general effect of decisions on groups, except perhaps as an indication of a flawed process..... it is markedly individualistic

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in its orientation: concentrating on securing fairness for the individual.'  

This principle of equality is generally applicable across all grounds and is clearly expressed in the prohibition of direct discrimination in the equal treatment/anti-discrimination directives emerging from the EU.

However, the formal approach to equality has been subject to criticism on several fronts, many of which are of particular significance to people with disabilities. Specifically, the effectiveness of such an approach depends on the ability of individuals to access the courts and the legal system – and for disabled people there are many barriers to be overcome in this. In addition this model demands that there be an appropriate comparator, but an obvious comparator may not be available where the type of discrimination experienced by a disabled claimant is specific to disability. Another major shortcoming of the individual justice model is its inability to deal with discrimination which is structural or institutional in nature. Where the discrimination experienced by an individual or by a group arises from the way in which society’s institutions are organized it is extremely difficult to prove using an individualistic approach because of the assumption of institutional neutrality.

### 7.2.2 Group Justice/Substantive Equality

The shortcomings of the formal equality approach give rise to the need for a more substantive theory of equality which has been termed the Group Justice Model. The Group Justice Model recognises the unequal starting points of individuals because of historic or current mistreatment or marginalization of the group to which they belong. It recognizes that much discrimination is structural in nature and that the ways in which societal institutions operate can unfairly disadvantage some groups or individuals. This recognition facilitates the development of special measures designed to provide genuine equality of opportunity to protected groups.

While the prohibition of direct discrimination in EU law is a direct reflection of the individualistic notion of equality, an attempt to deal with the institutional nature of certain types of discrimination is reflected in the prohibition of indirect discrimination in the EU draft ETD and the FED. Substantive equality or the Group Justice approach can be manifested in a variety of measures including equalization.

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of starting points, equalization of opportunity which encompasses measures to compensate for past and current disadvantage, and a focus on equality of results including positive action measures and monitoring of representation of various groups in the workplace and other social arenas. Positive or affirmative action measures have the potential to equalize the playing field for those who have been disadvantaged by either past or current structural inequalities. While positive action measures may help increase participation by marginalized groups they also include the dangers of ‘singling out’ of the group involved thus increasing resentment and stigma. In addition it is well recognized that a pitfall of positive action measures is their tendency to benefit the most able within the targeted groups while the most vulnerable and disadvantaged in the groups remain largely unaffected. De Schutter warns ‘any policy aimed at targeting specific categories defined by “suspect” characteristics for the distribution of certain benefits, should not become a disincentive for the adoption of more structural remedies which, once they will be put in place, will progressively bring about a situation where such special measures will be seen as redundant and unnecessary.’

The FED (at Article 7) and the draft ETD (at Article 5) include provisions which allow member states to put in place positive actions in relation to any of the covered grounds. Both state ‘With a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantages linked to any of the grounds.’ However, achieving consensus as to the types of positive actions has proven extremely problematic as illustrated by the attempt to introduce employment quotas for people with disabilities. Differing political, philosophical and policy approaches in member states meant that the original proposal for the introduction of employment quotas from the European Commission ‘...encountered a crowded and contended policy space, and this prevented any agreement at the European level.’

Bell and Waddington highlight a number of difficulties associated with this Group Justice approach. On the one hand the model recognizes that apparently neutral measures may impact negatively on members of a specific group because

of current or past disadvantages and attempt to compensate for this by adjusting the particular measure or putting in place supports or new measures aimed at equalizing the playing field. On the other hand, Group Justice inevitably draws attention to particular groups thus tending to compartmentalise groups and stressing their difference from other groups. As a consequence efforts to address multiple discriminations arising from an individual’s membership of more than group are undermined. In addition the focus on group identities may lead to priority setting between groups and, as pointed out by Bell and Waddington, ‘[g]roups vulnerable to discrimination vary in their numeric size, economic and political resources, as well as the looser criterion of “acceptability”. Consequently some groups will be regarded as more deserving of legal protection, or having more pressing social needs.’

Within the EU the compartmentalization of groups with their varying levels of influence and social acceptability has led to differences in the level and breadth of protections provided to different groups. Specifically the directives in relation to race and ethnic origin provide the greatest protections, while that provided on the basis of disability, age, religion and sexual orientation is the weakest. Forcing people into single identity groups, which occurs with this model, belies the fact that in reality people’s identity arises from many sources and many group affinities. The inability, then, of the group justice model, as reflected in EU legislation, to tackle multiple discriminations seriously undermines the models potential to tackle the complexity of discrimination or unequal treatment as experienced in the real world by individuals. The group-based model also assumes a commonality of traits and experiences among members of particular groups and, in the case of disability at least, this is a false assumption where the experience and impact of different impairments varies enormously.

It is arguable that the existence of multiple pieces of EU legislation applying to different groups in different circumstances is somewhat bizarre and that the obvious solution would be to develop a single legal instrument outlawing discrimination across all grounds and in all circumstances. It is notable that in its comments on the draft ETD the European Parliament recommend that a comprehensive Community legal framework relating to non-discrimination generally be enacted in the form of a single Directive to replace all of the existing

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506 ibid p 355
Article 13 Directives. While the CRPD largely falls within the group justice model of equality, in that it is specifically designed to ensure the rights of disabled people, it does refer to the phenomenon of multiple discrimination in the preamble and specifically in Article 6 speaks of the multiple discrimination experienced by disabled women and girls. Although this is somewhat limited it is certainly a step in the direction of giving recognition to the reality of how discrimination is experienced on many fronts.

However, there also benefits to having legislation which is specific to particular groups. Bell and Waddington point to several factors which help to explain why anti-discrimination legislation aimed at particular groups exist i.e. that there are substantive differences between the protected groups, that there are different levels of disadvantage among the protected groups, among legislators there is varying degrees of experience in dealing with discrimination in relation to particular groups, the differing political strengths of the various groups and finally the different goals of legislators in relation to the different groups. Indeed several leading advocacy groups are actively campaigning for an EU directive specific to disability on the basis that the discrimination experienced by disabled people is different from that experienced by other groups, and that specific measures are needed to combat it. Fredman on the other hand, suggests that legislation which provides group-based protection is ‘captured by categories’ necessitating clear distinctions between different groups which is highly problematic as it assumes that groups are mutually exclusive, that all group members are the same and fails to deal with the effects of cumulative discrimination. She suggests that the only way to move beyond the categorical approach inherent in the group justice model is to develop a ‘single harmonised statute which includes all the relevant grounds of discrimination, and does not necessitate harsh distinctions between different grounds.’

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507 European Parliament, legislative resolution of 2 April 2009 on the proposal for a Council directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, P6_TA(2009)0211 Amendment 79
509 Including the European Disability Forum, The European Network on Independent Living and Inclusion Europe
511 Ibid p159
7.2.3. Equality as Positive Duties/Fourth Generation Equality

A third model of equality is that of Equality as a Positive Duty and participation rights. Fredman, referring to this model as ‘Fourth Generation’ equality, outlines the essence of this model as ‘...a recognition that societal discrimination extends well beyond individual acts of racist prejudice. Equality can only be meaningfully advanced if practices and structures are altered proactively by those in a position to bring about real change, regardless of fault or original responsibility. Positive duties are therefore proactive rather than reactive, aiming to introduce equality measures rather than to respond to complaints by individual victims.’

A core mechanism for this model is that of Positive Duties, whereby employers or service providers are obliged to plan ahead for access for disabled people and other groups and to make provision for access even where no individual complaint has been received. The move away from the need for litigation on the part of individuals as a means of promoting equality addresses many of the barriers faced by disabled people in securing equal treatment. This model also includes provision for monitoring of representation of disadvantaged groups and for what is termed ‘participation rights’ in the development of policies and practices. Participation rights and the anticipatory nature of positive duties means that employers and service providers must engage directly with marginalized groups and consider their needs in formulating responses. As Bell and Waddington point out ‘This has the potential to sensitize policy-makers, as well as ensuring that future policy interventions are informed from the outset by the needs of diverse communities in society.’

Bell et al in their 2007 review of anti-discrimination law in the member states of the EU concluded that there are more structured means for PWD to participate in the policy development process than for many of the other covered grounds. Again both the FED (at Article 14) and the draft ETD (at Article 11) include provision for direct consultation with affected groups in the development of policies, as does the CRPD as one of its general obligations on state parties at Article 4.3.

The notion of anticipatory duties is encapsulated in the concept of ‘mainstreaming’ which has been adopted in recent years in EU policy development, particularly in relation to PWD. Mainstreaming means in effect that

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512 ibid p164
the need to ensure equality for all of the covered grounds is taken into account as a factor to be considered, not just at the policy development stage, but also at the implementation stage and in monitoring the impact of policies on the various groups. Mabette\textsuperscript{515} suggests, however, that the concept of mainstreaming utilized by the EU has been more evident and more applicable in the policy development sphere rather than at legislative level. Mainstreaming seeks to include the perspective of those at whom social policies are aimed in the policy making process rather than seeking remedies for individuals. However, as with the employment quotas, attempts to mainstream anti-discrimination at national level failed with states accepting the concept only at a ‘general rhetorical level’.\textsuperscript{516}

7.3. The EU Treaties

The Lisbon Treaty decisively commits the EU to the upholding of human rights in a more forthright manner than previously, as it provides both for the accession to the ECHR by the EU and accords the Charter the same legal value as the treaties of the EU. The adoption of the Charter by the EU in 2000 was an exercise in consolidating and making more visible the rights already protected in various EU statues and treaties.\textsuperscript{517} It represented a significant development in the place of human rights within the EU systems as, prior to Lisbon, the Charter rights did not have full legal effect.

The European Court of Justice (ECJ) has long relied heavily on the jurisprudence of the European Court of Human Rights (ECtHR) as providing general principles of EU law in its adjudications on fundamental rights issues. Nonetheless there has been a perception that human rights were not accorded the status they deserved within the EU legal system and that there is an imbalance between the protections afforded internally within the EU institutions and in its external relations. As stated by deBurca ‘... promotion of human rights is claimed and asserted as a conscious objective of EU foreign policy, there remains an express reluctance to adopt a positive, legally and constitutionally grounded internal Community human rights policy.’\textsuperscript{518} In addition the level of scrutiny applied to the human rights

\textsuperscript{516} ibid p109
standards within the EU by the ECtHR is of a different order – in fact it can be argued a lower standard\(^{519}\) to that applied to other Council of Europe (COE) member states resulting from the famous \textit{Bosphorus}\(^{520}\) case. This case centred on the issue raised where EU member states, in implementing EU law, could as a consequence be in violation of the ECHR. Member states are legally bound to implement EU directives and regulations, but if, in doing so, they are in breach of the ECHR this places such states in a legal dilemma. All EU member states are also members of the COE and have ratified the ECHR as a condition of membership of the EU, thus they are also bound to uphold the ECHR rights and can be held accountable for this. The ECtHR adopted an approach to this issue which is somewhat less stringent than that applied to other COE member states. In the case of the EU and its member states the ECtHR makes a presumption that the EU’s human rights standards were equivalent to those of the COE unless they are proven to be ‘manifestly deficient’ in a particular case – the so-called ‘Bosphorus test’. The court ruled that ‘\textit{If such [comparable] equivalent protection [of fundamental rights] is considered to be provided by the organisation, the presumption will be that a State has not departed from the requirements of the Convention when it does no more than implement legal obligations flowing from its membership of the organisation. However, any such presumption can be rebutted if, in the circumstances of a particular case, it is considered that the protection of Convention rights was manifestly deficient}.’\(^{521}\) The Court then confines itself to a general review of EU human rights protections unless there is a clear or manifest deficiency in such protections in a particular case. According to Kuhnert this means that ‘\textit{On the one hand, the ECtHR clarified its ambition to examine the specific circumstances of future cases in order to effectively review potential shortcomings in the protection of human rights at Community level. On the other hand, this also indicates that the Court will not fully review Community acts, but rather engage in a general abstract review of the Community system}.’\(^{522}\) Prior to the Lisbon treaty there was always a potential for a divergence in the human rights standards of the ECJ and the ECtHR. As highlighted by Groussot et al ‘\textit{... in the absence of formal accession to the ECHR, and strictly speaking, the ECJ has still no jurisdiction to apply...}’


\(^{520}\) Bosphorus v Ireland App. No. 45036/98 (ECtHR, 30 June 2005) para 156

\(^{521}\) \textit{ibid} para 156

the ECHR when reviewing EU law because the ECHR is not itself part of EU law."  

7.3.1 The Lisbon Treaty and the Charter of Fundamental Rights

The passage of the Lisbon treaty marks a significant move forward for human rights standards within the EU. The Treaty provides both for the Charter to be enshrined in EU law and for the accession of the EU to the ECHR. Article 6 of the Lisbon Treaty accords the rights set out in the Charter the same legal value as the EU Treaties. This means that the Charter rights rank above secondary EU law such as Directives and Regulations and are on a par with the treaties - in effect they become part of the binding primary law of the EU. Mathisen suggests that ‘... by not only creating the catalogue of rights contained in the Charter, but by also giving it binding force, the Union lawmakers and the member states have created a legal instrument that, although not technically higher ranking than other provisions of primary Union law, nevertheless appears destined to fill a special role.’ She suggests that the Charter is likely to become the new starting point for addressing fundamental rights issues in the EU. She also points out that one of the consequences of this positioning of the Charter rights in EU law post-Lisbon, is that where there is a direct conflict between fundamental rights and member state national legislation, the greater weight now given to the Charter rights means that fundamental rights ‘trump’ the national legislation.

Article 6 of the Lisbon Treaty also re-affirms the position stated in the Charter itself (at Article 51) that the Charter rights only apply to those area of law which fall within EU competence, and therefore, only to the actions of member states which implement EU law and to the institutions and bodies of the EU. However, EU competence means that it can have a decisive influence on the laws of member states as ‘Unlike rules developed by other international organisations, EU law automatically penetrates the national system, displacing national law that contradicts it.’

For disabled people the Charter is highly significant because they are specifically named as a group to be protected from discrimination (Article 21) and Article 26

identifies integration of people with disabilities and their right to benefit from measures to ensure their independence and participation in the community – closely mirroring Article 19 of the CRPD.

The European Commission published a strategy for the implementation of the Charter in 2010 which aims to ensure that the Charter rights are upheld at all stages of the policy cycle from drafting stage to implementation at EU and member state level. The stated objective of the strategy is that the EU be ‘exemplary’ in the implementation of the Charter’s fundamental rights asserting that ‘The Charter is not a text setting out abstract values, it is an instrument to enable people to enjoy the rights enshrined within it when they are in a situation governed by Union law.’ The strategy includes a ‘Fundamental Rights Checklist’ to be used at each stage of policy development and envisages the production of an annual report on progress towards successful implementation.

7.3.2 The ECHR post Lisbon

Accession to the ECHR by the EU, particularly when taken in conjunction with the new status accorded to the Charter, will be symbolically powerful sending a clear message that the EU takes its role in promoting and protecting the fundamental rights of all its citizens seriously. On a practical level accession will address the issue of external judicial supervision of the ECJ when ruling on fundamental rights issues, thus ensuring a greater degree of convergence between the human rights standards of the EU court and the ECtHR. Groussot and Pech argue that ‘… the most important reason for full EU accession to the ECHR … may be the imperative to guarantee a congruent development of the case law of the ECtHR and the ECJ in the area of fundamental rights. Indeed, EU accession would finally enable the ECtHR to directly review EU measures by allowing natural or legal persons to bring applications against the EU before the Strasbourg Court under the same conditions as those applying to applications brought against national authorities … ’

Accession by the EU to the ECHR has been supported by the revision of Protocol 14 of the ECHR in June 2012, which allows, at Article 17, for such accession. Any divergence in interpretation of the rights detailed in the ECHR and the Charter is

527 ibid p3
528 ibid p5
dealt with in Article 52 of the Charter which states that ‘In so far as this Charter contains rights which correspond to rights guaranteed by the Convention for the Protection of Human Rights and Fundamental Freedoms, the meaning and scope of those rights shall be the same as those laid down by the said Convention. This provision shall not prevent Union law providing more extensive protection.’

The process of acceding to the ECHR has begun with the publication of a draft accession agreement by the COE Committee for Human Rights (CDDH) which includes, in equal numbers, representatives of EU member states and representatives of COE member states which were not members of the EU. The process of accession is long and arduous including, as highlighted by Groussot and Pech, gaining the unanimous agreement of the EU Council of Ministers and consent from the European Parliament to the accession agreement, approval by each member state and approval from each of the contracting parties to the ECHR.

In a legal analysis of the draft accession agreement between the EU and the COE Groussot et. al. discuss the major issues arising from the proposed accession. These include the role of the ECtHR in reviewing primary EU law, the future of the ‘Bosphorus test’, the autonomy of the EU legal order and the jurisdiction of the ECJ. They conclude that although there are a number of outstanding, mainly procedural issues, to be resolved and the fact that the draft agreement is silent on the future of the Bosphorus test, that ‘... the draft accession agreement manages to preserve the autonomy of EU law and it is obvious that its drafters took great pains to guarantee compliance with the requirements laid down in EU Protocol No. 8. Firstly, the accession agreement does not create new competences for the EU. Secondly, the co-respondent mechanism largely ensures that cases will be correctly directed either against the EU or its member states. Finally, the autonomy of the EU’s legal order and the ECJ’s position as the ultimate guardian of EU law are preserved.’

533 ibid p16
7.4. The CRPD and EU law

In addition to the above the Treaty of Lisbon conferred legal personality on the EU, thus enshrining the right of the EU to enter into international agreements. Article 216 of the Lisbon Treaty enables the EU to conclude agreements with international organisations and provides that such agreements shall be binding both on the institutions of the EU and on the member states. As noted, the CRPD is the first international agreement ratified by the EU and it has been signed and/or ratified by all of the member states of the EU. The CRPD at Article 44 provides the basis for its ratification by ‘regional integration organisations’ to which member states have transferred competence, and, given the prominent role played by the EU in the convention negotiations, this provision can be seen as specifically tailored to include the EU.

The CRPD is a ‘mixed’ agreement as the obligations arising from it fall variously within the competence of the EU and the member states. Quinn and Doyle point out this means that ‘... the EU is bound by all provisions of the treaty which fall within its sphere of competence. As a result of the EU’s agreement, and in addition to their obligations as State parties to the treaty, Member States have an EU law obligation to implement the treaty to the extent that its provisions are “within the scope of Community competence.” Therefore, Member States which do not comply with the obligations arising from such mixed agreements have not only breached international law but EU law also.’ They suggest that this can be seen as a version of the ‘duty of loyal cooperation’ whereby member states and the EU are obliged to assist each other in fulfilling their obligations and refrain from any actions which would hinder the fulfillment of such obligations.

The legal bases upon which the CRPD was negotiated and ratified by the EU are Articles 13 and 95 of the Treaty of Amsterdam. Article 13 refers to actions to combat discrimination and is the only place where disability is mentioned in the EU treaties. Article 95 deals with the operation of the internal market. Ferri argues that the choice of these two legal bases for negotiating and ratifying the CRPD are appropriate because, firstly, ‘Article 13 EC, addressing discrimination on a number of grounds including disability, was the provision that best reflected the UN CRPD’s main purpose. In addition ... Article 13 was the only Article in EC Treaty


535 Treaty of the European Union Article 4(3)
which conferred upon the Community explicit powers regarding disabilities.\textsuperscript{536}

Secondly, the internal market is a broad concept which includes the removal of all types of barriers to trade and has been used as a basis for instruments in many areas. As Waddington\textsuperscript{537} highlights many of the Article 95 instruments developed to address barriers to trade have had a specific disability-related dimension including those dealing with passenger transport, lifts and radio and telecommunication terminal equipment. The fact that anti-discrimination and the internal market were adopted as the legal bases for the CRPD ratification, however, does not mean that its implementation is confined to these two areas. Ferri suggests that as a result of a ruling from the ECJ in 2006\textsuperscript{538} that ‘This means that Treaty provisions other that those mentioned in the Council decision can be chosen as legal bases to implement the Convention obligations in specific fields.’\textsuperscript{539}

\subsection*{7.4.1 Status of the CRPD in EU law}

The CRPD stands below the provision of the EU Treaties and above secondary EU law, which includes regulations and directions and other legislation enacted by the EU institutions. Article 300 of the Treaty of Amsterdam enables the EU to conclude agreements with international organisations and provides that ‘Agreements concluded under the conditions set out in this Article shall be binding on the institutions of the Community and on Member States.’\textsuperscript{540} The ECJ ruled in 2004 that such agreements prevail over secondary legislation\textsuperscript{541} and earlier in 1996 the Court ruled in The Commission v Germany that ‘When the wording of secondary Community legislation is open to more than one interpretation, preference should be given as far as possible to the interpretation which renders the provision consistent with the Treaty. … [t]he primacy of international agreements concluded by the Community over provisions of secondary Community legislation


\textsuperscript{538} Case C-178/03 Commission of the European Communities v European Parliament and Council of the European Union [2006] ECR I-107


\textsuperscript{540} Treaty of Amsterdam Article 300(7)

\textsuperscript{541} Case C-344/04 European Court of Justice International Air Transport and European Low Fares Airlines Association v Department of Transport [2004] para 35
means that such provisions must, so far as is possible, be interpreted in a manner that is consistent with those agreements.\textsuperscript{542} In effect this means, according to the European Foundation Centre\textsuperscript{543}, that ratification obliges the EU to interpret its laws in a manner consistent with the CRPD. All directives, regulations and agreements must be drafted so as to take full account of the content of the CRPD rather than considering disability as an add-on or passing reference. In addition Article 4 of the CRPD requires state parties, including the EU, to abolish or modify any existing legislation which discriminate against disabled people. The pressure to implement the CRPD then comes both from the EU’s own existing legislation and case law and from the CRPD itself. Ferri suggests that the CRPD seems likely to become part of the fundamental constitutional core law of the EU.\textsuperscript{544} However, the role of the ECJ in interpreting legislation cannot be under-estimated, and as discussed below, the Court has already delivered quite a conservative ruling in relation to the definition of ‘disability’.\textsuperscript{545} Ferri goes on to highlight that, ‘[t]he ECJ’s recognition of the constitutional value of the UN CRPD, if this comes to pass, will not be sufficient. For that matter, there is no guarantee that the Court’s rulings will be always in line with the UN CRPD. Although the ECJ plainly sees its role as that of a guarantor of fundamental rights, the balancing of competing interests may lead to different outcomes in different cases.’\textsuperscript{546}

7.4.2. Obligations arising from Article 19
Specifically in relation to Article 19 of the CRPD, Quinn and Doyle outline the obligations on the EU in implementation as follows:
1. The closure of all institutions for people with disabilities and ensuring that community-based alternatives do not replicate old institutional practices.
2. Ensuring that the right to IL and community inclusion applies to all disabled people regardless of the degree or type of impairment
3. Close involvement of disabled people in the development of plans and policies

\textsuperscript{542} Case C-61/94 Commission of the European Union v Federal Republic of Germany [1996] para 52
\textsuperscript{543} European Foundation Centre Study on the Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons with Disabilities, Brussels, EFC, October 2010 VC/2008/1214 p31
\textsuperscript{545} See Case C-13/05 Chanon Navas v Eurest Colectividades SA [2006]
to achieve the ends of Article 19.

4. Ensuring that disabled people have effective access to the same housing choices as others, subject only to the same limitations as others. Article 19’s aim is not to increase standards in housing but to ensure that disabled people have access to a home which reflects their personal choices and allows for the development of personhood.

5. The development of support services which are personalised and designed around the real needs of the individual and which maximise opportunities for engagement in the community. Individualised budgets or direct payments are not essential in achieving this end.

6. The progressive development of community-based services and an opening up of generic services which are responsive to the needs of disabled people.547

It is clear that the progressive realization of all of the elements of Article 19 by the EU and the member states will require planning and resources and that such plans must have definite targets and time-frames. It has been proposed548 that the EU Structural Funds be used as a support for the transition from institutional provision and the development of genuinely inclusive services and supports in the community. In fact, Parker and Clements suggest that ‘... the “progressive realization” obligation under Article 4(2) requires all States Parties, including the European Commission, to elaborate a “community living” plan. This must include a strategy and action plan for the closure of long-stay institutions ...’ 549 They also suggest that the use of Structural Funds to perpetuate any form of institutionalisation of disabled people would be ‘... manifestly unlawful and in breach of the high measure of protection against discrimination that EU law now accords to persons with disability.’550

548 ibid p30
550 ibid p12
7.5. The EU Directives

The Treaty of Rome provides at Article 189 for the issuance of Directives and Regulations to member states by the European Commission and the European Council. Regulations have general application, are binding in their entirety and are directly applicable in member states. Directives, on the other hand, are binding on member states as to the results to be achieved but leave to each state the methods by which the results are to be realized. While Regulations do not require the passing of legislation at national level, Directives may require new legislation or legislative changes by member states to ensure implementation in full. Directives thus give greater autonomy to member states as to the means adopted and they have a timeframe within which they must be implemented at national level. The EU has chosen to issue a Directive to outlaw discrimination in employment and is currently considering a second directive to prohibit discrimination in areas outside of employment. The fact that the EU chooses to implement its anti-discrimination law by way of Directives is, according to a 2008 study for European Commission on discrimination in areas outside of employment ‘...more realistic, in particular in view of the differences in public policy and distribution of funds to various beneficiaries between Member States. This also includes variations in legal rights...’

The Framework Employment Directive (FED) provides protection from discrimination for disabled people and other groups in the area of employment and training. The draft Equal Treatment Directive (ETD), first proposed in 2008, is designed to extend this protection to areas outside of employment. The draft ETD has been the subject of much debate and negotiations and at this stage seems to have stalled and, according to Waddington it seems unlikely that it will be adopted due to a lack of enthusiasm or outright opposition from member states. The drafting of the original proposal was significantly influenced by the CRPD with the staff working document to the Commission, which accompanied
the proposal, noting that it is ‘... part of the baseline scenario ...’\textsuperscript{555} for the EU and that it will have to be implemented by both member states and the EU. It is possible to detect the influence of the CRPD in the draft ETD particularly in the areas of how disability is defined, accessibility and reasonable accommodation. The development of the draft ETD represents an acknowledgement of the gap which exists in EU anti-discrimination law in relation to protections outside the area of employment for many groups of people. A study completed for the European Commission Directorate General Employment, Social Affairs and Equal Opportunities in 2008 estimated that there 84.4 million people with disabilities in the EU i.e. 17.1% of the total population. This report also noted that ‘There is no doubt that discrimination in accessing goods and services is a problem in the current situation in the EU for individuals belonging to – or being perceived as belonging to – the grounds covered .... Surveys with potential victims, i.e. persons belonging to these groups, confirm that discrimination is a widespread phenomenon across the EU.’\textsuperscript{556}

Both the FED and the draft ETD outline a general framework to combat discrimination on the grounds of religion or belief, disability, age or sexual orientation in their respective fields. Neither provide definitions of the grounds covered which, in the sphere of disability at least, presents particular problems and which has resulted in ECJ interpreting the concept of disability through its case law.

The fundamental purpose of the FED is to improve employment opportunities for PWD and the other protected groups. In this it is not proposing any special advantages be given to any of the groups, rather, as pointed out by Whittle, it seeks to ‘impose on employers no more than a duty to act fairly when making employment related decisions; its manifest purpose being, therefore, to implement and promote the principle of equality, not to deviate from it.’\textsuperscript{557} This means that employers are obliged to offer jobs based solely on the ability of candidates to do the job and are prohibited from taking into account any matters related to (or

\textsuperscript{556}European Policy Evaluation Consortium Study on discrimination on grounds of religion and belief, age, disability and sexual orientation outside of employment. Final report to the European commission, DG Employment, social affairs and equal opportunities. Brussels, EPEC (June 2008) p 4
perceived as being related to) a particular group when these are irrelevant. The FED is, therefore, designed to operate within a system based on meritocracy and formal equality, relying principally on the prohibition of discrimination to achieve this.

The purpose of the draft ETD is different from the FED in that access to goods and services is not based on any system of merit. Its fundamental purpose is to make accessible all goods and services which are available to the public to all of the protected groups. A significant advance on the FED is the obligation placed on services providers in the draft ETD to anticipate the access needs of disabled people in Article 4, which refers to Equal Treatment of persons with disabilities. It opens up the possibility for member states to adopt an approach espousing the ‘fourth generation’ concept of equality, though this only applies to people with disabilities and leaves untouched the other covered groups. There are dangers inherent in this as it may contribute to the perception that PWD are being singled out for ‘special’ treatment. This is problematic particularly where other groups experience problems with accessing services which, although perhaps different in nature, are nonetheless equally discriminatory. This is a serious flaw which could have negative consequences for people with disabilities as a group and arguably makes redundant the claim that this provision is in fact a fourth generation approach to equality. Article 4 elaborates what the principle of equal treatment means in relation to disabled people stating that ‘...effective non-discriminatory access to social protection, social advantages, health care, education and access to and supply of goods and services which are available to the public, including housing and transport, shall be provided by anticipation including through appropriate modifications or adjustments.’ This provision is limited by the ‘disproportionate burden’ and ‘fundamental alteration’ clauses more usually associated with the reasonable accommodation duty and by a further justification that the duty should not require the provision of alternative means of accessing the service.

These provision has been roundly criticized by disability advocacy groups as abandoning the equal treatment principal, firstly, on the basis that the possible justifications for not providing access by anticipation are too extensive and secondly, because it confuses the individualized reasonable accommodation duty

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with the broader anticipatory duty. Bell also strikes a note of caution when he points out that the draft ETD does not specify how this anticipatory duty should be enforced in the absence of an individual complaint and points out that there is no provision in the proposed directive for legal standing for equality bodies to act where there is evidence of service providers failing in this duty. He suggests that ‘If the anticipatory duty only bites in reaction to an individual complaint, then it adds little to a duty to provide reasonable accommodation.’\(^{559}\) Nonetheless the duty to provide access by anticipation indicates a willingness on the part of the EU to adopt a more pro-active approach to equality and holds the potential for more far-reaching advances in accessibility of goods and services for PWD across the member states than heretofore. Waddington suggests that ‘It is clear that the intention is that providing accessibility should involve more than an individualised response to the needs of a particular person, as and when those needs arise, but require anticipation of the likely access needs of the group of people with disabilities as a whole, and the taking of steps to meet those needs.’\(^{560}\)

Neither the FED nor the draft ETD address the issue of multiple discrimination i.e. where an individual is discriminated against on the basis of more than one of the grounds listed. This phenomenon is well recognized and it is somewhat surprising that in the explanatory memorandum accompanying the proposed ETD it is dealt with summarily as being beyond the scope of the directive.\(^{561}\) It is also interesting that the explanatory memorandum specifically notes that a report by the European Network of Independent Experts on the issue of multiple discrimination was used in preparing the draft proposal. This report recommends to the European Commission that the new EU anti-discrimination legislation (i.e. the draft ETD) should ‘…provide provisions to address intersectional discrimination…[including] the introduction of specific provisions to combat Multiple Discrimination…’\(^{562}\) The European Parliament too, in its comments on the proposed directive, suggested the inclusion of multiple discrimination within its

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\(^{562}\) European Commission Tackling Multiple Discrimination: practices, policies and laws. Luxembourg, DG for Employment, Social Affairs and Equal Opportunities (September 2007) p53
ambit and suggested a definition of the term encompassing both the listed grounds and race and gender. Bell comments that ‘A Directive dealing simultaneously with four grounds of discrimination seems entirely apt for addressing the question of multiple discrimination and there is no apparent question of legal competence which would restrain the EU from legislating in this direction.’

This is an area which remains to be developed further within EU law but as it stands at present multiple discrimination remains unrecognized and unaddressed.

7.6. Definition of Disability in EU law

There is a persuasive argument to be made that the focus of anti-discrimination should be on eliminating discrimination wherever it occurs, rather than of defining what groups are protected. This argument posits the view that discrimination against anyone, regardless of group membership, is unjust and the law’s role should be to respond to the discriminatory act not to any actual or perceived traits of the victim. Anti-discrimination law is based on the assumption that the individual has the capacity to participate in employment or other areas of social life and that individual acts or discriminatory barriers to participation should be removed, thus there is no need to describe the group(s) protected as the law should apply to everyone.

The symbolic power of disability discrimination law should not be underestimated and the message it sends to the general public about how PWD should be treated can have a major impact both on individual disabled people and on the cultural conceptions of disabled people. In this context it would appear that defining disability is necessary despite the seeming advantages of avoiding definition. The extent to which such definitions support a medical or social approach to disability varies. A comparative analysis of definitions used across the EU member states completed in 2002 suggests that there is ambiguity in anti-discrimination law about which people with disabilities it is designed to protect – those with relatively minor impairments or those with substantial

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564 European Commission, Definitions of Disability in Europe; A comparative analysis Brunel University, DG Employment and Social Affairs, European Commission (September 2002) p67
impairments.
The absence of a definition of disability in the FED and the draft ETD could be said
to be advantageous in that it draws attention to the discriminatory act ‘on the
ground’ of disability as opposed to focusing on the disability itself – and this is,
after all, the main purpose of the legislation i.e. to outlaw any acts of unfair
discrimination which are based on negative stereotyping or prejudices. Quinn
highlights that this construction in the directive has the potential to encompass
discrimination experienced not just by disabled people themselves but also by
people associated with a disabled person, people who are assumed to have a
disability and people who are susceptible to developing impairments at a later
stage. He suggests that ‘To limit the benefits of anti-discrimination law to certain
kinds of disability or to disabilities reaching a certain degree would not appear to be
consistent with the underlying goals of the Directive.’

Reiterating that the purpose of anti discrimination law is to prevent unequal
treatment based on stereotypes and stigma, Degener proposes that rather than
ignoring impairment any legal definition supportive of the social model must
make reference to impairments as ‘Disability-based prejudice and stigma are
always related to an actual or presumed abnormality called impairment or chronic
illness.’ This type of discrimination is quite specific to disability and as such
requires definition. The significant aspect of disability discrimination is people’s
reaction to impairment, and it is this reaction (rather than the impairment or the
individual with impairments) which needs to be addressed by anti-discrimination
law. This requires that the definition be sufficiently broad to encompass
stigmatizing reactions to all perceived, actual or predicted impairments.
Confining protection to only those with substantial impairments means that
people with relatively minor impairments which do not impact on their ability
to carry out everyday daily functions, but which nonetheless illicit negative
reactions, have no means of legally challenging the impact of stigma or prejudice
arising from their impairments. A narrow definition also forces victims of
discrimination arising form negative reactions to impairments to prove that they
the fit category - that they are disabled enough - to deserve protection, rather than

Press, Cambridge p249
566 Degener, T. Definitions of Disability, (August 2004) Network of Experts on Disability
Discrimination p5
www.nuigalway.ie/law/Disability_summer_school/Docs/2006/Marc%20De%20Vos%20Teaching%
focusing on the act of discrimination. Therefore, where the definition is narrow it tends to re-enforce a medical model implying that discrimination only occurs where there is a certain level of impairment, thus locating the problem within the individual. Degener concludes that anti-discrimination law should include a definition of ‘disability-based’ discrimination and that such a definition should ‘...be related to impairment, chronic illness or malfunctions, should not be based on a certain severity of disability, should cover past, present, future and imputed impairments or chronic diseases and associates.’

Neither the FED nor the draft ETD include a definition of disability and in the negotiations leading to the CRPD the EU representatives resisted the notion of defining disability, only dropping their opposition following the ECJ decision in the Chacon Navas case where ‘disability’ was, in fact, defined, albeit it a limiting way.

A significant consequence of the decision not to include a definition of disability in the Directives was that it then fell to the ECJ to elaborate what it means in the context of cases brought before it – and as a result excluding the drafters and negotiators from this crucial decision. The rationale behind the decision not to define disability in the Directives appears to have been to allow member states leeway to develop their own national definitions. Bell suggests that the failure to provide a definition of disability in the draft ETD represents a ‘...missed opportunity to give the Court a clearer steer on how it should interpret the concept of disability’. And comments by the European Parliament on the proposed ETD recommend inserting a definition based on that provided by the CRPD, which is more in line with the general trend of disability law and policy internationally. The proposal from the Parliament is that the category ‘disabled people’ should be defined as including ‘... those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, whether environmental or attitudinal, may hinder their full and effective participation in

568 Case C-13/05 Chacon Navas v Eurest Colectividades SA [2006]
society on an equal basis with others.\textsuperscript{570} This definition is almost identical to that included in the CRPD, and even though the proposal is only to include it in the recital to the draft ETD, nonetheless, it could have an important impact particularly in how the ECJ interprets ‘disability’ in the future.

7.6.1 European Court of Justice, Definition of Disability

In the absence of a definition of disability in EU legislation it has fallen to the ECJ to develop one, and the \textit{Chanon Navas} case in 2006 is very significant in this. In this case a Spanish woman had been dismissed from her job following prolonged sick leave. The applicant challenged her dismissal on the grounds that it was contrary to the FED. The Spanish court referred the matter to the ECJ to ascertain whether sickness was covered by the Directive as part of the disability ground or, if not, whether sickness could be included as an additional protected ground. The court found that sickness could not be taken to equate with disability – noting that the drafters of the legislation deliberately chose the term ‘disability’ which is different from ‘sickness’. The Court reiterated that the FED prohibits discrimination on the basis of disability and obliges employers to make reasonable accommodation for an employee who would be able to do the job if this was provided. However, the court stated that for any limitation to fall within the concept of ‘disability’ it must be probable that it will last a long [though unspecified] time, stating that ‘There is nothing in Directive 2000/78 to suggest that workers are protected by the prohibition of discrimination on grounds of disability as soon as they develop any type of sickness\textsuperscript{571}. The court provided the following definition of ‘disability’: ‘...the concept of ‘disability’ must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life.’\textsuperscript{572} Referring to the need for EU law to have a general framework for combating discrimination the court stated that the definition provided must be given a ‘uniform and autonomous interpretation’\textsuperscript{573} throughout the member states i.e. it should be applicable in all member states.

This judgment is disappointing on several fronts, although as the only ECJ case

\textsuperscript{570} European Parliament, legislative resolution of 2 April 2009 on the proposal for a Council directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, P6_TA(2009)0211 Amendment 17

\textsuperscript{571} Case C-13/05 \textit{Chanon Navas v Eurest Colectividades SA} [2006] para 46

\textsuperscript{572} \textit{ibid} para 43

\textsuperscript{573} \textit{ibid} para 42
referring to the definition of disability, it is the standard by which potential applicants to the court must now abide until such time as a more expansive definition emerges, which, in the light of accession by the EU to the CRPD may happen relatively soon.

The definition appears to adhere to a medical model of disability, locating the problem in the person’s impairment which is hindering his/her participation in professional life, rather than on discriminatory acts. The definition also means that victims of discrimination must first prove that they fit the category of ‘disabled’ provided in order to claim protection from discrimination. The court judgment left undefined the length of time an impairment must be present which presents the difficulty that ‘It therefore seems that a person who has a temporary disability may not be protected from discrimination. Should such a person be dismissed, perhaps before long-term implications can be identified, it seems that this is compatible with Community law.’

Waddington suggests that the statement by the Court that the definition should be ‘autonomous and uniform’ throughout the EU could impact on the opportunities of member states to develop or maintain their own definitions which are perhaps more expansive, leading to the adoption of more limited definitions than already exist in some states – apparently clashing with the non-regression clause of the FED. She also suggests that ‘...by embracing the medical model of disability, and focusing on the limitation caused by impairment and the need to prove such limitation, the Court’s decision flies in the face of values underlying the Directive and Community disability policy, and may thereby create barriers to achieving the goals of the Directive.’ However, elsewhere she is more hopeful that if the draft ETD directive is amended in line with the proposal from the European Parliament to include a definition akin to that in the CRPD that this could have an important influence on Court decisions. She suggests that ‘While, technically speaking, the definition would only apply to the new Directive, and not the older Employment Equality Directive, one could expect the Court to pick up (quietly) on the message being sent.

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576 ibid p 496
7.7. Discrimination and EU law

The CRPD defines discrimination on the basis of disability at Article 2 as ‘... any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.’

The definition of discrimination in both the FED and the draft ETD include a) direct discrimination, b) indirect discrimination, c) harassment and d) instruction to discriminate. The proposed ETD also includes the denial of reasonable accommodation as a form of discrimination specific to disabled people, reflecting the CRPDs definition. The Charter is less specific providing a broad prohibition of discrimination at Article 21, but it does not offer a definition of what constitutes discrimination.

7.7.1. Direct and Indirect Discrimination

Direct discrimination in both the draft ETD and the FED is defined as occurring where ‘...where one person is treated less favourably than another is, has been or would be treated in a comparable situation, on any of the grounds referred to in Article 1.’ Direct discrimination in the directives reflects the classic individual justice or formal equality model. It prohibits service providers and employers from treating one individual less favourably than another on the basis of prejudice and it would appear to be relatively uncontroversial. Intuitively treating everyone equally seems morally, legally and politically correct. For people with disabilities, however, it does present a difficulty as proving direct discrimination involves comparing the treatment of one person with that of another person similarly situated. And where the type of discrimination is specific to disability, locating an appropriate comparator may be difficult. For example, if the health care received by a physically disabled person for illnesses connected to his impairment is poor, who then is the appropriate person to compare his treatment with? Should this be a non-disabled user of the same health service, a person with a different disability using the service? Whittle\textsuperscript{578} suggests that this is, in fact, addressed in the FED by the use of the terms ‘has been’ or ‘would be’ in the definition, thus

allowing the use of an actual or hypothetical comparator.

The concept of indirect discrimination, which moves towards a group-based or substantive equality model, recognizes that treating everyone the same may not equate with equality, but that in fact entrench existing inequalities where structures and policies are their cause. It holds the potential to achieve powerful and far-reaching change by tackling the underlying structures and systems which unfairly disadvantages people on the basis of their membership of specific groups. The inclusion of the prohibition of indirect or disparate impact discrimination in the FED and the draft ETD is an acknowledgement of structural discrimination and an attempt to deal with it. Both define indirect discrimination as occurring ‘...where an apparently neutral provision, criterion or practice would put persons having a particular religion or belief, a particular disability, a particular age, or a particular sexual orientation at a particular disadvantage compared with other persons...’

However, as highlighted by DeSchutter, proving indirect discrimination can also be problematic for victims of discrimination particularly as ‘...it requires the reliance on a specific methodology, based on the collection and analysis of statistical data, which may be particularly burdensome or even unavailable to victims of discrimination.’ Both directives allow for the use of statistical data to establish that indirect discrimination has occurred. DeSchutter explores the issues involved in demonstrating the disparate impact of particular measures on identified groups as compared to the general population. These issues, which could limit the effectiveness of indirect discrimination cases, include, firstly, proving indirect discrimination necessarily involves comparison of the impact of particular measures on different groups. In the case of people with disabilities at least (but also for others of the protected groups) such statistical evidence may be inaccessible or simply not available because of inadequate or non-existent monitoring. Secondly, the ‘particular

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disadvantage’ condition in the definition implies that all or most members of the group share certain common characteristics and that these are sufficiently well known. Very often such is not the case – in relation to the group called ‘people with disabilities’ there are vast differences in traits, characteristics and experiences and the only trait shared universally by group members of that of having some form of impairment. The ‘particular disadvantage’ clause may also add to the conformist pressures referred to by Fredman.  

That is, whether the victims of indirect discrimination arising from the application of an apparently neutral measure could have avoided being discriminated against by changing their behaviour or making alternative choices which conform to societal norms – thus possibly abandoning some of the traits or lifestyle choices associated with their group membership. This scenario may be more likely to occur in relation to ethnicity, sexual orientation or religion, but could also impact on people with disabilities. For example would it be possible for the authors of a particular suspect measure to argue that deaf people should/could acquire lip reading skills in addition to sign language so that they can access employment or other services?

The indirect discrimination provision in the FED is limited by three justifications namely, that measures which, although indirectly discriminatory, may continue to exist if they serve a legitimate aim, are necessary and proportionate (both of which are also present in the proposed ETD) and where employers are obliged under Article 5 to provide reasonable accommodation to a particular individual. Gooding and Casserley point out that ‘The scope of legal ‘justifications’ for potentially discriminatory treatment will be a powerful determinant of both the symbolic and instrumental efficacy of the law.’ What exactly constitutes a legitimate aim or a necessary and proportionate measure is not specified in either the FED or the proposed ETD.

Whether justifications such as those allowed for in Irish anti-discrimination law, would be permissible with the implementation of the draft ETD is debatable, however, the leverage allowable to member states as to the method of implementation of the FED would appear to indicate that there could be

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585 The Equal Status Act 2000 allows for numerous circumstances where neither the direct nor indirect discrimination provisions apply - for example in Section 5.2(i) differences in treatment on the basis of disability, age or gender is allowable for reasons of authenticity, aesthetics or tradition in relation to dramatic performances or other entertainment.
considerable variation in how its provisions are implemented across Europe. Waddington points out, in relation to the FED, that the considerable margin of appreciation allowed to member states in implementation, means that it is to be expected that there will be significant differences between member states’ methods of implementation. She also highlights the ‘...importance of national ‘peculiarities’, which can result in unusual and unconventional approaches to implementation of specific provisions of the Framework Employment Directive.’

The purpose of the prohibition on indirect discrimination is to root out the structural causes of discrimination thus benefiting all those impacted by the suspect measure. There is a danger, however, that the interaction of the indirect discrimination and the reasonable accommodation measures in the directives could have the unintended consequence of remedying the situation for a specific individual while leaving untouched the structural factors which caused the unfair treatment – and therefore any potential benefits to the group remain unrealized.

7.7.2 Discrimination by Association

The ECJ, in the Coleman\textsuperscript{587} case, ruled that discrimination by association is also covered by the FED, although it is not specifically mentioned in the Directives text. Ms Coleman was employed by Attridge Law firm in London and following the birth of her disabled son in 2002 she became the primary carer of the boy. She alleged that she had been treated less favourably than employees with non-disabled children and had been subjected to harassment by her employer. She lodged a claim with the Employment Tribunal in the UK alleging that she had been discriminated against because of her son’s disability, not her own. The Tribunal referred the case to the ECJ as the UK Disability Discrimination Act only provided protection to those who themselves have a disability, not to those who are discriminated against because of their connection with a disabled person. The FED prohibits discrimination ‘on the grounds of’ disability in the employment sphere, as such, the Court found that it is the nature of the discrimination rather than any particular category of person that is at issue. Reiterating the fundamental purpose of the FED the Court stated ‘...the purpose of the directive, as regards employment and occupation, is to combat all forms of discrimination on


\textsuperscript{587} Case C-303/06 S. Coleman v Attridge Law and Steve Law [2008]
grounds of disability. The principle of equal treatment enshrined in the directive in that area applies, not to a particular category of person, but by reference to the grounds mentioned in Article 1.\textsuperscript{588} This implies that employees who are not themselves disabled, but who are discriminated against because of their connection with a disabled person, are also covered by the FED. Excluding people who experience such discrimination from the scope of the directive would, according to the Court, deprive it of much of effectiveness in achieving its aim. The Court commented that the Directive ‘...must be interpreted as meaning that the prohibition of direct discrimination laid down by those provisions is not limited only to people who are themselves disabled. Where an employer treats an employee who is not himself disabled less favourably than another employee is, has been or would be treated in a comparable situation, and it is established that the less favourable treatment of that employee is based on the disability of his child, whose care is provided primarily by that employee, such treatment is contrary to the prohibition of direct discrimination laid down by Article 2(2)(a).’\textsuperscript{589}

Thus the concept of discrimination by association is now included in the definition of disability as interpreted by the ECJ. This broadens the scope of EU non-discrimination law in relation to disability and the concept should be applicable across each of the grounds covered by the FED, the race Directives and the gender Directives. Eriksson\textsuperscript{590} highlights two areas which remain to be clarified by the ECJ in relation to discrimination by association as defined in the Coleman judgment: 1) The nature of the association between the person with disability and the victim of discrimination. This case concerned a parent-child relationship, it is not yet clear whether similar protection can or will be extended to other relationships. 2) Whether indirect discrimination by association is also prohibited by the FED.

7.8 Reasonable Accommodation
The importance of the concept of reasonable accommodation for the inclusion of people with disabilities in society cannot be underestimated. Reasonable accommodation shifts the obligation on to society to adjust its means of operation in order to facilitate access for disabled people – rather than obliging the disabled

\textsuperscript{588} \textit{ibid} para 38
\textsuperscript{589} \textit{ibid} para 56 2(a)
\textsuperscript{590} Eriksson, A. ‘European Court of Justice: Broadening the scope of European nondiscrimination law’ (2009) Vol. 7, No. 4 \textit{International Journal of Constitutional Law} pp 731 - 753
person to either adjust to the existing structures or remain excluded. The obligation, which applies on a case-by-case basis, urges employers and service providers to explore ways of enabling a specific individual with disability use their service or enter into their employment. Its inclusion in the FED represents according to Lawson ‘...a significant deepening and enriching of the principal of equal treatment which underlies EC equality law.’ An important consequence of the inclusion of the obligation to make reasonable accommodation is that it gives people with disabilities legal standing to challenge the manner in which they have been accommodated (or not) in the workplace.

Article 5 of the FED obliges employers to make reasonable accommodation for individuals with disabilities in particular cases in order to comply with the equal treatment principal. Reasonable accommodation is defined as ‘…appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.’ The trigger to provide reasonable accommodation is, therefore, ‘when needed in a particular case’ which would appear to make this quite an open-ended and extensive duty. Gooding and Casserley, however, suggest that ‘This terminology undermines the principle of inclusivity. It detracts from the obligation to ensure access and focuses instead on a conception of disabled people as ‘special’ and, as such, in need of ‘special treatment’, rather than adjustments which may benefit the whole of society and which are required in the interests of broad inclusivity.’

While the FED imposes a reasonable accommodation duty on employers it does not describe a failure to do so as discrimination – although this may appear to be the logical outcome. The draft ETD resolves this issue by ensuring that denial of reasonable accommodation is recognized as a form of unlawful discrimination reflecting the position of the CRPD. Article 4 of the draft ETD appears to address both positive duties and reasonable accommodation in relation to people with

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disabilities. It outlines that effective non-discriminatory access to goods and services should be provided by anticipation - seemingly paving the way for positive duties – and goes on to state 'Notwithstanding the obligation to ensure effective non-discriminatory access and where needed in a particular case, reasonable accommodation shall be provided unless this would impose a disproportionate burden.' Including both concepts in the same article could lead to confusion at implementation stage as they are quite distinct and serve different purposes – reasonable accommodation addresses individual measures and anticipatory duties addresses measures applicable to people with disabilities in general. This Article therefore appears to serve two purposes – on the one hand requiring service providers to anticipate the needs of disabled customers in advance and on the other, to make any reasonable adjustment to their service to facilitate access by particular customers with disabilities. Bell\(^\text{593}\) points to a weakness of this article when he suggests that the lack of clarity about how or by whom the anticipatory duty should be enforced could result in a reliance on individual complaints as a trigger – a process which a positive obligations approach is designed to avoid.

A potential limit on the usefulness of the concept reasonable accommodation in EU legislation is its interaction with the indirect discrimination provision. While the concept of reasonable accommodation is widely recognized as being potentially a very powerful tool for disabled people, its use as an alternative to amending rules or practices which adversely impact on people with disabilities is, as discussed earlier, an obvious means of limiting the effectiveness of the indirect discrimination clause in EU legislation. This issue arises from what Whittle terms the ‘second unless’ clause at Article 2(2)(b)(ii) of the FED whereby a policy or practice causing indirect adverse impact on people with disabilities may remain in place if the employer provides reasonable accommodation to the particular individual. Whittle points out that ‘...whilst this clause does not prevent an individual from addressing his/her own particular concerns, the operation of the relevant provision, criterion or practice will still be allowed to continue provided that the individual in question can and should be accommodated...... One effect of the “second unless” clause, therefore, is to remove any group benefits that may have

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otherwise accrued from a successful action in this regard.\textsuperscript{594}

Overall the challenge to reasonable accommodation suggests that in accommodating a specific individual, the structures which are causing the exclusion can remain untouched and that reasonable accommodation only really belongs in the formal equality or individual justice model of equality. Suggesting that providing reasonable accommodation is assimilationist Day and Brodsky object that 'The difficulty with this [accommodation] paradigm is that it does not challenge the imbalances of power, or the discourses of dominance, such as racism, ablebodyism and sexism, which result in a society being designed well for some and not for others. It allows those who consider themselves 'normal' to continue to construct institutions and relations in their image, as long as others, when they challenge this construction, are 'accommodated' ... . Accommodation does not go to the heart of the equality question, ... Its goal is to try to make 'different' people fit into existing systems.'\textsuperscript{595} It is however, arguable that the inclusion of the anticipatory duty in the draft ETD moves some way towards a more expansive concept of equality and, in combination with the obligation to provide reasonable accommodation and its denial defined as discrimination, can be seen as a definite evolution in anti-discrimination and equality law within the EU.

Article 5 of the FED set out the limits to the reasonable accommodation duty i.e. that the accommodation should not impose a disproportionate burden on the employer. This is also included in the CRPD definition and in Article 4 of the draft ETD. The draft ETD specifies two further limits on the duty to provide reasonable accommodation i.e. that the accommodation should not require a fundamental alteration of the service or the provision of an alternative thereto. While the FED states only that the burden on employers will not be considered disproportionate if it can be offset by other measures within the member state’s disability policy, the proposed ETD is more specific in its definition. The draft ETD states that the assessment of whether a particular accommodation is disproportionate must take account of the size and resources of the organisation, its nature, the cost, the life cycle of the goods and services and the possible benefits of increased access for people with disabilities. Whittle\textsuperscript{596} points out that the duty to accommodate must

also take heed of other adaptations/accommodations employers are obliged to make in order to comply with other legislation such as health and safety – which they are obliged to fulfill regardless of cost. The purpose of reasonable accommodation is to remove barriers to participation for people with disabilities and in this context, as suggested by Waddington, it is important to ensure that the ‘reasonableness’ of an accommodation ‘…does not refer to its limited cost or inconvenience to the employer, but rather to its potential to provide equal opportunity, reliability and efficiency’\textsuperscript{597}. Reasonable accommodation by definition involves the adaptation of practices or policies to ensure access by a particular individual, as such it entails a certain ‘singling out’ of a particular individual for what can be seen as special treatment. Therefore, it is important that any reasonable accommodation provided be seen as a measure to remove barriers for the individual, rather than as a welfare measure or a form of special treatment.

The ‘fundamental alteration’ limitations on the duty to provide reasonable accommodation in the proposed ETD have been heavily criticized by disability NGOs. In particular the European Disability Forum (EDF)\textsuperscript{598} and Inclusion Europe\textsuperscript{599} have objected that some structures or systems may well require a fundamental alteration in order to become non-discriminatory. States across Europe and beyond have a long tradition of segregated provision for people with disabilities. Although this is changing it is still an entrenched practice in many places and, as Quinn points out, the ‘separate but equal’ doctrine which supports it can lead to ‘…a crude and pernicious form of social determinism that arbitrarily telescopes the life chances of persons with disabilities. Such social determinism suggests that persons with disabilities have no place in the mainstream and no productive role to play in the labour market.’\textsuperscript{600} One obvious example of the need to undertake a fundamental alteration is the practice of accommodating people with intellectual disabilities and mental illnesses in long-term institutional care, which is widespread across Europe. This practice, and the systems and structures which support it, is undoubtedly discriminatory and there is a clear need to


fundamentally alter it to ensure effective non-discriminatory access for people with mental illness and intellectual disability to community services. The EDF state that ‘It is extremely problematic that the proposed directive explicitly exempts Member States from imposing an obligation to introduce fundamental alterations ... to social protection, social advantages, healthcare, education or goods and services, even if these are inherently discriminatory and inaccessible to people with disabilities. This seems to mean that, in practice, minor problems must be removed, but global, deeply rooted institutionalised discrimination will be allowed to remain because addressing such problems requires fundamental alteration of the system.’

It is doubtful if this is the intention of the drafters of the proposed ETD, but for many people with disabilities in the EU segregation in all types of services is the norm – including residential services, health services, education services and day services. These segregated services are by definition discriminatory and require a fundamental alteration to facilitate access to and integration into the community. As it stands the proposed ETD would be unlikely to reach people in such situations.

7.9. Accessibility

The area of access is comprehensively address in both the FED and the draft ETD and it forms a central plank of the CRPD. It is also an area which has received positive attention within the EU, leading to the proposal to enact a European Accessibility Act in 2011. Accessibility is a core element of the European Disability Strategy 2010 – 2020 which commits to consider whether to propose a ‘European Accessibility Act’ by 2012. This could include developing specific standards for particular sectors to substantially improve the proper functioning of the internal market for accessible goods and services.

A public consultation process has been completed and the Act is due for publication in 2013. The background document presented as part of the consultation process defines ‘accessibility’ as ‘... meaning that people with disabilities have access, on an equal basis with others, to the physical environment, transportation, information and communications including technologies and systems (ICT), and other facilities and

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services in line with Art. 9 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which the EU is a party. Article 9 of the CRPD provides extensive detail on the requirements for accessibility, covering the areas of physical infrastructure, transport, communication and information technologies and systems and information provision generally. It also requires the development and implementation of minimum accessibility standards for services and facilities open to the public.

The proposed European Accessibility Act will aim to address the problems of insufficient supply of accessible goods and services and the fragmentation of the EU market for accessible goods and services. There is a clear link here with the adoption of the operation of the internal market as the second legal basis for the ratification of the CRPD. As noted above several Article 95 instruments designed to address barriers to trade in the internal market already have a specific disability-access dimension.

Both the FED and the draft ETD address accessibility in their specific domains. Waddington highlights that the provision for access by anticipation to goods and services has encountered much opposition from member states on the basis that it is too vague and uncertain, and, as a result, has been amended in later versions of the draft ETD. She notes that 'It is clear that the intention is that providing accessibility should involve more than an individualised response to the needs of a particular person, as and when those needs arise, but require anticipation of the likely access needs of the group of people with disabilities as a whole, and the taking of steps to meet those needs.' The potential costs of providing accessibility – including anticipatory accessibility, reasonable accommodation and general accessibility of goods and services - would appear to be a major stumbling block in the passage of the draft ETD. It is noted that under the Danish Presidency in 2012 that accessibility remains one of the outstanding issues to be addressed and that 'there is a clear need for further work on this proposal.'

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603 European Commission, Consultation Document European Accessibility Act. DG Justice p1
604 ibid p1
606 European Council, Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation - Progress Report 8724/12, 10 May 2012 p7
7.10. Conclusion

At a legislative level significant progress has been made by the EU in the area of disability rights, especially with the incorporation of the Charter into EU law, accession to the ECHR and ratification of the CRPD. On the other hand the fact that the draft ETD appears to be floundering is a significant obstacle. The implementation of the provisions of the CRPD by the EU will require some form of legislative instrument such as a directive. It would be unfortunate if any such instrument only served to promote the rights of disabled people while leaving unaddressed the rights of other marginalized groups. If rights for disabled people are to be properly upheld within the EU this should occur in the context of equal rights for all citizens, otherwise it contributes to the singling out of, and differentiation of, people with disabilities - a problem which is at the heart of the way society has historically treated them. The possibility remains that in the event of the draft ETD being dropped that a disability-specific directive could garner more support among member states and within the EU.

Waddington, although personally favouring a multi-ground directive, suggests that while there is a reluctance to adopt additional ‘horizontal’ instruments, there is more likelihood that member states and the Council would be willing to adopt a disability-specific non-discrimination directive. She warns that stalemate on the draft ETD could mean that important progress on EU disability discrimination law could be hindered. States which have ratified the CRPD are required to comply with their obligations and to report on progress to the UN Committee on the Rights of Persons with Disabilities two years after ratification. The implications are that if no common EU approach is achieved either through a horizontal or disability-specific directive that each state will implement the CRPD in their own way. This may well meet the requirements of the CRPD, but is likely to lead to differing standards and approaches across the member states. While this may not necessarily be a problem at member state level it could lead to difficulty in achieving greater harmonization among the member states on significant issues such as accessibility standards, which initiatives, such as the proposed European Accessibility Act, are designed to achieve.

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Chapter 8: Independent Living in Irish Law

8.1. Introduction

The right to IL and community participation as formulated in the CRPD does not appear in Irish law, however, the core elements of the right are inherent in pre-existing international human rights and some can also be detected in Irish law. The core elements of the right to IL are individual autonomy, equality of access – to housing, generic community services and facilities - and social/personal support, all of which are required to enable participation in community.

This chapter will explore the extent to which current Irish legislation supports the core elements of the right to IL and community inclusion for PWID and for PWD in general i.e. autonomy, participation and accessibility and support services. It will outline the current legal framework in the area of disability-specific law, legislation in the areas of housing, legal capacity, equality and human rights and the legal basis for funding and delivering personal support to disabled people. As a starting point it is necessary to look to the Irish Constitution (Bunreacht na hÉireann) to ascertain the extent to which the rights delineated in the CRPD, especially those most relevant to the IL right, are reflected therein. Ms Justice Mary Laffoy suggests that ‘... the Constitution remains the primary and most effective source of the protection of human rights in the State. I believe it has been and it will continue to be “a ready, efficient weapon for the procurement of true justice”.’ The extent to which the Constitution affords protection to those rights which are inherent to the IL right will be explored first.

8.2. The Constitution of Ireland - Bunreacht na hÉireann

The Irish constitution is the basic law of the state and all acts of the Oireachtas must be congruent with it. The aim of the Constitution as expressed in its opening statement is ‘... to promote the common good, with due observance of Prudence, Justice and Charity, so that the dignity and freedom of the individual may be assured, true social order attained, the unity of our country restored, and concord established

The Constitution outlines the structures and powers of government and the judiciary and establishes in law the fundamental rights of citizens. It has also provided the basis for unenumerated rights identified by the Courts as implied rights derived from Article 40. The power of the constitution is both practical and symbolic. It frames the laws and legal instruments of the state and ensures that the work of the courts, in interpreting statutory provisions, are within the constitutional framework. On a symbolic level the constitution makes important statements about the political and moral values which underlie our society, the goals to which we aspire and it represents how we wish to perceive ourselves and to be perceived by others. Where the fundamental rights of disabled people or indeed all citizens are incorporated into the constitution this has ‘... the symbolic value of proclaiming to the community at large that people with disabilities are valued members of the community, who are entitled to be treated with dignity and respect.’ The Irish constitution names significant fundamental human rights along with the unenumerated rights identified by the Courts. These rights are applicable to all citizens including citizens with disabilities. The fundamental rights most relevant to IL and community inclusion present in the Irish Constitution are:

The right to vote (Article 16)

Equality of all citizens before the law, but account may be taken of differences in capacity and social function (Article 40)

Right not to be unlawfully deprived of one’s liberty (Article 40)

The inviolability of the dwellings of citizens and protection from unlawful forcible entry (Article 40)

The primacy of the family as the fundamental unit of society (Article 41)

The right to own private property (Article 43)

Freedom of conscience and religion (Article 44)

In addition to those fundamental rights specified in the Constitution the courts have held that there are a several ‘unenumerated’ individual rights which,

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609 Constitution of Ireland, Preamble
although not spelled out can be implied, and are therefore guaranteed by the Constitution. The existence of implied or unenumerated rights was established by the Supreme Court in the case of Ryan v the Attorney General\(^{611}\) in 1965. Article 40.3 of the Constitution states

‘3.1 The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.

3.2 The State shall, in particular, by its laws protect as best it may from unjust attack and, in the case of injustice done, vindicate the life, person, good name, and property rights of every citizen.’\(^{612}\)

Justice Kenny in Ryan v the Attorney General, commenting on this provision stated ‘... the general guarantee in sub-s. 1 must extend to rights not specified in Article 40. Secondly, there are many personal rights of the citizen which follow from the Christian and democratic nature of the State which are not mentioned in Article 40 at all. The right to free movement within the State and the right to marry are examples of this. This also leads to the conclusion that the general guarantee extends to rights not specified in Article 40.’\(^{613}\) The importance of this judgment was that it recognized that there existed rights not named in the constitution which could nonetheless, be inferred. This opened the way for other unenumerated rights to be explicated by the courts where individuals brought relevant cases.

The most significant unenumerated rights defined by the courts since this judgment in relation to the elements of IL and community inclusion are the right to bodily integrity\(^{614}\), the right to marital privacy,\(^{615}\) the right to individual privacy\(^{616}\) and the right to communicate\(^{617}\), the right to be free from inhuman and degrading treatment or punishment\(^{618}\), the right to earn a livelihood\(^{619}\) the right to have access to the courts\(^{620}\).

The expansion of unenumerated fundamental rights by the courts was effectively halted in 2001 in the case of TD v Minister for Education and others in the Supreme

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\(^{611}\) Ryan v Attorney General [1965] IR 294

\(^{612}\) Constitution of Ireland Article 40.3.1 and 40.3.2

\(^{613}\) Ryan v Attorney General [1965] IR 294 para 313

\(^{614}\) Ryan v Attorney General [1965] IR 294

\(^{615}\) McGee v Attorney General [1974] IR 284

\(^{616}\) Kennedy v Ireland [1987] IR 587

\(^{617}\) Attorney General v Paperlink Ltd [1984] ILRM 343

\(^{618}\) The State v Frawley [1976] IR 365

\(^{619}\) Murphy v Stewart [1973] IR 97

\(^{620}\) Macauley v Minister for Posts and Telegraphs [1966] IR 345
Court. In this case Judge Keane questioned whether it is the role of the courts to declare unenumerated rights, proposing that this is correctly a function of the Oireachtas. He expressed ‘...the gravest doubts as to whether the courts at any stage should assume the function of declaring what are today frequently described as "socio-economic rights" to be unenumerated rights guaranteed by Article 40.’

In effect this judgment limited the development of unenumerated rights to those already explicated by the Courts. Kenna suggests that ‘... there appears to be a political reaction among the judiciary to the development of such rights ...’

There are problems with the fundamental constitutional rights, which were addressed in the report of the Constitutional Review Group in 1996. The Review Group concluded that Articles 40 to 44, which outline the fundamental rights of citizens and facilitate the explication of unenumerated rights, are flawed and require revision. The report concluded ‘... there are three key features of these provisions (Articles 40 – 44) which require attention, namely the incomplete nature of the rights protected; the development of the unenumerated rights doctrine and the varying language of the clauses which qualify both the enumerated and unenumerated rights protected by the Constitution.’ These difficulties have meant that the development of unenumerated rights arising from court judgments have been somewhat ad hoc depending on the presentation of a particular case. In addition the rights delineated by the courts may not actually constitute fundamental rights as usually understood in international human rights instruments but may form parts of such rights. As highlighted by the Review Group ‘...the list of rights identified to date is by no means complete and many rights contained in international conventions dealing with fundamental rights, such as the right not to be held in slavery or the right not to be imprisoned for non-payment of debt, have not yet been recognised because of the absence of case law in this area.’

To address these shortcomings the Group recommend a re-drafting of Article 40 to include a comprehensive list of fundamental rights including those presently in the constitution, the unenumerated rights identified by the courts and rights from the European Convention on Human Rights and the International Covenant on

621 TD v Minister for Education and Others [2001] 4 259 para 66
624 ibid p 223
Civil and Political Rights. Although these rights are primarily civil and political in nature – and the right to IL includes elements of civil and political and socio-economic rights – the proposed list of rights to be considered includes the right to freedom of movement and choice of residence which speaks directly to the core of the IL right.

The Constitution does not contain a right to housing. The issue of the inclusion of specific personal economic rights – in particular a right to be free from poverty or the right to other social entitlements (which could be construed to include a right to adequate housing) – was considered by the Review Group. They rejected the proposal to include such socio-economic rights on the basis that such decisions are essentially political in nature and properly should be made by the government of the day, not the judiciary. Casey suggests that the reason for not including socio-economic rights in the constitution are that ‘A right to housing or to social welfare assistance ... imposes obligations on someone else to supply that housing or that assistance. For this reason, such rights would appear to be suitable material for legislative deliberation rather than for judicial action.’ However, the proposal by the Constitutional Review Group that an extended list of fundamental rights be incorporated into a revised Article 40, would address the issue of choice of residence, thus asserting the right of disabled people to have this choice in the same way as all other citizens. Clearly this is not a right to have the state provide the housing, rather it would ensure that the housing choices of disabled people would be limited only by the same factors as limit this choice to others i.e. factors such as income, occupation and family circumstances. Where people’s choice of residence is limited by the availability or location of disability-related support, this would represent a breach of the right to choice of place of residence.

The provisions of Article 45, which are akin to socio-economic rights, outline the directive principles of social policy which are intended as a guide for the Oireachtas. Importantly the Article states that the principles are not cognisable by the courts and cannot be used by the courts in interpreting legislation, which limits their effectiveness. Nonetheless Article 45 asserts certain principles of social policy, which have significant implications for disabled people and for the

625 ibid p 235
626 ibid p 242
627 ibid p 210
right to IL. In particular it states the common good of the whole people is of paramount importance and that ...

2. The State shall, in particular, direct its policy towards securing:

i. That the citizens (all of whom, men and women equally, have the right to an adequate means of livelihood) may through their occupations find the means of making reasonable provision for their domestic needs.

ii. That the ownership and control of the material resources of the community may be so distributed amongst private individuals and the various classes as best to subserve the common good …’

4.1 The State pledges itself to safeguard with especial care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged.629

Clearly this article is aimed at the welfare of the population and the pledge to support the weaker sections of the community are important in the light of the need of many disabled people for economic and other supports. The Constitutional Review Group was undecided as to whether Article 45 should be deleted or amended. They propose that if it is retained that it should include principles reflecting socio-economic rights which could be derived from state obligations arising from international human rights instruments such as the Covenant on Economic, Social and Cultural Rights and the European Social Charter. 630 This proposal, if adopted, would leave open the possibility that obligations related to the CRPD would also be incorporated as principles in Article 45 as guidance for the development of social policies effecting disabled people.

The intent of Article 45 is to provide direction to the Oireachtas in the development of social policies aimed at the common good, which remains undefined. However, its emphasis on welfare provision means that it does not endorse a rights-based approach to housing, IL or indeed any other human rights.

While Article 40 – 44 incorporate certain fundamental enumerated and unenumerated rights into the Irish constitution, nonetheless according to Kenna ‘The legacy of socio-economic rights under the Irish Constitution is of a minimalist nature for individuals, as opposed to the owners of accumulated property and

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629 Constitution of Ireland Article 45
The constitution, in general, accords much greater weight to property rights than to socio-economic rights for individuals and this appears to be unlikely to change in the near future. Article 43, which forms part of the fundamental rights section of the constitution, outlines the ‘natural right’ of people to private property and guarantees to enact no legislation which would abolish this right. However, this article goes on to recognize the need to regulate the exercise of this right by the principles of social justice and states that ‘The State, accordingly, may as occasion requires delimit by law the exercise of the said rights with a view to reconciling their exercise with the exigencies of the common good.’ Accordingly the state has interfered with private property rights in the interests of the common good in such areas as zoning of land for planning purposes and compulsory purchase of land for infrastructure development.

Kenna outlines several arguments for the inclusion of housing rights in the constitution – which are a key element of the right to IL and community inclusion. He suggests that the most powerful argument for their inclusion is that it would ‘... offer a means of empowerment to those excluded from the dominant housing market, and grant access to a minimum unit of social housing as a human right. Remarkably this is denied to many people in Ireland, including Travellers, people with disabilities, homeless people and others....... The question of latent discrimination in the role and functioning of the housing market could be evaluated through the set of indicators arising from the international human rights framework.’ Kenna goes on to point out that such a move has been resisted by the Irish government on the basis that, firstly, it would undermine the doctrine of the separation of powers between the courts and the legislature i.e. it would encourage citizens to pursue rights through the courts, rather than look to the Oireachtas for this. Secondly, the government argues that incorporation of a rights-based approach in the constitution is unnecessary as this approach is already inherent in the social-partnership process. Given the waning influence of social partnership in Ireland, particularly since the beginning of the economic downturn, the merits of this latter stance is at least questionable.


\[632\] Constitution of Ireland Article 44.2.2

\[633\] Part V, Section 96 of the Planning and Development Act 2000 enabled local authorities to purchase up to 20% of land zoned for housing development at ‘existing use’ value for the construction of social and affordable housing. This entailed purchasing the land at the market price it would have achieved before re-zoning for housing development.

8.3. Definition of Disability in Irish legislation

How ‘disability’ is defined in law forms an important part of the social construction of disability and it provides the legal basis for the development of policies and services which directly impact on the lives of disabled people. How well the definitions provided in Irish legislation support the core aspects of IL and to what extent they support the social or universalist models of disability and the conception of disability in the CRPD will be discussed in this section.

The definitions of disability provided in legislation are determined by the purpose for which the statute is intended. Thus in social welfare law the definition is reflective of the resource distribution nature of social welfare systems and the need to delineate access to public resources. As a result it is likely to focus on the physical, cogitative or psychological limitations of the person which hinder access to employment, education or training and the consequent need for financial support from the state. The purpose of anti-discrimination law on the other hand is to outlaw unfair and irrational treatment on the basis of prejudice about a particular characteristic of the person. In the case of people with disability prejudice and resultant mistreatment is often based on a perception that because of the existence of an impairment that the individual will be unable to perform or participate in normal life activities. It is necessary in this context to define the groups or individuals protected and, in the case of PWD, should reflect not just actual impairment, but also impairments which a person is assumed to have or to have had which attract the prohibited treatment.

Disability is not defined in housing or health legislation but it receives mention as a criterion for specific measures under both legislative schemes. In social welfare law the category of ‘disabled’ varies depending on the particular benefit in question and its eligibility criteria.\(^{635}\) While such definitions may serve their purpose well they may also cause difficulties when alternative definitions are used in other legislation, especially those in anti-discrimination law as will be discussed below.

Irish anti-discrimination statutes comprise of the Employment Equality Act 1998

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\(^{635}\) To qualify for Disability Allowance applicants must have an injury or illness of at least one year’s duration and be substantially restricted in undertaking work [www.welfare.ie/EN/publications/SW29/Pages/2Howdolqualify.aspx](http://www.welfare.ie/EN/publications/SW29/Pages/2Howdolqualify.aspx) Accessed 23/12/2012

Invalidity Pension applicants must be medically unfit for work for at least 12 months as determined by a medical doctor or be permanently incapable of work [www.welfare.ie/EN/Publications/SW44/Pages/2Howdolqualify.aspx](http://www.welfare.ie/EN/Publications/SW44/Pages/2Howdolqualify.aspx) Accessed 23/12/2012
and the Equal Status Act 2000, later jointly amended by the Equality Act 2004. Both Acts define disability as:

(a) the total or partial absence of a person’s bodily or mental functions, including the absence of a part of a person’s body,  
(b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness,  
(c) the malfunction, malformation or disfigurement of a part of a person’s body,  
(d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction, or  
(e) a condition, illness or disease which affects a person’s thought processes, perception of reality, emotions or judgment or which results in disturbed behaviour.

The Equal Status Act extends protection against discrimination based on assumptions about membership of any of the groups specified in the present, the past or the future. The outlawing of discrimination on the basis of an association with a person who is a member of one of the suspect groups, which is part of the Equal Status Act, was extended to the area of employment in the Equality Act 2004.

This definition appears at first to be quite heavily medically orientated with its listing of illnesses, malfunctions and diseases and the lack of any reference to environmental factors. However, as noted above the purpose of anti-discrimination law is to outlaw unfair treatment on the basis of particular traits of the individual and it is therefore necessary to clearly specify what these traits might be. In the case of PWD the discrimination is based always on the actual or presumed presence of an impairment. The actual impairment is not the focus here, but rather the reaction of employers or suppliers of goods or services to it – and where the reaction to the impairment is discriminatory this is prohibited behaviour under these Acts. For this reason, Degener suggests, it is necessary to include impairments in anti-discrimination legislation and that this does not perpetuate the medical model of disability. She concludes that the Irish definition compares favourably with those in similar legislation in Germany, Sweden and the United Kingdom and that it ‘... seems to circumvent almost all the pitfalls [of anti-discrimination law]. It does not portray disabled persons as helpless or needy, because it makes no assumptions about the effects of a given impairment or

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636 Employment Equality Act 1998 Part 1, Section 2.1 and Equal Status Act 2000 Part 1, Section 2.2  
637 Equal Status Act Part 1, Section 3.1  
638 Equality Act 2004 Section 4 (b)
malfunction. It is not based on a “truly disabled” notion and it covers past, present, future and imputed disabilities. It thus can be regarded as truly endorsing the social model of disability.639

The Disability Act 2005 defines disability as meaning ‘… a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.’640 The same definition is used in the Citizen’s Information Act 2007 under which the National Advocacy Service for people with disabilities was established in 2011. The purpose of both these Acts is to provide for services for people with disabilities and for enhanced access to mainstream services and facilities. It therefore, serves a different purpose that equality or social welfare legislation. Flynn highlights that while this definition incorporates both the impairment and the environmental elements, that ‘… unfortunately it regards impairment as the sole barrier which creates disability, rather than acknowledging that current societal structures contribute to ‘disabling’ individuals.’641 She goes on to suggest that the Disability Act definition nonetheless represents an improvement on that offered by the Equal Status Act as it more closely reflects the social model bias of the CRPD definition. This, however, fails to take account of the fact that both pieces of legislation serve distinct purposes and that each as a consequence require quite distinct definitions. Access to mainstream and specialist services are important in enabling people with disabilities to live independently in the community, at the same time strong ant-discrimination law is essential. Both of these are recognized in the CRPD but the dilemma of how to define disability in different context remains.

While people with mental illness and intellectual disability are clearly covered by the legislation cited above, the Mental Health Act 2001 also provides definitions of these particular disabilities. The definition of ‘mental disorder’ in the Act includes people with mental illness and people with significant intellectual disability. Mental illness is defined as ‘… a state of mind of a person which affects the person’s

640 Disability Act 2005 Part 1, Section 1, 2.1.
thinking, perceiving, emotion or judgment and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons.642’ And ‘significant intellectual disability’ is defined as ‘... a state of arrested or incomplete development of mind of a person which includes significant impairment of intelligence and social functioning and abnormally aggressive or seriously irresponsible conduct on the part of the person.’643 The purpose of the Act is to establish legal rules surrounding admissions to psychiatric services and the rights of patients. Neither of these definitions make any reference to environmental factors and can, therefore, be seen as heavily orientated towards the medical view of disability. O’Mahony suggests however, that they are welcome as they provide ‘... greater clarity about whether or not an individual is mentally ill for the purposes of involuntary detention ... [and]... a relatively unambiguous basis upon which treatment is given voluntarily and involuntarily.’644 The recognition of and support for legal capacity is a cornerstone of independent living. At present Ireland’s legislative framework in this area is governed by the 1871 Lunacy Regulations (Ireland) Act. This legislation, which is generally acknowledged as antiquated and inappropriate, covers ‘... any person found by inquisition idiot, lunatic, or of unsound mind, and incapable of managing himself or his affairs.’645 New legal capacity legislation, hopefully reflective of the CRPD is currently under consideration and will be discussed below.

In this area it can be concluded that save for the glaring anomaly in the area of legal capacity, there is nothing in the definitions of disability in Irish legislation which impacts negatively on the right to IL and community inclusion. Assuming that the new legal capacity legislation establishes a functional or universal approach to capacity the legal framework around how disability is defined should present no obstacles. However, there is equally no positive assertion of the right to IL for disabled people, and while this is not an essential element, it could serve as an important signal to society that this is the direction in which all future legislation, policy and services must develop.

642 Mental Health Act 2001 Part 1 Section 3.2
643 Mental Health Act 2001 Part 1, Section 3.2
645 Lunacy Regulations (Ireland) Act 1871 Section 2
8.4 The National Disability Strategy

The National Disability Strategy (NDS) was launched in 2004 with the aim of supporting the participation of people with disabilities in society. The key arms of the strategy are legislation (Disability Act, Citizens Information Act and Education of Persons with Special Educational Needs Act), the development of sectoral plans by specific government departments for delivering services to PWD and the allocation of multi-annual funding. Membership of the NDS monitoring group was extended in 2011 and now includes representation from relevant government departments, the National Disability Authority (NDA), the Disability Stakeholders Group, disability umbrella groups and the County and City Managers Association. The inclusion of this latter group is important, as local authorities are key in the area of social housing and the delivery of public services at local level. The new group also has a revised terms of reference which recognize the need to place renewed emphasis on the delivery of the NDS and the development and monitoring of implementation plans. Relevant aspects of the NDA will be discussed in specific sections below.

8.5. The Disability Act 2005

The need for a Disability Act to provide a framework for the development and delivery for services for people with disabilities was identified several years before its actual enactment in 2005. The Act which was eventually passed, followed the withdrawal of an earlier Disability Bill in 2002. The original Bill was heavily criticized for its failure to include a right of redress through the courts for people whose needs had not been met by health and social services. Following this an extensive consultation process was undertaken and the Disability Legislation Consultation Group (DLCG) was established. The revised Disability Act was passed in 2005, which provides complaints and appeals mechanism for failure to provide services to individuals, but still does not contain a right to services. The Act has been criticized by the Law Reform Commission which noted that ‘The “rights-based” approach of the Convention does not sit easily with the approach in the Disability Act 2005, although the Commission accepts that the sectoral plans and funding arrangements surrounding the 2005 Act provide tangible

movement towards the objectives of the UN Convention. The question to be addressed here is to what extent the provisions of the Disability Act supports the right to IL and community inclusion.

The main planks for the Act are provision for an independent assessment of need for all PWD and preparation of individual service statements, provision for access to facilities, information and services, the development of sectoral plans by key government departments, provisions relating to genetic testing, establishment of a public service employment quota and the establishment of the Centre for Excellence in Universal Design.

8.5.1. Needs assessment and service statement

The Disability Act provides for a right to have ones health and educational needs assessed, but does not provide a right to services arising from this assessment. The establishment of an independent needs assessment process for each individual with disability was identified by the report of the Commission on the Status of People with Disabilities in 1996 and this was reiterated by the DLCG which recommended that ‘... there should be a statutory right to an independent assessment of need leading to a Statement of Need .... which should result in services that are made available as a right for people with disabilities. The DLCG also recommended that the assessment of needs should cover all areas of need including independent living, accommodation, advocacy, health, income, education and social activities. The Act however confines the assessment and service statement processes to health and education needs occasioned by the disability.

While a demand for a right to services from disabled people is understandable it poses problems on a wider level. Meeting service needs as a right could potentially be economically unattainable where public resources are necessarily limited. In addition, as suggested by de Wispelaere and Walsh, it ‘... might be considered undemocratic if the goal of ensuring disability rights conflicts with other

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values that a democratic community holds dear, including the power of legislators to set social and economic policy.\textsuperscript{650} This of course is one of the dangers inherent in a minority rights approach to disability and in the long-term may actually hinder the full inclusion of disabled people as fully equal citizens. The rationale behind an individual needs assessment and service statement is that it enables people to access supports tailored to their individual needs and, as a result, have control over how they live their lives and not be bound by the types of services available from any particular service provider. In this scenario individual needs assessment should be extremely beneficial in furthering IL, however, the reality of how the processes have been delivered have been heavily criticized as being overly medical, too narrowly confined to clinical areas of people’s lives and overly bureaucratic. The assessment of needs process began in 2007 with children in the 0 – 5 age group. Plans to extend the process to older children and adults was suspended in 2008 due to financial constraints, and to date this extension has not been activated.

The fact that this provision has so far only been applied to young children and that its remit only extends to health and education service may have contributed to the medicalisation of the process. Understandably the focus of parents of young children with disabilities is on the medical, para-medical and educational interventions which will enable their child to develop their full capacity. Even though the Department of Health and the HSE are responsible for the provision of health and personal social services, the application of the Act in practice has focused only on health and education as provided for in the legislation- and not on social supports. In 2010 the Disability Appeals Officer appointed under the Act commented in her review of the assessment process that ‘...regardless of the wide variety of disabilities which children present with, many Assessment Reports appear simply to identify a child’s needs as requiring referral to a particular service or services... Assessment reports therefore appear to be largely indistinguishable apart from the identities of the clinicians who have undertaken the assessments.’\textsuperscript{651}

The Act provides that the independent needs assessment be carried out without regard to the capacity to deliver the identified service needs\textsuperscript{652} and that the

\textsuperscript{652} Disability Act 2005 Part 2, Section 8.5
service statement, which includes information about who will provide which aspects of the service, be undertaken separately. In practice, however, as highlighted by the NDA ‘... assessors are extremely mindful of the resource allocation or service eligibility rules of the health and education systems from which parents are seeking supports. Such rules play a critical role in driving a diagnostic approach to assessments that assessors conduct as part of the statutory assessment of need.’ The disconnection between the two is problematic in that if needs are identified and the capacity to deliver these services is non-existent or restricted, then there is a problem of unfulfilled or partially fulfilled expectations. This problem was considered in the UK by the House of Lords in 1997 when the position taken by Gloucestershire County Council was that resources must be taken into account in assessing the needs of a disabled person under the Chronically Sick and Disabled Persons Act 1970. The majority verdict allowed the appeal of the Council and Lord Steyn stated that ‘... needs for services cannot sensibly be assessed without having some regard to the cost of providing them. A person’s need for a particular type or level of service cannot be decided in a vacuum from which all considerations of cost have been expelled.’ The growing acceptance, both within and without the health services, that the current assessment of needs and service statement processes are ineffective is reflected by the comment in the report of the Expert Reference Group on disability policy issued by the Department of Health that the system ‘... does not correspond to a ‘needs assessment’ as understood in the wider, international disability sector’ and ‘... it excludes a consideration of the totality of needs of the individual.’ The assessment of need and service statement processes which operate at present are inefficient and overly medicalised. And more importantly they do not contribute towards enhancing the ability of people to realize the right to IL. In fact, they may even be detrimental in that these processes consume resources which could be used to provide needed services and supports for disabled people. The Centre for Disability Law and Policy, NUI Galway in its submission to the review of the Disability Act suggests that ‘There is serious concern that to date the implementation may not have improved the situation for children with disabilities

654 Barry R v Gloucestershire County Council & Another [1997] UKHL 58
and their families." New proposals from the Department of Health for an individual needs assessment process using standardized tools and incorporating supports needs in all areas of people’s life are to be welcomed.

8.5.2. Complaints procedure

People may make a complaint to a HSE appointed Complaints Officer about the decisions of the assessment officer, the content of the service statement, a delay in carrying out the assessment or a failure to deliver the services specified. Where initial efforts to resolve the dispute informally are unsuccessful, a formal process is undertaken and recommendations made. Dissatisfaction with the outcome of this process on the part of the person or service provider, may be appealed to an Appeals Officer appointed by the Minister who is charged with making a final decision. Decisions of the Appeals Officer cannot be appealed to the Courts except on a point of law or if there is a failure to implement the recommendations. This process has been criticized on the basis that it is internal to the HSE and, because of the private nature of the hearings and decisions, the outcomes do not help provide precedence from the Disability Act. Furthermore it is extremely bureaucratic and complex which, especially for people with intellectual disabilities, is as aspect of the wider legal system which poses major problems in accessing justice. De Wispelaere and Walsh conclude that ‘... a disabled individual is effectively prohibited from accessing an independent arbiter, such as the Ombudsman or the regular court system until the internal review procedures have been exhausted, which serves as a genuinely ‘dis-abling’ procedure.’ They go on to suggest that an effective route out of the dilemma of a lack of a right to service on one hand and the concern about the potentially open-ended nature of providing for a such right on the other, would be the inclusion of a Right to Challenge. This would entail putting in place a system - through the courts, a tribunal or the Ombudsman - which would enable the disabled person to challenge the needs assessment and service statement processes and the quality of the service delivery. This process would have to ensure effective access for individuals, be

657 Department of Health Value for Money and Policy Review of Disability Services in Ireland, Dublin, Department of Health (July 2012) p36

282
fair procedurally and be truly independent. This would not guarantee that the assessment or statementing processes or the service delivery would be altered, but would allow for public scrutiny and reasoning. Importantly they suggest that ‘The right to challenge does not offer disabled individuals the sort of expansive right to a particular service delivery sought by radical disability advocates. Instead, it acknowledges explicitly that there may be legitimate reasons to deny that a particular disability implies a need that generates a duty for the state to meet at all costs. Most importantly, it acknowledges that legitimate reasons may exist that override the entitlement to a particular service even where a genuine need has been identified.’ Experience from the Equality Tribunal would indicate that making such a process available under the Disability Act could potentially be extremely useful in informing debate and policy formation, while avoiding the resource implications of providing a fully-fledged right to service for disabled people.

8.5.3. Access

Accessibility to all areas of life is key to the realization of the right to IL and community inclusion. Accessibility covers both the physical aspects of buildings and infrastructure but equally importantly communication and access to services. Improving access to public buildings, transport and infrastructure is a long-term project and requires significant resources and planning. Improving access to services is a central aspect of the sectoral plans of several government departments under the NDS. Over recent years the Irish government has instituted and improved guidance on and regulation of accessibility, most recently publishing an upgraded Technical Guidance document on Part M of the Building Regulations governing accessibility and introducing the Disability Access Certificate both in 2010. In addition, a Code of Practice on Accessibility of Public Services and Information Provided by Public Bodies and a Code of Practice on Access to Heritage Sites have been issued by the Department of Justice and Equality. The accessibility of public services code outlines the requirements of public bodies to ensure access and provides guidance on how this can be achieved.

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659 ibid p529
661 Department of Justice and Equality A Code of Practice on Accessibility of Public Services and Information provided by Public Bodies www.justice.ie/en/JELR/Pages/Disability%20Policy Accessed 14/2/2012
The following areas are covered by the code:

1. Provision of services for the general population to PWD in an integrated manner i.e. in the same location
2. Provision of assistance to disabled people to access public services where necessary.
3. Ensuring the availability of expert advise to ensure accessibility of public services
4. Appointment of authorized Access Officers
5. Accessibility of services supplied to the public body
6. Provision of information in formats accessible to people with hearing and visual impairments and intellectual disabilities

The Act provides for enhancing access to public buildings. However, the definition of ‘public body’ - and therefore of a public building - is such as to exclude many buildings where public services are provided including state-funded services provided by private or non-profit agencies such as post offices and citizens information services.

8.5.4. Sectoral Plans

The Disability Act requires six government departments to produce plans outlining measures each would take to fulfill their obligations arising from the Act. These are the Department of Health, the Department of Social and Family Affairs, the Department of Transport, the Department of Communications, Marine and Natural Resources, the Department of the Environment and the Department of Enterprise.

The sectoral plan of the Department of Health sets out the arrangements for the implementation of the assessment of needs, service statement and the complaints procedures. It also committed to the development of protocols between the housing authorities and the HSE concerning the housing needs of people with disabilities. A protocol to this effect has been developed but, as the assessment...

665 See Department of the Environment, Community and Local Government Assessment of Need Protocol between the HSE and Housing Authorities.
of need has so far largely only been provided to children aged 5 and under, the protocol, therefore, only refers to young disabled children who have a housing need. The implementation framework for the National Housing Strategy for People with a Disability published in 2012 identifies as one of its priority actions ‘... the implementation of a national protocol governing the strategic assessment of housing needs of people with disabilities ’ and the production of a statement of housing need for each individual which will include ‘... in conjunction with the HSE, service providers and relevant disability organisations, the nature and extent of care and supports required., through interagency cooperation.’ This would seem to indicate a commitment to enhance access by disabled people to mainstream housing and certainly represents progress on systems developed as a result of the Disability Act.

The key aspect of the sectoral plan of the Department of Social and Family Affairs (now Social Protection) as it relates to IL were the development of an advocacy service for disabled people and addressing the ‘benefits trap’ hindering people in accessing employment. In 2011 the National Advocacy Service for People with Disabilities was established under the aegis of the Citizens Information Board. For disabled people, especially those with impaired capacity, independent advocacy is one of the key supports needed to enable people to make important choices in their lives.

The Sectoral plan of the Department of the Environment crucially dealt with the issue of housing for disabled people and accessible housing. Several of the commitments in this plan have been implemented, including the up-dating of the Building Regulations, the development of a Disability Access Certificate and the publication of the National Housing Strategy for People with Disabilities. In the review of the operation of the Disability Act conducted by the Department of Community, Equality and Gaeltacht Affairs in 2010, the feedback about the process of the sectoral plans was in general positive. The proposal that each government department, local authorities and all government bodies be required


to develop, implement and monitor their own sectoral plans could be a fruitful route to pursue.667

8.6. Legal capacity in Irish Law

The importance of legal capacity (LC) in the lives of all people cannot be overstated and in relation to the realization of IL for PWID it is foundational. Put simply legal capacity is the ability to make one's own decisions and to have these decisions respected in law. It affords autonomy and dignity to all people in how they live their lives and it is essential if people are to achieve the ideals of IL and community participation. As Keys suggest the ‘ ... right to autonomy and self determination, strongly supported in many jurisdictions, is central to full participation in society, and yet legal capacity can be achieved only if the law permits persons to make their own decisions or supports them in doing so.’668

For many PWID in Ireland the denial of capacity is epitomized by the routine appointment of ‘agents’ for recipients of disability allowance who are deemed by a medical doctor to be ‘unable to manage their own financial affairs.’669 Although there is scope for the Department of Social Protection to revoke the appointment of an agent where there is evidence of abuse, there is no system of regularly reviewing the capacity of the person to manage their own affairs and in practice such arrangements can remain in place throughout the person’s adult life. Where people are denied control over their income, control in almost every area of life is also denied, and importantly, the opportunity to acquire one of the key skills needed to achieve IL - money management - is also denied.

As well as incurring negative legal consequences for the individual, a denial of LC also has negative personal, social and psychological consequences. In his influential paper on the effects of being labeled legally incompetent Winick670 highlights possible side-effects as including diminished self-esteem,  

stigmatization, diminished motivation, diminished problem-solving abilities, depression, learned helplessness and a lack of a sense of self-control. Drawing on the work of Deci he argues that making decisions for oneself is a basic human need and that the denial of this ‘... diminishes intrinsic motivation and produces dysfunctional behavior, withdrawal, passivity, and lack of response. ... Labeling people as incompetent deprives them of the opportunity for self-determining behavior. Having others make decisions for them produces amotivational behaviors, low self-esteem, passivity, and feelings of inadequacy and incompetency.’ Being deprived of one’s LC, as is permissible under Irish law at present, has devastating consequences – it denies the person the status of full personhood, it severely limits their opportunities to grow and develop in the community, it limits their access to other fundamental rights and it deeply harms the person both in their own eyes and in the eyes of others.

8.6.1 Approaches to Legal Capacity

The Law Reform Commission defines ‘capacity’ as ‘... an adult’s cognitive ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made.’ This appears to refer only to one’s cognitive ability to understand and make decisions. There is a difference between legal capacity and mental capacity although both are often used interchangeably. LC is the right of an individual to make decisions for him or herself and to have those decisions respected in law. Mental capacity on the other hand refers to the cognitive ability of an individual to make decisions, the ability to understand and weigh up the options and to comprehend the consequences of the various options - more akin to the definition given by the Law Reform Commission.

a) Traditional Approaches to Legal Capacity

Two traditional approaches to legal capacity can be found in legislation i.e. the status approach and the outcomes approach. The Status Approach involves

making a decision on a person’s legal capacity based on the presence or absence of certain characteristics. It ‘usually involves an across-the-board assessment of a person’s capacity based on disability rather than capacity in relation to the particular decision being made at a particular time.’\textsuperscript{674} Arising from this approach, which is used in current Irish legislation, a person’s LC is determined usually by the court and is based heavily on medical opinion as to the presence or nature of a cognitive impairment. It is an ‘all or nothing approach’ meaning that if it is decided the a person lacks LC, then this applies in all areas of life and renders people powerless over how they live their lives.

With the Outcomes Approach a decision on a person’s LC is based on a judgment about the outcomes or consequences of decisions they have made in the past. If these outcomes are deemed to be dangerous or otherwise bad for the person then s/he is deemed to lack LC. The Law Reform Commission suggests that this, by definition, involves a moral judgment about what is correct or good, that ‘under this standard, a person who makes a decision that reflects values which are not widely held or which rejects conventional wisdom is found to lack capacity.’\textsuperscript{675} As with the status approach, the designation of a lack of LC under this approach is general and a person’s ability to make decisions with any legal consequences in all areas of life is removed.

In addition to excluding people form decision-making, both these approaches fail to take account of the fact that there are graduations in capacity, that capacity can fluctuate over time and that one’s capacity to make different types of decisions may vary in different contexts.\textsuperscript{676} In reality capacity is specific to particular issues, situations or times. These approaches also do not recognize that people make decisions for all types of reasons based not only - or even mainly - on their cognitive ability to understand the decision to be made and its consequences. As a matter of routine people act on emotions, on considerations for others or on hope, and very often make decisions in consultation with others who are close to them.

\textsuperscript{674} Law Reform Commission Vulnerable Adults and the Law: Capacity Consultation Paper (2005) LRC, Dublin para 2.04 p42
\textsuperscript{675} ibid para 2.12 p44
b) The Functional Approach

The Functional approach recognises that a person may have the capacity to make some decisions but not others and that LC must be assessed in relation to specific contexts and specific issues - in other words that it is issue-specific and time-specific. A decision that an individual lacks the LC to make a particular decision does not result in their being deemed to lack this capacity in other areas of their lives. Thus a person may be deemed incapable of making a decision to purchase a house but retain the LC to undertake other decisions with legal consequences such as the decision to marry or to have children.

According to the Law Reform Commission ‘The fundamental premise behind a functional view of capacity is that the fact that a person belongs to a category of people who are often unable to make decisions for their own wellbeing may open the possibility of a lack of decisional capacity - but it does not of itself resolve the matter.’677 The functional approach has been adopted by recent law reform in this area678 but it has been subject to criticism in the light of an evolving understanding of LC as expressed in Article 12 of the CRPD.

Despite the fact that the functional approach is gaining ground in recent LC law reform and that it is a more inclusive approach, it still excludes some people from its reach. The functional assessment of capacity under this approach, by definition, determines the capability to a person to make a specific decision and can results in a ruling that a person is incapable in a particular context and their LC in this specific area is denied. Positing the view that capacity is a constructed concept, Dhanda679 refers to all of these approaches as ‘incapacity models’, all of which are models of exclusion. With the functional approach the onus is on those alleging incapacity to prove that it exists and the role of the court is to ensure that no one is unfairly stripped if their LC, rather than on ensuring that the individual has the supports necessary to enable them exercise their LC. She suggests that ‘The only concern of the [law] reform is that the process of exclusion should be as

fool proof as possible and no one should be wrongfully excluded. As with other functional parameters, disability figures as a threshold condition. The legal capacity of all persons with disabilities can be subjected to interrogation under this model.\textsuperscript{680}

c) The Universal Approach

The universal approach to LC can be seen as an evolution of the functional approach in that both starts from the assumption that people have LC. However, they differ in that the functional approach makes an assessment of capacity in order to determine whether this capacity exists in particular contexts and consequently people can be deprived of their LC in these contexts. The universal approach on the other hand makes an assessment of capacity in order to determine what supports are required to enable the person exercise their innate LC. The Universal approach is based on the premise that everyone requires opportunities to develop their decision-making skills and that to do this everyone needs opportunities to grow and develop. The role of the court is to safeguard people’s LC and the assessment of capacity is aimed at identifying what the necessary supports are. These supports will be tailored to the needs of the individual and can include alternative communication systems, advocacy, taking account of the person’s past wishes and supported decision-making mechanisms. The latter is core to enabling people whose cognitive abilities are impaired exercise their LC. It recognises that everyone requires support in their lives, but that for many PWID these supports may be restricted by assumptions about their abilities and by inaccessible systems. Supported decision-making draws on the past wishes of the individual, what is know in the present about the person’s wishes, information from people with whom the person has important relationships and their wider support network. As Dhanda states ‘With the recognition of universal capacity, there is recognition that, given the opportunity, all human beings can grow and develop. However, for this growth and development to happen, it is important that opportunities be tailored according to the needs of each person.’ For people with impaired capacity opportunities for growth and development may be different from those already built into the structures of society but they are essential to ensure the outcome of equality in the exercise of LC for all. A key ingredient in facilitating people to develop their LC is supporting

\textsuperscript{680} ibid p460
people to exercise choice in how they live their lives and participate in the community, because it is through experience and connections with others that people’s capacity is developed. Thus the obligation to provide IL opportunities with the appropriate supports for all people is essential in ensuring that all people learn how to exercise LC which is universal to all citizens.

8.6.2. Legal Capacity in the CRPD

Article 12 on LC is at the heart of the CRPD and it has been suggested that it is in fact emblematic of the ‘paradigm shift’ which places people with disabilities as ‘subjects’ rather than ‘objects’. A universal approach of LC is strongly supported by Article 12 although it does not preclude a functional approach which could include substitute decision-making. Article 12 asserts the right of people with disabilities to equal recognition as persons before the law, their right to enjoy LC on an equal basis with others in all areas of life and their right to supports to exercise their LC. The recognition of the right to support to exercise LC is central to the realisation of this right and, as noted above, for most people, these supports are in-built in the structures of society in terms of education, opportunities for growth and development and social connectedness in community. For many disabled people, especially those who have been isolated or segregated, these supports have often been absent. Article 12 demands that whatever supports the person requires to exercise their LC be put in place and this includes in large measure a re-configuration of how society provides services and supports to this population group – as part of the mainstream community not in separate places. Article 1 of the CRPD makes explicit that all of the rights contained therein are applicable to all people with disabilities regardless of type or degree of impairment, this is equally the case in relation to LC. Quinn suggests that even though there will be cases where decisions are made ‘for’ rather that ‘with’ some disabled people “… we have to ensure that the paradigm shift means that even in this category it is now necessary on foot of Article 12.3. to take additional steps … To me we should never give up on this possibility [that a glimpse of the person’s ‘will and preferences’ can be found] – no matter how remote.

Secondly, and with respect to those whose social connectedness has been severed due to institutionalization it seems to me to be the correct response to try to create social conditions in the hope of kindling some kernel or preferences.682

Part 4 of Article 12 details the safeguard needed to ensure that the supports provided are free from conflict of interest, avoid abuses, are tailored to individual need and are focused at all times on the ‘rights, will and preference’ of the individual. It is this aspect of Article 12 which gives rise to the concern that substitute decision-making could be justified. Dhanda suggests that ‘The text of Article 12 does not prohibit substituted decision-making and there is language which could even be used to justify substitution. Under the circumstances, it could well be argued that the Article would be a stranglehold of the past on the Convention. However, such a contention can be made only if the universal reach of the capacity formulation is diluted or ignored and the article is read divorced from the process of advocacy and negotiation.’683 The safeguards needed to protect and support the exercise of LC for all disabled people must be conceptualized in the overall context of the CRPD and its universal reach i.e. the right to LC applies to everyone regardless of type or degree of impairment, the supports required are part of this right regardless of type or degree of impairment and the safeguards on the provision of supports apply to all regardless of type or degree of impairment.

8.6.3. Current Irish Legal Capacity Legislation and proposed changes

Irish legislation in relation to LC is governed by the Lunacy Regulations (Ireland) Act 1871 which established the framework for the Wardship system.684 This legislation has been described as ‘… archaic, inappropriate and at odds with human rights instruments …’685 and heavily orientated towards a medical model of

684 It should be noted that the Irish courts have adopted an approach to testamentary capacity which is functional in nature – it is sufficient that the person had ample understanding at the time of making their will and a subsequent decline in understanding does not rule out testamentary capacity. The Courts have also rules that unusual choices in the making of a will or the presence of a mental illness do not in themselves constitute evidence of a lack of testamentary capacity. See Law Reform Commission Vulnerable Adults and the Law, Report (2006) LRC, Dublin
685 Centre for Disability Law and Policy, NUI Galway Submission on Legal Capacity the Oireachtas Committee on Justice, Defense & Equality (2012) p9
disability. The deficiency of the current framework, the urgency of the need for change and the barrier it presents in ratifying the CRPD has been acknowledged by the Irish government.

The Ward of Court system is the primary mechanism for managing the affairs of people deemed to lack decision-making capacity in Irish law. People with impaired cognitive capacity may be brought into wardship because they own or inherit property or money and require protection in the use or maintenance of this property or money. Although the numbers of people brought into wardship is relatively small, the implications are all-pervasive in the person's life. Wardship is of indefinite duration unless the person can produce medical evidence that he is now 'of sound mind and capable of managing his affairs'. Wards cannot buy or sell property, have a bank account, enter a contract, consent to medical treatment or travel outside of the country without permission of the court. In addition a ward may not marry and in fact sexual relationships are prohibited to people with intellectual disabilities under Section 5 of the Criminal Law (Sexual Offences) Act 1993. As stated by the EU Fundamental Rights Agency 'A person who is made a ward loses the right to make any decisions about their person and property' and while the court takes account of the views of the ward’s committee and the family, it is the court which makes decisions about the ward based on his/her 'best interests'. The 'best interests' principles is usually associated with law as it relates to children and is ‘... increasingly considered inappropriate in relation to adults ... ‘ bringing with it a ‘... significant risk of paternalism.’ Finally, as noted by the EU

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688 Houses of the Oireachtas, Joint Committee on Justice, Defense and Equality Report on Hearings in Relation to the Scheme of the Mental Capacity Bill (May 2012) Observations of the Committee
689 Court Services, Annual Report 2011, Dublin, The Courts Service (2011) indicates that 313 people were taken into wardship by the High Court in 2010 p55
690 EU Fundamental Rights Agency Country thematic reports on the fundamental rights of persons with intellectual disabilities and persons with mental health problems, November 2009 FRA, p43
691 Centre for Disability Law and Policy, NUI Galway Submission on Legal Capacity the Oireachtas Committee on Justice, Defense & Equality (2012) p21
Fundamental Rights Agency, ‘One of the big issues with the wardship procedure is that it does not contain sufficient procedural safeguards in terms of protecting the human rights of the ward.’

The focus of the system is primarily on the protection and management of the person’s property and money rather than on protecting his/her human rights.

In 2008 the government published the Scheme of Mental Capacity Bill in order to replace the outdate wardship system. The current government established a joint committee of both houses of the Oireachtas to consider the Bill and sought submissions from the public. The report on these hearings were published on May 2012. The proposed Bill adopts a functional approach to LC and is largely based on the recommendations of the Law Reform Commissions report on Vulnerable Adults and the Law. The government suggested that the Bill will ‘... give effect to the Convention in so far as it applies to the legal capacity issues in Article 12d of the Convention.’ However, no reference is made to other crucial parts of Article 12 and part D refers only to the right to people with disabilities to own or inherit property, control their financial affairs, have access to bank credit and not to be arbitrarily deprived of their property - so on first appearances it appears to be quite narrowly focused. The principles of the Bill include a presumption of LC unless proven otherwise, the obligation to take all practical measures to help the individual exercise LC, the adoption of the least restrictive principle, respect for the dignity, privacy and autonomy of the individual, taking account of the past and present wishes of the person, taking account of the views of people close to the person and the principle of the ‘best interests’ of the person in making decisions related to him or her. The Bill provides for time-specific and issue-specific assessments of capacity and for the provision of supports to enable the person to make decisions including accessible information and communication systems. It provides for the appointment by the court of personal guardians to make decisions in the person's best interests where the person is
deemed to lack capacity in specific contexts - thus allowing substitute decision-making in defined areas. These areas can range from decisions about where and with whom the person will live, whom the person may see or not see, diet and dress, consent to health care interventions and decisions related to the person’s property. All decisions regarding LC can be reviewed by the court regularly. The Bill provides for the establishment of an Office of the Public Guardian which will supervise personal guardians, develop codes of practice for health care and other professionals in assessing capacity and for the guidance of personal guardians. The area of informal decision-making is governed by the ‘best interest’ principle and the Bill allows for the making of personal and health care decisions by another person if they have established that the person lacks capacity to make the decision themselves and that it is the person’s best interest that the act be carried out. In determining a persons best interests the Bill outlines that it must be determined whether at some point the person will have capacity in relation to the particular matter, the person must be encouraged to participate in the decision and consideration must be given to the person’s past and present wishes and his/her beliefs and values. In addition people connected to or caring for the person should be consulted.

The Scheme of Mental Capacity Bill has been welcomed on some counts but has been subject to criticisms in other areas. It has been argued that the use of the ‘best interests’ concept undermines an acknowledgement that everyone has LC, is paternalistic and that what is required is supports to exercise LC, not any form of substitute decision making. It has also been suggested that the area of informal decision-making lacks detail and needs to be amended to ensure that it does not become de facto substitute decision-making. The Fundamental Rights Agency highlights the lack of provision for specialist courts and specialists judges as a shortcoming of the Bill suggesting that the formality of the courtroom is

inappropriate as a venue for assessing capacity.\textsuperscript{699} Perhaps the most significant criticism of the Bill is that while it adopts a functional approach to LC, it leaves considerable space for substitute decision-making and the deprivation of LC in specific situations. This is at odds with a recognition of universal LC as explicated in Article 12 and could mean that the Bill if enacted in its current form could be in breach of the State’s obligations under the ECHR. The CDLP states that ‘... if the functional model in the Scheme of the Bill is retained without modification then it is certainly a possibility that Ireland will be found in breach of the ECHR in time.’\textsuperscript{700} A reorientation towards a functional approach focused on the assessment of supports needed to exercise LC and supported decision-making appears to have been accepted by the Joint Oireachtas Committee\textsuperscript{701} which augers well for a re-drafted Bill.

\textbf{8.6.4. What is required to realize Article 12 in Irish legislation?}

In order to realize the spirit and intent of Article 12 of the CRPD major changes are required to the Scheme of the Mental Capacity Bill. The International Disability Alliance proposes a set of principles for the implementation of Article 12 which include a recognition of universal LC, the provision of tailored supports to exercise LC, the promotion of advance planning for people who may need supports in the future and the provision of safeguards to ensure the integrity of supports. As a last resort interim measures which may be required where supports fail may be put in place for defined times. Where a person agrees that a particular decision may be made by another person this does not mean that s/he loses his/her right to make this decision and the support person is bound to make continuous efforts to discern the wishes of the person.\textsuperscript{702} In the Irish context a group of 15 non-government organisations published a set of principles reflecting international human rights law, and Article 12 in particular, which should inform

\textsuperscript{699} ibid p48
the new LC legislation. This document proposes that any new LC legislation start from the principle that everyone should be presumed to be capable of making their own decisions and that the focus should be on the supports needed to enable people to do this. It proposes three levels of support:

1. Minimal support required to make decisions such as accessible information
2. Supported decision-making where the person is supported by a trusted other in making decisions
3. Facilitated decision-making – to be used as a last resort where the person’s ‘will and preferences’ are not known and where a representative determines what the person would want based on what they know about the person and their best understanding of their wishes.

The recognition of universal LC, with facilitated decision-making as a last resort, would alter significantly the role of the court from that envisaged in the Scheme of Mental Capacity Bill. A central focus on universal LC would mean that the court’s role would be to protect LC and to ensure that the supports required for the exercise of LC were in place. The requirement then would be for the state and its agents to establish these support structures and mechanisms and ensure that they are tailored to the individual needs of the person, even in ‘hard cases’ where the person’s will and preferences are extremely difficult to discern. This is a major shift in attitude for many, and the change would have to be accompanied by efforts to inform and train those within legal, health and personal social services who have responsibility and influence over the lives of people with impaired cognitive abilities. As Keys points out ‘Successful law reform presupposes a significant attitudinal change in the mind-set of public and civil servants, policy makers and other key players, like the judiciary, and medical and other assessors of capacity. Law reform, as the key change, has to be underpinned at a more substantive level by embracing the notion of capacity as an integral part of all human beings.’ Highlighting the need for a universal conception of LC she also notes the need for an on-going assessment of LC, for advocacy supports to be available to the person and for accessible information and communication systems. Fundamental to the shift to a universal LC framework is the need to

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provide opportunities for people to develop their decision-making skills in real life and in order for this to happen people must be enabled to live and participate in their communities on an equal basis with all other citizens.

8.7. Equality legislation

The prohibition of discrimination against people with disabilities is one of the building blocks of a society that supports the right to IL and community inclusion. To achieve IL disabled people must have access to all of the same services and facilities as the rest of the population and have the support needed to do this. This entails prohibiting discrimination, adapting or designing services to include disabled people, provision of reasonable accommodation and the availability of support for individuals to access services. Equality legislation in Ireland aims to eliminate discrimination in the areas of employment and access to goods and services. As noted the definition of disability in the legislation while being medically orientated appears to be well suited to the purpose of prohibiting discrimination.

The Equality Tribunal was established under the Employment Equality Act 1998 to hear complaints of alleged discrimination in employment on the basis of any of the nine grounds stipulated in the Act i.e. age, family status, marital status, religious belief, sexual orientation, membership of the Traveller community, disability, gender and race. The Tribunals’ mandate was extended under the Equal Status Act 2004 to cover discrimination in the provision of goods and services. It is an independent quasi-legal institution and its decisions are legally binding. Decisions of the Tribunal can be appealed to the Circuit Court and thereafter to the High Court.

The Equality Authority was also established as an independent body under the Employment Equality Act in order to work towards the elimination of discrimination and promote equality of opportunity. Like the Tribunal the mandate of the Authority was extended to encompass the Equal Status Act. One of its functions is to provide information about, and keep under review, workings of the equality legislation. One of methods used by the Authority in combating discrimination is to pursue cases which have strategic significance in bringing about change. In 2008 the Equality Authority budget was cut by 43%, raising questions about the commitment of government to combating discrimination.
8.7.1 Discrimination

Both the Equal Status Act and the Employment Equality Act (amended by the Equality Act in 2004) prohibit discrimination in the basis any of the nine grounds. Discrimination in general is defined as less favourable treatment of a person on the basis of any of the grounds than another person who is not a member of any of the groups named. In the case of disabled people it includes situations where a person is treated less favourably than a person with a different disability. The definition also includes mistreatment on the basis of present, past and possible future membership of any of the suspect groups as well as imputed membership and discrimination by association.\textsuperscript{705} Disability-based discrimination is defined as including a denial of reasonable accommodation which is ‘... a refusal or failure by the provider of a service to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities, if without such special treatment or facilities it would be impossible or unduly difficult for the person to avail himself or herself of the service.’\textsuperscript{706} The Equality Act 2004 in amending the Employment Equality Act also states that reasonable accommodation must be provided to enable a disabled person access employment or training or advance in employment.\textsuperscript{707} In the context of the Irish social housing system reasonable accommodation has been found by the Equality Tribunal to include a) direct consultation with disabled housing applicants b) housing policies and practices which are transparent, fair, timely and flexible, c) provision of information in accessible formats and d) assessment and allocation processes which take account of the full range of disability-related needs.\textsuperscript{708}

Reasonable accommodation is limited in the employment area by the ‘disproportionate burden’ clause whereby a failure to accommodate a person with a disability does not constitute discrimination if the costs to the employer would be represent a ‘disproportionate burden.’ For Providers of goods and services reasonable accommodation is confined to measures which give rise to no greater than a ‘nominal cost’. In assessing what would be considered disproportionate the Equality Act specifies that account should be taken of the cost of the adaptation, the size and resources of the business and the availability of public

\textsuperscript{705} Equal Status Act 2000, Section 3.1 (a) and (b) and Employment Equality Act
\textsuperscript{706} Equal Status Act 2000 Part 1 Section 3 (4) (1)
\textsuperscript{707} Equality Act 2004 Part 2, Section 9 (3)(a)
funding. Until the enactment of the Equality Act in 2004 failure by employers or service providers to provide reasonable accommodation was permissible if the costs were other than nominal. The Equality Act removed the ‘nominal cost’ provision in relation to reasonable accommodation in the employment context, but did not do so in the supply of goods and services. O’Cinneide highlights the discrepancy between the duties on service providers and on employers in providing reasonable accommodation on the basis of cost. Highlighting that the amendments in the Equality Act regarding costs of providing reasonable accommodation only apply to employment, he points out that ‘… providers of education, goods and services, and housing (i.e. those areas where the Equal Status Act 2000 applies) are still only obliged to incur nominal costs in making reasonable accommodation.’

The denial of reasonable accommodation as a form of disability-based discrimination is recognized in international human rights law. The CRPD’s definition of disability-based discrimination also includes the denial of reasonable accommodation along with the undue burden provision.

Indirect discrimination is prohibited under the Equality Act where it is defined as occurring ‘… where an apparently neutral provision puts a person referred to in any paragraph of section 3(2) at a particular disadvantage compared with other persons, unless the provision is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary.’ Where indirect discrimination can be proven it holds the potential to be a powerful tool. It can lever system-wide change, which has implications for the particular group to which the individual belongs as well as for other suspect groups. However, proving indirect discrimination is complex and there have been few cases in Ireland in relation to disabled people where it has been successfully proven. However, in relation to the supply of goods and services an important case of indirect discrimination was successfully proven in 2009. In the case of Thompson v Iarnrod Eireann the Equality Tribunal found that the rule requiring free travel pass holders to acquire their train ticket on the day of travel indirectly

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711 Equality Act 2004 Part 3, Section 48(c) amending Equal Status Act 2000 Section 3
712 Equality Tribunal, Thompson v Iarnrod Eireann/Irish Rail DEC – S2009-015
discriminated against disabled people. This rule only applied to holders of free travel passes and other options such as acquiring monthly tickets was also unavailable to free travel pass holders. The tribunal concluded that ticketing rules for travel pass holders put the complainant at a disadvantage compared to other users of the service and that this amounted to indirect discrimination on the basis of his disability.

A recent case, alleging that a school’s admission policy which gave priority to sons of past pupils, indirectly discriminated against Travellers was upheld by the Equality Tribunal. It was appealed by the school to the Circuit Court, where the tribunal’s judgment was overturned and in 2012 the lower court’s judgment was affirmed by the High Court. This case, although ultimately unsuccessful, illustrates the potential of indirect discrimination cases to impact on wider systems. If it had succeeded, the implications for school admission policies across the state would have been very significant not just for members of the Traveller community, but also for other groups who are less likely to meet the ‘children of past pupils’ criterion.

8.7.2. Goods and Services and Accommodation

Part II of the Equal Status Act prohibits discrimination in the provision of goods and services including services generally available to the public or a section of the public. Services include financial services, recreation facilities, transport, cultural activities and clubs. Discrimination in relation to disposal of premises, termination of tenancies and provision of accommodation is also expressly prohibited by the Act. However, this section also provides that a premises reserved for ‘... the use of persons in a particular category of persons for a religious purpose or as a refuge, nursing home, retirement home, home for persons with a disability or hostel for homeless persons or for a similar purpose, a refusal to dispose of the premises or provide the accommodation to a person who is not in that category does not, for that reason alone, constitute discrimination.’ This could be seen to cement the segregated nature of residential accommodation for PWD, as a refusal to accommodate non-disabled people does not amount to discrimination. The likelihood of non-disabled people seeking accommodation in traditional...
residential centres is low, however, several Housing Associations cater exclusively for people with disability, in particular people with intellectual disabilities.\textsuperscript{715} Some of these housing associations are in effect sister organisations of the disability service providers, although they are legally separate entities. There is no doubt that these housing associations have provided a route to good quality social housing for many people with disabilities. The housing provided by these housing associations can accommodate several people with intellectual disability together with additional space for support staff. Each person holds a tenancy with the housing association, bringing a security of tenure unavailable in group homes or residential centres – and an assumption of legal capacity on the part of the tenants. However, beyond this, there can often be little distinction between the character of a traditional group home and a housing association house. Both represent in effect segregated or special housing for people with disabilities. The recent HSE Report of the Disability Policy Review Group, commenting on the phenomenon of housing associations established by disability service providers, recommend that disability services no longer establish and run housing associations.\textsuperscript{716} An alternative to this which could usefully be considered would be broadening membership of the boards of disability-specific housing associations and/or broadening of eligibility criteria for housing applicants to include people other than those with disability. As it stands at present a refusal by a disability-specific housing association to provide housing to non-disabled applicants is legitimate in law and does not constitute discrimination.

Section 6 of the 2009 Housing Act allows housing authorities, in their allocation schemes, to reserve a proportion of their housing stock for particular classes of households and under the Equality legislation this is not discriminatory. In the context of the large numbers of people with intellectual disabilities currently living in institutions, the HSE report \textit{Time to Move on from Congregated Settings} recommends that housing authorities adopt this approach in order to facilitate the move into mainstream community-based housing.\textsuperscript{717} Local authorities currently adopt this approach in attempting to address the housing needs of older people and Travellers. There is a danger in this that specialist housing for particular

\textsuperscript{715} For example Cope Foundation Housing Association, St Michael’s House Housing Association, Roscara Housing Association, Mayo Living Western Care
\textsuperscript{716} Department of Health \textit{Value for Money and Policy Review of Disability Services in Ireland}, Dublin, Department of Health (July 2012) p98
\textsuperscript{717} Health Services Executive, \textit{Time to Move on from Congregated Settings: A strategy for Community Inclusion}, Dublin, HSE (June 2011) p151.
groups of people could lead to ghettoisation and segregation but the stipulation in Section 15 that housing plans must take account of the need to avoid undue segregation between people of different social backgrounds should counteract this possibility.

8.8. Housing legislation

8.8.1 Housing Act 1966

The first mention of disabled people in Irish housing legislation appears in the Housing Act of 1966. Prior to this time people with disabilities presumably lived at home with family or were accommodated in state-funded institutions operated by religious or voluntary bodies under the Health Acts. The invisibility of disabled people in mainstream housing legislation to this point is reflective of their general invisibility in official statistics, so that for example the 1961 and 1966 census's of population only record disabled people living in ‘mental homes and certain other institutions’.[718] This exclusion was not unique to disabled people and in the case of Travellers this exclusion of their housing needs from legislation was more extreme.[719] The overall thrust of the 1966 Act was to improve the standard of housing in rural and urban areas, eliminate unfit housing and relieve overcrowding. To this end it made provision for the awarding of grants and loans for house improvements and for the purchase, building of extensions of farm houses.

The Act also provided for the granting of loans to local authorities to provide housing for old people, people living in overcrowded conditions and for people in housing need because of medical/compassionate reasons, including presumably disabled people. Importantly the Act stipulates that Housing Authorities should, every five years, conduct inspections of overcrowded and inadequate housing in their areas and prepare proposed building programmes to meet identified housing needs. These building programmes could give priority to particular categories of people, projects or areas. The local authority building programmes were required to, among other priorities, have regard to ‘... the provision of

[718] CSO, Census of Population 1966 Table 3 Persons, Male and Female Classified by Occupation in 1961 and 1966
s/census1966volume4-occupations Accessed 13/12/2011
[719] Kenna, P. Housing Law, Rights and Policy. (2011) Clarus Press, Dublin, points out that it was not until the enactment of the Housing Act 1988 that the housing needs of Travellers were included in legislation. p52
adequate and suitable housing accommodation for persons (including elderly or disabled persons) who, in the opinion of the authority, are in need of and are unable to provide such accommodation from their own resources. Section 60 formed the legislative basis for a Scheme of Letting Priorities (SLP) to be developed by housing authorities in the allocation of its housing stock to those in housing need. The SLPs were to have regard to the provision of housing for people with disabilities and, reflecting public health concerns of the time, to the provision of suitable housing to people with tuberculosis - among other priorities. This section of the Act was amended by the Housing (Miscellaneous Provisions) Act 1979 which provided for prioritisation by housing authorities of particular classes of people and that, where allocations were to be made on medical or compassionate grounds, that a report from the medical officer of health was required.

Section 62 of 1966 Act established the process by which housing authorities may repossess their property for non-payment of rent or where the tenant is no longer residing there. This section was amended in 1997 to include eviction on the basis of anti-social behaviour. This section of the Act has been judged by the Supreme Court to be incompatible with the European Convention on Human Rights. This will be discussed further below.

8.8.2. Housing (Miscellaneous Provisions) Act 1979

In terms of accommodation for people with disabilities, one of the most important feature of the 1979 Housing (Miscellaneous Provisions) Act was the introduction of grant schemes to approved voluntary bodies or cooperatives for the provision of housing. Under Section 7 approved housing bodies providing housing to elderly people or their carers are covered by the Act. This section was amended by the 1988 Housing Act to include approved housing bodies providing housing to elderly persons or ‘... such other class or classes of persons as may be specified in the regulation, or for the accommodation, as his normal place of residence, in the house or houses or within the precincts thereof, of a person providing welfare or caretaker services for such persons or such class or classes of persons.

This allowed, in effect, for the development of supported social housing for

720 Housing Act 1966 Part 5, Section 55, 3 (c)
721 Housing (Miscellaneous Provisions) Act 1979 Section 16
722 Housing (Miscellaneous Provisions) act 1997 Section 3
723 Housing Act 1988 Section 26
disabled people. As such it was a key advance in the housing options open to people with disabilities who required support to live in their own home. It has proved to be one of the most effective routes into mainstream housing for disabled people with the Irish Council for Social Housing reporting that in 2006 82 housing associations were providing 2064 housing units for PWD.\textsuperscript{724} This survey also reported that these housing associations provided practical and functional support to tenant, including domestic and support staffing funded by the HSE or from the associations own resources. It is, however, important to note that the support provided by many of the housing associations was described as including ‘... communal meals, laundry, security, wardens and houseparents ...’ which must raise the question of the qualitative difference between some housing association provision and that provided in traditional group homes.

The 1979 Act enabled the provision of grants to PWD to adapt their homes and the Housing Regulations in 1980 provided the statutory basis for this grant scheme. These regulations which provided that housing authorities could ‘... pay a grant to a person for the provision of an additional room or chalet or the carrying out of other structural works that, in the opinion of the authority, are reasonably necessary for the purpose of rendering a house more suitable for the accommodation of a member of the household, ...’\textsuperscript{725} The grant is payable in the cases of people with physical or intellectual disabilities or mental illness

While the provision for grant-aided home adaptations for disabled people was already in place, it was updated in 1993 with the introduction of the Disabled People’s Grant Scheme (DPG) under the Housing (Disabled Persons and Essential Repairs Grants) Regulations\textsuperscript{726}. In 2006 the NDA published a review of the operation of the DPG\textsuperscript{727} which pointed to an increase in usage of and costs of the DPG from 1994 to 2002 at which point a decrease was recorded. About 2% of the total housing stock had had an adaptation financed from the DPG in 2002.\textsuperscript{728} The report concluded however, that there was an uneven geographic distribution of payments under the scheme, different local authorities had different prioritization of disability criteria and waiting times varied across the country. The review

\textsuperscript{724} Irish Council for Social Housing \textit{Enhancing Choices for People with Disabilities in the Community: Survey Findings on Social Housing Provision for People with Disabilities in the Voluntary Housing Sector} (September 2007) Policy and Research Series, ICSH, Dublin
\textsuperscript{725} Housing Regulations 1980 SI 296/1980, Section 22
\textsuperscript{726} Housing (Disabled Persons and Essential Repairs Grants) Regulations, Statutory Instrument 1993 SI 262/1993
\textsuperscript{727} National Disability Authority \textit{A Review of the Operation of the Disabled Persons Grant Scheme and Recommendations for Change}, Disability Research Series 6, Dublin, NDA (October 2006)
\textsuperscript{728} \textit{ibid} p29
recommended, among other things, the introduction of a formal national policy to standardize the scheme, the targeting of funding at those areas with the largest proportions of disabled people, an increase in the level of grant aid available and the inclusion of the definition of ‘disability’ from the Disability Act. Following the NDA review the scheme was updated to include national income limits and grant levels and the scheme was renamed as the Housing Adaptation Grant for People with a Disability. In 2008 a total of 788 grants were paid by local authorities under the new scheme to the value of €7,626,000 giving an average grant level of €9,677 per claimant. In addition 415 grants were made under the Mobility Aids Grants scheme in 2008 to the value of €1,442,000, an average of €3,475.00 per claimant. The Mobility Aids grants form part of the Housing Adaptation Scheme and is primarily, but not exclusively, aimed at older people.

Provision for the re-payment of adaptation grants in the event of the sale of the adapted property was made under Section 99 of the 2009 Housing (Miscellaneous Provisions) Act. Where the house is sold within one year of the awarding of the grant 85% of the total amount must be repaid with this percentage falling annually for the following 4 years.

8.8.3. Housing Act 1988

One of the main issues dealt with in the 1988 Housing Act is that of homelessness.

The Act defines a person as homeless where

(a) there is no accommodation available which, in the opinion of the authority, he, together with any other person who normally resides with him or who might reasonably be expected to reside with him, can reasonably occupy or remain in occupation of, or

(b) he is living in a hospital, county home, night shelter or other such institution, and is so living because he has no accommodation of the kind referred to in paragraph (a), and he is, in the opinion of the authority, unable to provide accommodation from his own resources.

This has a particular relevance for PWID and people with mental illness living in

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730 Department of the Environment, Community and Local Government Housing Statistics: Social and Affordable Housing
731 Housing Act 1988 Section 2
accommodation owned or operated by the HSE or voluntary bodies. People living in group homes or residential centres\textsuperscript{732} and in community residences\textsuperscript{733} usually are long-term residents and have no security of tenure. It is arguable that they fall within the definition of homeless in the Act in that they are living in a ‘hospital, county home, night shelter or other such institution’ because they do not have anywhere else to live. For many this is because the support they receive in these establishments - which they require - is not available elsewhere in the community. Yet people in these situations are not recorded as homeless in official statistics and, on the whole, do not appear on local authority housing waiting lists as requiring housing or housing supports.

Sections 8 and 9 outline the duties of housing authorities to conduct regular housing needs assessments and to prepare reports on housing need. Reports on housing needs assessment should include information on the numbers of households with a housing need arising from currently unfit housing conditions, overcrowding, involuntary sharing and homelessness. The criterion of housing need arising from involuntary sharing is also pertinent to disabled people in residential settings as the extent to which people voluntarily share with their co-residents must be at least questionable. Is it more likely that they share because it is only in such places that the support they require is available and would they continue to share if the necessary support was available in their own homes or in mainstream housing?

The housing needs of disabled people are mentioned specifically in these provisions in that regard must be given to people whose housing needs arise from a disability and on medical or compassionate grounds. In addition regard must be given to needs arising from the sharing of accommodation where people have a requirement for separate accommodation. As noted, this stipulation could be applicable to people involuntarily sharing in group homes, residential centres and community residences.

A significant development in the assessment process is the requirement that housing authorities notify local health board and voluntary organisations providing residential or welfare services of their intention to conduct the housing

\textsuperscript{732} According to the Health Research Board, *National Intellectual Disabilities Database Annual Report 2011*, Dublin, HRB (2011) Table 3.2, p37 this figure amounts to 8,214 people - includes group homes (possibly including housing association housing), residential centres, ‘other’ defined as psychiatric hospitals, intensive placements, nursing homes, mental health community residences and full-time residential support places.

needs assessment. Clearly this represented an intention to include the housing needs of people with disabilities and other groups supported by the health authorities in the assessment. However, as discussed above, despite this, the numbers of people with disabilities recorded as having a housing need remain extremely low\textsuperscript{734}. The apparent low level of housing need among disabled people, as reflected in the numbers appearing on housing authority waiting lists, must be taken in the context of the numbers of people living on health service-funded accommodation and the fact that in 2008 over 4,000 PWID were living in large congregated settings\textsuperscript{735}. Clearly these people are not being recorded as in need of housing by the housing authorities despite the fact that their current accommodation is inadequate in many respects. Not least of which, is the lack of security of tenure, which is one of the hallmarks of adequate housing as defined by the UN\textsuperscript{736}. The pattern of institutionalisation and segregated residential provision for disabled people still remains endemic in Irish society and despite some efforts in the legislation to become more inclusive, this has still not been achieved.

Each housing authority is required to develop a SLP to be approved by the Minister, which determines the order of priority to be accorded in the letting of dwellings to people in housing need who are included in the housing needs assessment. It is clear that many people with disabilities in need of housing are failing to get to this first stage. This section of the Act allows housing authorities to set aside a number of dwellings for particular categories of people, and this provision has been used by several local authorities to provide accommodation specifically designed for elderly people, Travellers and people with physical disabilities. In developing their SLPs housing authorities are required to have regard to medical reports, which is clearly relevant to disabled people who will require evidence of the existence of an impairment. In assessing housing need housing authorities are required to ‘... maintain a reasonable balance between the respective needs of the classes of persons.’\textsuperscript{737} Housing authorities have responsibilities towards all people assessed as having a housing need and must be

\textsuperscript{734} Department of the Environment 2005 Housing Needs Assessment – Extract from 2005 Annual Statistics Bulletin - noted that in 2002 423 households were recorded as in need of housing because of a disability, this rose very slightly to 480 in the 2005. The DoE Annual Housing Statistics Bulletin 2008 recorded a significant increase to 1,155. Housing Agency Housing Needs Assessment 2011 Housing Agency, Dublin (2011) recorded a further increase to 1,315.

\textsuperscript{735} Health Services Executive, Time to Move on from Congregated Settings: A strategy for Community Inclusion, Dublin, HSE (June 2011) p50


\textsuperscript{737} Housing Act 1988 Section 20.1
fair in their procedures to all applicants. It is arguable that housing authorities should set aside a proportion of their dwellings for people with disabilities, given their exclusion from mainstream housing options for many decades. This is, in fact, one of the recommendations of the HSE report on congregated settings.\(^\text{738}\) Of course other groups can equally make the same arguments, but the particular history of institutionalisation on the basis of disability strengthens the argument that positive actions to address this by housing authorities is warranted. This arguably should be the case at least until the numbers of people with disabilities accessing mainstream social housing reflects the actual numbers of disabled people needing housing and/or until the larger congregated settings in which people currently live are replaced by community-based housing.

### 8.8.4. Housing (Miscellaneous Provisions) Act 1997

The 1997 Act deals primarily with the issue of anti-social behaviour. It provides a definition of anti-social behaviour as firstly, the possession, manufacture or distribution of drugs and secondly, any behaviour which causes danger, injury, damage, loss or fear to another person. This includes violence, threats, intimidation, coercion, harassment or obstruction. An Excluding Order may be issued by the District Court at the request of the housing authority to any tenant considered to be involved in anti-social behaviour. In addition a housing authority may refuse to let a property to a person whom they consider to have been engaged in anti-social behaviour. While the Act makes no reference to people with disabilities, or to any other specific groups, the issue can be of particular significance to disabled people living independently in their own homes. A 2007 report by the Disability Rights Commission in the UK reviewing studies of anti-social behaviour and disabled people indicated that ‘... a consistent picture emerges ... of very high rates of susceptibility to behaviour which falls within the definition of anti-social behaviour, and which is often targeted at people because of their impairment.’\(^\text{739}\) The same report also states that the evidence suggests that those subject to anti-social behaviour interventions (such as anti-social behaviour orders) often have mental health problems, intellectual disabilities and neurological disorders.\(^\text{740}\) It is likely that the picture of anti-social behaviour

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\(^{738}\) Health Services Executive, *Time to Move on from Congregated Settings: A strategy for Community Inclusion*, Dublin, HSE (June 2011) p515

\(^{739}\) Disability Rights Commission *Disabled people’s experience of anti-social behaviour and harassment in social housing: a critical review*. London, DRC (August 2007) p74

\(^{740}\) *ibid* p95
directed at and perpetrated by disabled people is similar in Ireland.

8.8.5. Housing (Miscellaneous Provisions) Act 2009

The enactment of the 2009 Act marked a change in emphasis in relation to social housing in Ireland. The emphasis moved from provision of housing to an increased emphasis on social housing supports. Social Housing Supports is defined in Section 19 as including direct provision of housing, provision of housing by approved housing bodies, the sale of dwellings, rental accommodation agreements, provision of caravans sites for Travellers and the provision of sites for building. The housing needs assessment incorporates both housing and housing supports needs and the services to be provided by housing authorities include both.

The Act introduced the concept of Housing Service Plans by housing authorities. Housing authorities must set out the requirements for the provision of housing services in their area and the means by which they plans to meet these needs. The Act also draws a distinction between financial supports – such as the shared ownership scheme, adaptations, housing grants etc – and non-financial supports such as support to formerly homeless people to enable them live in their new homes. Housing service plans must include both types of support as well as plans in relation to building standards, regeneration plans and social housing needs assessment. Comments on the content of the plan must be sought from relevant bodies including adjoining local authorities, the HSE, bodies providing accommodation or shelter, the homelessness consultative forum, the Traveller accommodation consultative committee and any other relevant local community bodies. Although not listed in the Act, this consultation process is open to input from disability advocacy groups and from disability service which provide residential services.

From the perspective of disabled people one of the most significant developments in the housing needs assessment process is the expansion of the criteria used in the assessment to include a greater emphasis on disability-related needs. Statutory Instrument 84 (2011) giving effect to this part of the Act at Section 23 specifies that

‘In determining a household’s need for social housing support, the housing authority of application shall have regard to the following matters relating to the household’s current accommodation.’
(a) whether it is an institution, emergency accommodation or a hostel,
(b) whether it is overcrowded within the meaning of section 63 of the Act of 1966,
(c) its fitness for human habitation, having regard to the matters set out in the Second Schedule to the Act of 1966,
(d) the extent to which it meets any accommodation requirement arising from the enduring physical, sensory, mental health or intellectual impairment of a household member
(e) where it is shared with another household, whether the household that has applied for social housing support has a reasonable requirement for separate accommodation, and
(f) whether it is unsuitable for the household’s adequate housing -
   (i) in any other material respect, having regard to particular household circumstances, or12 [84]
   (ii) on exceptional medical or compassionate grounds.

For disabled people this is an important development and, in particular, the enquiry as to whether the applicant is currently living in an institution, opens the way for people living in segregated residential services.

Section 22 details the framework for allocation schemes (scheme of letting priorities in previous Act) to be developed by housing authorities determining the order of priority for allocations. Allocation schemes may include provision for reserving a proportion of dwellings for particular classes of households and for people transferring from other forms of social housing support – a provision which may have particular relevance for people with disabilities moving from accommodation provided by health or disability agencies.

An important feature of the 2009 Act was the legislative provision for the Residential Accommodation Scheme (RAS), which to this time had been operated on a pilot basis. The scheme was first introduced in 2004 as a government initiative aimed at eliminating long-term dependence on Rent Supplement - which was designed as a short-term income support – and enhancing local authority response to long-term housing need. Rent Supplement is one part of the broader Supplementary Welfare Allowance scheme operated by the Community Welfare Service, which provides short-term or emergency support to people whose means are insufficient to meet their needs. While Rent Supplement is an income support measure, the RAS is designed as a longer-term accommodation support scheme which can be used to provide accommodation to people assessed by housing authorities as having a housing need. It operates to enable local authorities access
the private and voluntary housing sectors in order to meet long-term housing needs, moving housing authorities away from direct provision of social housing. It provides a greater degree of security to tenants than in the private sector, as housing authorities are obliged to source suitable alternative accommodation for tenants where private landlords participating in RAS wish to discontinue their leasing agreement. It should also operate to improve standards of accommodation in the private rental sector as all RAS properties must meet minimum statutory standards and RAS landlords must be registered with the Private Residential Tenancies Board. The scheme was evaluated as part of the Value for Money and Policy Review conducted by the government in 2009. Although the scheme was still in its infancy at this point, the review concluded that overall RAS is an effective and efficient way of meeting housing need. Importantly the review concluded that the objectives of ‘... acquisition of high quality accommodation, security of tenure, facilitation of greater social inclusion through return to employment, and the provision of quality customer service was generally positive and revealed a high degree of satisfaction among recipients.’

In order to qualify for RAS people must, in general, be in receipt of Rent Supplement for a minimum of 18 months, so in effect eligibility for Rent Supplement is a pre requisite for eligibility for RAS. However, people living in HSE provided accommodation or accommodation provided by an organisation on behalf of the HSE where there is residential care staff, are deemed to be ineligible for Rent Supplement. Practices in this regard vary across the country with some people leaving residential accommodation being granted Rent Supplement and some being deemed ineligible. This is an issue which requires attention in order to facilitate access to mainstream housing for PWD.

The transfer of people from Rent Supplement to RAS began in 2005 and by 2008 9,401 long-term recipients had moved to the new scheme. So although RAS has been successful in enabling housing authorities to access the private and voluntary housing sectors in order to meet housing need, the overall demand for

social housing has increased significantly\textsuperscript{744}. Nonetheless it provides a cost-effective\textsuperscript{745} additional route to more secure good quality housing for disabled people and others in need of housing.

RAS and Rent Supplement provide no specific disability-related provisions and in this context it is interesting to note a recent decision in the UK in relation to Housing Benefit - the equivalent accommodation supports. Since 2011 Housing Benefit regulations provide that account be taken of the additional space required by disabled claimants who require overnight care.\textsuperscript{746} In May 2012 the Court of Appeal ruled that this provision should be extended to families with disabled children who cannot share a room because of the nature of their disability.\textsuperscript{747}

8.9. European Convention on Human Rights Act

Prior to the enactment of the European Convention on Human Rights Act in 2003 the influence of the ECHR in Irish law and in the courts was one of moral authority as opposed to having legal enforceability. Although the Irish government had signed up to several international human rights instruments and treaties, the enforceability of such international law in the courts was presented with an ‘\textit{insuperable obstacle}’\textsuperscript{748} by the traditional interpretation of certain articles of the Irish Constitution. Article 29.6 states that ‘\textit{No international agreement shall be part of the domestic law of the State save as may be determined by the Oireachtas}.’ This Article read in conjunction with Article 15.2, which vests the power of law-making solely in the Oireachtas, represented, according to O’Connell an obstacle to ‘\textit{the enforcement of international human rights law before the Irish courts in the absence of some legislative instruments of incorporation of such laws}’\textsuperscript{749} He points to the traditional orthodoxy which means that ‘\textit{unincorporated international human rights treaties apply to but not within Ireland when it comes to judicial...}’

\textsuperscript{744} Demand for social housing rose from 42,946 in 2005 (Dept of Environment, Community and Local Government 2008 Housing Needs Assessment – Extract from 2008 Annual Housing Statistics Bulletin Table 1 Net Housing Need) to 98,318 in the 2011 (The Housing Agency Housing Needs Assessment 2011 p1 Table 1 – Net Housing Need 31\textsuperscript{st} March 2011)

\textsuperscript{745} See Housing Agency Comparative Financial Appraisal of the Projected Long-Term Costs of Social Housing Delivery Mechanisms, Dublin, The Housing Agency (January 2011) Tables 3.13a and 3.13b Cost variance between RAS units and Rent Supplement units p52-53

\textsuperscript{746} Social Security Housing Benefit (Amendment) Regulations 2010 SI No. 2835 Section 2

\textsuperscript{747} Burnip v Birmingham City Council & Anor [2012] EWCA Civ 629


\textsuperscript{749} ibid p4
enforcement. The passage of the ECHR Act charts a route around this dualistic approach which draws a sharp distinction between international and domestic law in the Irish courts, and enables the courts to more directly apply the ECHR in its decisions and considerations and bring a closer alignment between the two.

As part of the Good Friday agreement the Irish government undertook to establish a Human Rights Commission and to examine the question of incorporation of the ECHR into Irish law. Following some debate the ECHR Act was incorporated at sub-constitutional level, which in effect means that the courts are obliged to consider the protections provided by the Constitution in the first instance and thereafter those provided by the ECHR. The ECHR Act provides for three significant measures, which offer potential in the domestication of European Court jurisprudence into Irish law and practice.

### 8.9.1 The interpretative obligation

Section 2 of the ECHR Act outlines the interpretative obligation which requires the courts to interpret and apply the law in a manner compatible with the ECHR. The courts must take judicial notice of declarations, decisions and opinions of the European Court, the European Commission of Human Rights and the Council of Europe.

Since incorporation the Irish courts are increasingly relying on the jurisprudence of the European Court in conjunction with Irish case law in their decisions. Two cases which came before the high court, both of which were decided on the basis of ECHR Article 8 rights as they apply to people with disabilities, illustrate the application of the European Court case law in the Irish context. In the case of *O’Donnell (a minor) and Others v South Dublin County Council* the plaintiffs alleged that the failure of the local authority to provide them with a second mobile home to adequately accommodate the family was an infringement of their rights under Article 8. The family, who were members of the Travelling community, included three children with very significant disabilities. Justice Laffoy recognized that the family had an urgent need for more appropriate accommodation as their living conditions were over-crowded, unsafe and unsuited to the needs of the

750 ibid p5
752 European Convention of Human Rights Act 2003 Section 2(1)
753 *O’Donnell (a minor) and others v South Dublin County Council* [2007] IEHC 204
children. In deciding whether the local authority was obliged to provide alternative accommodation she examined pertinent cases from the European Court. In particular reference was made to the case of *Chapman v United Kingdom* 

754 in which the European Court noted that there is ‘...a positive obligation imposed on the Contracting States by virtue of Article 8 to facilitate the Gypsy way of life’. 

755 However, in this case the European Court also noted that Article 8 does not recognize the right to be provided with a home and that decisions about the provision of housing rests with national legislators. 

756 Justice Laffoy considered whether the Housing Act 1988 was ECHR compatible in accordance with Sections 2 and 3 of the ECHR Act. Section 13(2) of the 1988 Housing Act provides that ‘A housing authority may provide, improve, manage and control sites for caravans used by persons to whom this section applies, and may carry out any works incidental to such provision, improvement, management or control, including the provision of services for such sites’. In agreeing with the defense that this did not imply that they should directly provide caravans for people, she accepted that such an interpretation would have a significant knock-on effect on the local authority’s housing policy in terms of resources and that this would ‘...cross the boundary between interpretation and amendment [of the 1988 Act]’. 

757 From the point of view of obligations towards Traveller families in need of accommodation, therefore, the State was adjudged to be fulfilling its ECHR commitments in accordance with Section 2 of the ECHR Act. However, obligations towards people with disabilities arising from the ECHR were also considered. Looking at the circumstances of the three disabled members of the family, Justice Laffoy noted that the issue was whether compliance with Article 8 required the local authority to provide an additional wheelchair accessible mobile home to the family. In deciding this she stated ‘In determining that issue the court must strike a fair balance between competing interests, the interests of the community as a whole, on the one hand, and the interests of the individual plaintiffs, on the other hand, within the margin of appreciation which the ECHR has held the State has.’ 

758 The Court found that the cost to the State of providing appropriate accommodation to this particular family would not be prohibitive and that the Article 8 rights of the three disabled members of the family had been breached. This finding did not, according

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754 Chapman v United Kingdom App. No. 27238/95 (ECtHR, 18 January 2001)
755 ibid para 96
756 ibid para 99
757 O’Donnell (a minor) and others v South Dublin County Council [2007] IEHC 204 p19
758 ibid p36
to Justice Laffoy, represent a ‘second guessing’ of the housing authority, but rather a decision to ensure that they carry out their functions in a manner compatible with the ECHR.\textsuperscript{759} In another case involving a Traveller family which included a disabled child, a similar conclusion was reached by the High Court in 2008\textsuperscript{760} with the Court holding that the Article 8 rights of a disabled daughter had been breached, but not those of the family as a whole.

\textbf{8.9.2. Obligations on organs of the state}

Section 3 of the ECHR Act obliges all ‘organs of the State’ to perform their functions in manner compatible with the ECHR.\textsuperscript{761} The Courts are specifically excluded from the definition of ‘organs of the State’. The Courts in the Irish judicial system may direct attention to legislative deficiencies but may not rewrite legislation. They do, however, have the power to direct administrative or operational changes on the part of organs of the state to ensure they comply with the principles of the European Court. This was the case in the \textit{M v Mental Health Commissioners} High Court case where the plaintiff challenged the review procedures of the Mental Health Tribunal, under the Mental Health Act 2001\textsuperscript{762}. The plaintiff alleged that the procedures available to her did not provide a sufficient independent review mechanism for the purposes of Article 5 of the ECHR in that the intervals for review were not specific enough. As a result of this ruling in favour of the plaintiff, the Mental Health Tribunal was required to amend its procedures to include a facility for more speedy reviews specific to individual cases. The issue of review procedures under the Mental Health Act for patients in mental health facilities again came under scrutiny in the recent \textit{M.X v HSE.}\textsuperscript{763} The plaintiff, who was deemed to lack the capacity to consent, was being treated for a mental illness against her wishes in the Central Mental Health Hospital. She alleged that her rights as outlined in the Constitution, the ECHR Act and the CRPD were being infringed. The Court found that there were adequate safeguards and review procedures in place to take account of the fact that the plaintiff lacked the capacity to consent to treatment. An important aspect of this judgment was that

\textsuperscript{759} ibid p38
\textsuperscript{760} O’Donnell and Others v South Dublin County Council [2008] IEHC 454
\textsuperscript{761} European Convention on Human Rights Act 2003 Section 3(1)
\textsuperscript{762} M v Mental Health Commissioners [2008] IEHC 441
\textsuperscript{763} M.X v Health Service Executive [2012] IEHC 491
consideration was given to the applicability of Article 12 of the CRPD in Irish law and as derived from EU law. Acknowledging that Ireland has not yet ratified the CRPD, the plaintiff argued that as an EU member State – and given that the EU has ratified the CRPD - Ireland is obliged to give effect to Article 12 as part of their obligations under the EU legal order. However, Justice McMenamin found that Article 12 does not fall within EU competence to act stating that ‘... the court does not consider that the UNCRPD can, as yet, be seen as a rule in the interpretation of an application of EHCR jurisprudence or, through that avenue, to E.U. rights law.’ Nonetheless the Court noted that ‘Although the UN Convention itself is not part of our law, it can form a helpful reference point for the identification of “prevailing ideas and concepts”, which are to be assessed in harmony with the constitutional requirements of what is “practicable” in mind.’ This latter statement is a strong indication that the Courts will be willing to pay heed to the CRPD and the case law arising from it even though it will not enjoy the same status in Irish law as the ECHR does under the ECHR Act.

In the housing sphere a case concerning the implications of Section 3 of the ECHR Act for local authorities using Section 62 of the Housing Act 1966 which was heard in 2008 is of particular interest. In the case of Pullen v Dublin City Council the local authority had instigated Section 62 proceedings against the plaintiffs in order to regain possession of the property and evict the Pullen’s from their house on the basis that they had engaged in anti-social behaviour. Mr. and Mrs. Pullen strongly denied this claiming that they had, in fact, been harassed and victimized by their neighbours. Both plaintiffs had disabilities, which was largely incidental to the case save for the additional vulnerability this created for them in the event of their eviction. The consequences for individuals who are evicted for anti-social behaviour from local authority accommodation are extremely serious – people in this situation are deemed to have made themselves deliberately homeless and become ineligible for re-housing by the local authority until such time as the local authority decides that they are fit to be reinstated on the housing waiting list. The Pullen’s claim in Court was that Dublin City Council by using Section 62 procedures, was, as an organ of the State, failing to perform its duties in a manner compatible with Articles 6 and 8 of the ECHR. Section 62 does not allow for an independent hearing on the merits of the decision to evict local authority tenants.

764 ibid para 45
765 ibid para 61
766 Pullen and Others v Dublin City Council [2008] IEHC 379
The Pullen’s claimed that there was an alternative mechanism available to the Council in the form of Section 14 of the Conveyencing Act 1881 which would have provided an independent forum to assess the merits of their case.

In his judgment of the case Justice Irvine referred extensively to earlier cases heard in the Irish courts and in the European Court. The lack of an independent tribunal, which could assess the facts of a disputed case raised particular concern for the Irish Court and for the European Court. Referring to the European Court case of Tsfayo v United Kingdom,\(^{767}\) in which a violation of Article 6 had been found, Justice Irvine pointed out that the Housing Benefit Review Board which decided on the applicants claim for back-dated housing benefit was lacking independence and expertise. He stated that ‘To my mind, the nature of the issues in the present case, having regard to the lack of independence at the first stage of the process, required a right to an independent merits-based hearing’.\(^{768}\) He further found that judicial review would be insufficient where there is a dispute as to the facts to meet the requirements of fair procedure of Article 6.

In relation to Article 8 Justice Irvine cited the landmark Connors case which outlined the standards to be used in determining whether an interference with these rights is justified i.e. it is ‘necessary in a democratic society’, is in pursuit of a legitimate aim, answers a pressing social need and is proportionate to the aim. Dublin City Council had claimed that although the resort to summary eviction was a sanction of last resort, it is nonetheless an essential management tool in their attempts to control anti-social behaviour and ensure good estate management.

The judge rejected this line of argument stating that ‘Whilst the defendants aim of swiftly recovering possession from those engaged in anti-social behaviour is laudable, having regard to the shortage of housing stock, such aims do not, in my view, justify the interference with the plaintiffs’ rights, as occurred in the present case, absent the presence of real procedural safeguards.’\(^{770}\) He concluded that the use of Section 62 proceedings in this case was not ‘necessary in a democratic society’ and that the Council had not carried out its functions in this regard in compliance with Article 8 of the Convention as required by under Section 3 of the ECHR Act.

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\(^{767}\) Tsfayo v United Kingdom App. No. 60860/00 (ECtHR, 14 November 2006) para 46

\(^{768}\) Pullen and Others v Dublin City Council [2008] IEHC 379 p36

\(^{769}\) Connors v United Kingdom App. No. 66746/01 (ECtHR, 27 May 2004)

\(^{770}\) Pullen and Others v Dublin City Council [2008] IEHC 379 p57
8.9.3 Declarations of Incompatibility

Section 5 of the ECHR Act allows the High Court or the Supreme Court to ‘...where no other legal remedy is adequate and available, make a declaration that a statutory provision or rule of law is incompatible with the State’s obligations under the Convention provisions.’ Where such a Declaration has been made by either Court the Taoiseach is obliged to lay it before the Dail within 21 days in order for the necessary legislative changes to be considered. However, pending such changes the Act allows for the ‘continuing operation or enforcement of the statutory provision or rule of law in respect of which it is made’.

Three Declarations of incompatibility have been issued by the High Court to date. The first of these was the case of Lydia Foy, a transgendered woman who wished to have her birth certificate altered in recognition her acquired gender. Of greater relevance here are the two further declarations issued, again in relation to Section 62 of the Housing Act 1966. Section 62, as noted, provides a process for local authorities to re-possess their property, but does not allow for any independent mechanism to review the merits of the decision to evict the tenants. Where a tenant refuses to give up possession of a property the local authority may apply to the District court for a warrant for possession. The District court may only examine whether the correct procedural formalities were followed by the local authority, and may not enquire as to the merits of the case. Where the correct procedures were followed by the local authority, the District court must issue a warrant – regardless of the arguments which the tenants may wish to put forward. Decisions of local authorities to evict tenants may be the subject of judicial review proceedings in the High Court. However, here also the merits of the case may not be considered, rather the Court may only consider the legality of the procedures followed. It should be noted that private tenants have recourse to such an independent tribunal under the Private Residential Tenancies Act 2004, which established the Private Residential Tenancies Board whose principal function is the arbitration of disputes between landlords and tenants in the private sector. The Irish Human Rights Commission in their policy statement on Section 62 point out that this difference in provision as between private and public tenants constitutes discrimination in contravention of Article 14 of the

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771 European Convention on Human Rights Act 2003 Section 5(1)
772 European Convention on Human Rights Act 2003 Section 5 (2)(a)
773 Foy v An t-Ard Chlárataimeoir & Ors [2007] IEHC 470
774 Donegan v Dublin City Council and Others [2008] IESC 288 and Donegan v Dublin City Council and Others [2008] IESC 288
Convention and recommends that this be rectified by amending legislation.\textsuperscript{775} In the \textit{Donegan}\textsuperscript{776} case the tenant was served with a Notice to Quit by the City Council for anti-social behaviour on the part of his son, who was residing with him. Mr. Donegan claimed that his son was a drug user not a dealer and was not engaged in anti-social behaviour. He claimed that Section 62 was incompatible with the ECHR and that the City Council was failing in its duty as an organ of the State to perform its function in compatibility with Section 3 of the ECHR Act. The claim that Section 62 was in breach of Article 8 of the ECHR was accepted by Justice Laffoy. In reaching this conclusion she extensively cited Connors \textit{v} UK\textsuperscript{777}, noting the standards set therein in relation to the justifications for interferences with Article 8 rights. In this case the Court agreed that that the applicant had been evicted in breach of Article 8 and turned to exploring whether this interference was ‘in accordance with the law’ and ‘necessary in a democratic society’ as required by Article 8(2). She further noted the ‘margin of appreciation’ allowable to States in deciding these issues but quoted the Connors judgment that ‘\textit{...in spheres such as housing, which play a central role in the welfare and economic policies of modern societies, it (the Court) will respect the legislature’s judgment as to what is in the general interest unless that judgment is manifestly without reasonable foundation ... Where general social and economic policy considerations have arisen in the context of Article 8 itself, the scope of the margin of appreciation depends on the context of the case, with particular significance attaching to the extent of the intrusion into the personal sphere of the applicant}’\textsuperscript{778}. The need for procedural safeguards to ensure that the State remained within its margin of appreciation was noted by the European Court – ‘\textit{In particular, the Court must examine whether the decision-making process leading to measures of interference was fair and such as to afford due respect to the interests safeguarded to the individual by Article 8}’\textsuperscript{779}. In applying these ECHR and European Court principles to the Donegan case, Justice Laffoy found that, although Section 62 is indeed in accordance with the law as it stands, it does not meet the ECHR requirement of ensuring that the decision-making process afford due respect to the Article 8


\textsuperscript{776} \textit{Donegan v Dublin City Council and Others} [2008] IEHC 288

\textsuperscript{777} Connors \textit{v United Kingdom} App. No. 66746/01 (ECtHR, 27 May 2004)

\textsuperscript{778} \textit{ibid} para 82.

\textsuperscript{779} \textit{ibid} para 83
interests of individual citizens. She concluded ‘There is no procedural safeguard built in to s. 62 under which the plaintiff’s contention that he is not in breach of his tenancy agreement can be adjudicated on independently on the merits nor is there any other means available to him under Irish law by which he can achieve that objective and, if his contention that he is not in breach is correct, stave off eviction from his home. In short, it is the law that is defective vis-à-vis Article 8.’ On this basis she granted a Declaration of Incompatibility under Section 5 of the ECHR Act. The decision was appealed to the Supreme Court where is was confirmed in 2012. The compatibility of Section 62 with the ECHR was again challenged in the High Court in the case of Dublin City Council v Gallagher and again found wanting. Another declaration of incompatibility was issued which was appealed to the Supreme Court where it was affirmed jointly with Donegan. Ms Justice Mary Laffoy noted that ‘... during its almost forty years lifespan up to the enactment of the Act of 2003, s. 62(3) was secure against a finding of constitutional invalidity.’ But the enactment of the ECHR Act has meant that finally, the inadequacy of Irish law in this particular instance has been demonstrated and legislative action to rectify this inadequacy is mandated.

8.10. Health and Personal Social Services

For many people with disabilities achieving independent living depends on having support to live in their own home and to be included in the community. This support is at least as important as having accessible housing or accessible community facilities. It is an inherent part of Article 19 which specifies that in addition to people having choice in where and with whom to live, that people must also have in-home, residential, personal assistance and community supports in order to prevent isolation or segregation and enable participation in the community. Where support is provided to groups or is specific to particular geographic locations this severely limits people’s ability to achieve IL and inclusion in the community.

The legislation which governs the state provision of personal support is contained...
in the Health Acts 1947 – 2007. The fact that personal support is provided for within health legislation reflects a historically predominant medical approach to disability on the part of the State and of society.

On the whole, Irish housing systems are reasonably accessible for disabled people, but the configuration of personal supports in legislation, policy and practice represents a major obstacle in achieving IL for many people. There are three fundamental issues inherent in current Irish legislation and policy regarding personal support services which create barriers to IL for many disabled people, in particular people with intellectual disabilities, which will be discussed in this section. These are

a) the lack of a clear definition of what exactly personal supports are and what the State is obliged to provide to PWID

b) the legislative skewing of support services towards groups as opposed to individuals and the lack of legislative provision for directing support funding towards individuals

c) the channeling of personal support services through the large voluntary disability service providers and the consequent challenges arising from managing the relationships between these agencies and the State.

8.10.1. History of institutionalisation and disability

Ireland has a long and sorry history of institutionalizing people who did not fit a rather narrow conception of what was considered normal and acceptable. This included not only people with intellectual and physical disabilities, but also people with mental illnesses, women who had children outside of marriage or were otherwise considered to be a moral threat and children who were orphaned, neglected, abandoned, committed criminal offenses or whose parents could not support them. In fact during the 1960’s Ireland had the highest rate of

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784 See Department of Justice and Equality Report of the Inter-Departmental Committee to establish the facts of State involvement with the Magdalen Laundries. Recorded 14,607 admissions to the Magdalen Laundries between 1922 and 1996 with the primary routes of entry being ‘self referral’, family, priest, transfer from other institutions and through the criminal justice system www.justice.ie/en/JELR/Pages/MagdalenRpt2013 Accessed 10/1/2013

institutionalisation in the world. Most of these institutions were run by religious orders with varying levels of State support, or in the case of mental illness, by the public authorities or by private benefactors. As suggested by the Department of Health policy document on mental health these institutions of various types ‘... represented an economic way of dealing with a whole range of social problems. This resulted in a lack of social service infrastructure, the effects of which are still seen today.’ Many people who were homeless, disabled, destitute, infirm or ill were admitted to institutions simply because they had nowhere else to go. In addition to providing a convenient and economic way of dealing with social problems, institutions often served as important local employers. According to the Department of Health Expert Group on Mental Health Policy ‘These influences have shaped today’s mental health services; an historically generous provision of institutional places with poorly defined admission policies; a lack of comprehensive social care services for children, adults with social problems, individuals with intellectual disability and others; the importance of the institution to the local economy; and the expectation of individuals and families, in spite of stigma, that admission to institutions could be gained whenever it was felt necessary.’ People with intellectual disabilities were as vulnerable to institutionalisation as many others but the first residential institution specifically for this population group opened in Dublin in 1869 when the Stewart Institution was founded to provide education, training and maintenance for children with disabilities. Prior to this they were accommodated with all other misfits in institutions such as the Dublin House of Industry, which opened in 1773 and had a number of cells set aside for ‘lunatics and idiots’. By the end of the 19th century there were 22 lunatic asylums accommodating all manner of socially excluded people, including people with disabilities. These asylums, McCormack suggests, bore all of the hallmarks of Goffman’s ‘total institution’ with staff and inmates living in the compound, no interaction with the outside world and abuses of power by the keepers. They also ‘... allowed society to be happily ignorant of how fellow human beings were being treated, to continue to under-resource these

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786 Commission of Inquiry on Mental Illness (1966) Stationery Office, Dublin Reported that in 1961 Ireland had approximately 7.3 psychiatric beds per 1000 of the population – a rate which ‘... appears to be the highest in the world.’ P xiii
788 ibid p242
The move towards specialist institutions for disabled people gained ground with the establishment by the Daughters of Charity of a home for disabled children in the 1920’s with support of the State and the Archbishop of Dublin. The development of residential institutions by religious congregations catering for disabled people across the country progressed rapidly from this time up until the 1950’s. In parallel with this, there was an increasing emphasis on the development of specialist therapies and professions, especially from the 1960’s onward, based on the assumption that disabled people had special needs which required special therapies or treatment. In the Irish context, where many specialist services and supports were provided by religious orders, the connotations of ‘special’ were quite distinct seeing the disabled child as ‘...innocent, angel-like and close to God. ... In working with people with learning disabilities, religious orders imbued their services with the desirable qualities of religious life – removed from the hustle and bustle of everyday life, freed from the cares and distractions of ordinary living.’

During the 1950’s and 1960’s several Parents and Friends Associations were established, as a response to the lack of facilities beyond those provided by the large institutions. Such groups were established in Kildare, Mayo, Galway, Longford and elsewhere. The services established by Parents and Friends Associations tended to be more community-based and indicated a significant shift in thinking away from institutional care to services in the community. This coincided with the growing influence of the work of writers such as John O’Brien and Wolf Wolfensberger. O’Brien’s emphasis on social roles, inclusion and person-centred planning and Wolfensberger’s work on Social Role Valorisation were very influential in Ireland as was the development of the ‘care in the community’ approach in the UK and elsewhere which increasingly saw the development of community services where people were not confined to residential institutions.

While there have undoubtedly been major changes in policy and practice in the

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790 ibid p16
provision of residential support services for disabled people, the legislative framework has not changed significantly in recent years. Funding for personal support services is still largely directed to the large voluntary disability service providers, there is a lack of provision for individualized funding directed towards the person and a lack of definition of what personal support services are exactly. Because of this and the historic cultural dependence on institutional residential provision there remains a significant number of people living in large residential centres throughout the country. As noted the HSE report *Time to Move on from Congregated Settings* found in 2008 that there were over 4,000 PWID living in congregated setting and that during the period when the report was being compiled, more people were admitted to these settings than were discharged. The report found widespread sharing of bedrooms and bathrooms, limited day activities and lack of privacy stating that ‘... the picture that emerged ... is one of a group of people who live isolated lives apart from any community and from families; many experience institutional living conditions where they lack basic privacy and dignity.’ Plans to implement the recommendations of this report are currently being developed but for the moment they remain a significant feature of residential provision for people with intellectual disabilities in the State.

8.10.2. Definition of personal social services.

For many disabled people what determines their level of access to mainstream services, including housing, and to the community is the availability of personal support. Under the Health Acts the obligation to provide health services, including ‘personal social services’ rests in the first instance with the family and, thereafter, with the State which can sub-contract out this function to voluntary groups. However, the legislation provides no clear definition of what precisely such services include. The majority of personal social service funding for PWID is channeled through voluntary disability service providers, which, in general, serve distinct geographic areas. In effect this means that how ‘personal social services’ is interpreted varies between providers and where one lives determines much about the type and level of support which is available. As noted above, the absence of a legal right to services in the Disability Act compounds the difficulty,

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793 Health Services Executive, *Time to Move on from Congregated Settings: A strategy for Community Inclusion*, Dublin, HSE (June 2011) p50
794 *ibid* p3
795 *ibid* p10
as the Health Acts do not make clear what personal social services the State is obliged to provide and, even if this were clear, people do not have a legal right to these services anyway.

The 1947 Health Act originally placed responsibility for the delivery of health services on local authorities and this was transferred to the newly created Health Boards by the 1970 Health Act. In 2004 this responsibility was again moved to the centralized Health Services Executive. Under the Health Act 2004 the HSE may deliver these services directly or arrange for their delivery. Other than specifying that health and personal social services do not include any services provided for under the Social Welfare Acts, the legislation does not offer any further direction. Because of this ambiguity it is difficult to be precise about what disabled people are entitled to in terms of state support for day, residential or IL services. Emily O’Reilly, Ombudsman and Information Commissioner suggests that ‘...the HSE does not have a statutory responsibility to provide day care services for people with disabilities nor to provide physiotherapy, speech and language therapy or occupational therapy. ...[I]n the event of these services being curtailed or dropped, people who need them seem not to have any enforceable right to the services. ... [D]ecisions on rationing these services may be influenced by the fact that they are not services which the HSE is legally obliged to provide.’ She concludes therefore, that while the HSE or its agents may deliver day services to disabled people, it is not legally obliged to do so and this is reinforced by the lack of a right to services arising from the Disability Act.

The Irish Human Rights Commission attempted to identify the constituent elements of health and personal social services in their 2010 evaluation of a residential and day centre for people with severe and profound intellectual disabilities. The Department of Health, in a background paper submitted to the Commission, defined Personal Social Services as those services which entail a personal relationship between the client and provider including social work, family care, day care and alternatives to family care. The Department further

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796 Health Act 2004 Section 7(4)
797 Health Act 2004 Section 28(2)
798 Office of the Ombudsman, *Health services and the Law – Some Reflections* Address by Emily O’Reilly to the Medico-Legal Society of Ireland 23 February 2012
stated that personal social services are distinct from health care ‘... to the extent that they are aimed at improving the quality of life of individuals and families and assisting them to achieve their full potential. However, when this is set in the context of individuals or care groups ... the distinction is not so easily made. Care for these groups is a continuum linked to the level of dependency ranging from home help to institutional care and with potentially significant medical intervention.’

It appears then that personal social services can encompass what might be seen as purely social services (such as social work), personal assistance support (such as home help), traditional day care and medical care. How this is defined in practice is left to the discretion of the local HSE disability services and the particular disability service provider operating in each area.

The problem is further compounded by the question of what services people in residential care are entitled to in legislation. Section 54 of the Health Act 1953 specifies that ‘institutional assistance’ means shelter and maintenance in a County Home. This was extended by the Section 51 of the 1970 Act which defined ‘in-patient services’ as ‘... institutional services provided for persons while maintained in a hospital, convalescent home or home for persons suffering from physical or mental disability or in accommodation ancillary thereto.’ The 1970 Act goes on to provide that these services shall be made available without charge to people with full eligibility, which includes medical card holders - and as the majority of PWID are in receipt of State disability income supports, they are likely to be holders of medical cards, thus bringing them into the category of those eligible for these services. The distinction between ‘institutional assistance’ under the 1953 Act and ‘in-patient services’ under the 1970 Act was addressed by the Supreme Court in the case of A Ward of Court who was an elderly woman, being transferred from a long-term psychiatric hospital to a nursing home. Justice Henchy concluded that ‘The ward ... gets more than shelter and maintenance. She gets the nursing care requisite for a patient of her age and state of health in a geriatric institution. ... the regimen of treatment provided for her ... involves nursing ... supervision, activation, and other para-medical services, which are given in an institutional setting and which are above and beyond the range of mere ’shelter and maintenance’. In other words, what she is getting is ‘in-patient services’ ... ’

In her 2010 report the Ombudsman brings attention to the ‘convoluted interpretation’ of the statutory

800 ibid p61
801 Maud McInerney [a ward of court] [1976-7] I.L.R.M. 229
provisions in the Health Acts by the Department of Health and the HSE in relation to nursing home care, with the Department drawing a distinction between ‘eligibility’ for and ‘entitlement’ to inpatient services for older people in need of nursing home care. The Ombudsman suggests that ‘... while the law appears to require the State to provide nursing home care for the elderly, the State has been acting as if this were not the case. The State agencies concerned have shown a remarkable capacity to impose a convoluted interpretation on legal provisions which, in fact, are much more likely to mean just what they say - no more and no less.’\(^{802}\) In effect then it appears that people may be eligible for ‘in patient’ residential services including nursing care, activation, supervision and paramedical services, but the State is reluctant to construct this as an entitlement, which the Ombudsman concludes is cost-related.

Presumably at local level attempts are made to provide personal social services which are responsive to the needs of people in the area, however, it leaves wide scope for inconsistency and lack of standardization of personal social services provision across the country. In reality most of the large voluntary bodies provide a range of personal social services which come within this definition. But the way in which they are provided varies considerably so that for example, residential support may be provided primarily in group homes or residential centres by one agency, while it may be provided in a way which promotes independent living by another. The Human Rights Commission concludes that the ‘... statutory responsibility of the HSE to deliver “health and personal social services” under the Health Act 2004 ... appears sufficiently broad to include residential services to persons with an intellectual disability where the residential element is ancillary or necessary to the provision of health and personal social services to such persons.’\(^{803}\)

At the same time it is also broad enough to deliver quite different personal social services in relation to residential services. This can have a significant impact on the ability of individuals with disabilities in the area to choose where and with whom to live and to be included in the community.

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8.10.3. Service delivery by voluntary bodies

As noted above Ireland has a long history of service provision to various groups by independent voluntary or religious bodies on behalf of the State. The legislative basis for this can be found initially in the 1947 Act which provided for bodies, other than the health authority, to provide an institution for particular classes of people.\^804 The 1953 Act expanded the class of people to whom institutional care could be provided to include ‘... persons suffering from physical or mental disability’.\^805 More clarity was brought to the provision of services by independent bodies with Sections 10 and 65 of the 1953 Act. Section 10 provided that the health authority could ‘... make and carry out an arrangement for the giving of institutional services to any person or to persons of any class, being a person or persons who is or are entitled to receive institutional services from such authority’. Section 65 allowed for the health authority to assist bodies providing services ‘... similar or ancillary to a service which the health authority may provide.’ Thus the sub-contracting of service provision to voluntary or religious bodies was legitimated. Most services to PWID are provided by voluntary bodies\^806 although the HSE provides services directly in some part of the country, and these voluntary bodies are largely funded by the state.

The legislation governing the provision and funding of personal support services for people with disabilities does not currently have any basis for direct payments to individuals or for individualizing of budgets. The latter could potentially be included in the agreements between the HSE and the independent service providers, but the former is not provided for at all.

Funding for health and personal social services is decided each year as part of the HSE Vote 40 on government expenditure. The HSE then determines the level of funding to be allocated to different parts of the HSE’s work, including that to be allocated to voluntary disability service providers. The 2004 Health Act outlines conditions to be included in Service Level Agreements (SLA) between the HSE and the independent providers. Under Section 38 of the 2004 Act the HSE may enter agreements with an agency or a person to provide services on its behalf subject to such conditions as it considers appropriate. This section also outlines that agencies delivering such services must provide information on accounts and other

\^804 Health Act 1947 Section 12(1)
\^805 Health Act 1953 Section 6
\^806 See National Disability Authority Advise Paper to the Value for Money and Policy Review of Disability Services Programme. Dublin, NDA (July 2010) p14 90% of specialist intellectual disability services are provided by the voluntary/independent sector.
aspects of their work and be subject to such monitoring as it considers appropriate. Section 39 allows for the HSE to grant assistance to agencies to “… provide a service similar or ancillary to a service that the Executive may provide.”

Perhaps importantly this section specifies that ‘Assistance may be provided to a person under this section whether or not the person is a service provider.’ This could potentially be a route through which people could be provided with direct payments for support from the HSE. To date, however, direct payments have not been allocated in this way. Although there are supposed differences between Section 38 and Section 39 agencies the reality is that “… there is generally little to distinguish the types of activities carried out within Section 38 or 39 disability organisations. Often these could fall under either definition … For instance, many organisations that developed out of Parents and Friends Associations, but provide equally essential services, are often under the Section 39 funding stream, whereas many larger non-statutory organisations fall under Section 38.” These voluntary bodies dominate the service delivery field in the area of intellectual disability/autism and are major employers.

The level of State funding to these agencies is also very significant. The NDA indicated that in 2009 some €1,166 million was allocated to 242 agencies under Section 38 and Section 39 to provide services to people with disabilities. The largest 40 of these agencies received 90% of the total funding with an average €26.4 million per agency. Residential service provision accounts for about half the total budget. In 2009 the Department of Health indicated to the Human Rights Commission that the average cost of providing a new residential place was in the region of €80,000 per person.

A report by the Comptroller and Auditor General described the SLAs between the HSE and service providers as ‘… high-level framework documents describing in broad terms the services to be delivered, the principles according to which they are

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807 Health Act 2004 Section 39 (1)
808 Health Act 2004 Section 39 (3)
810 National Federation of Voluntary Bodies Service Plan 2012 Galway, NFV (2012) p1 indicates that that its 62 member organisations provide services to 22,000 people and employ 15,500 staff
812 Ibid p16
to be delivered and indicating information required for monitoring purposes. He found that there are substantial differences across the country between SLAs in terms of format, content and detail of services to be provided. The report also highlights the disconnection between the funding, the needs of the service users and the services and supports provided. Funding to the voluntary bodies is based on an incremental system whereby the non-capital allocation in the current year is used as the basis for the allocation in the following year. Adjustments to this baseline are made for new services, salary adjustments, and overall cuts in health services budget. Planning for new services for individuals is undertaken by regional committees, which include representatives of the HSE and voluntary bodies. These regional committees function primarily to prioritise and recommend funding allocations for the placement of people with particular providers based on need. These allocations are then included in the SLAs between the provider and the HSE. When a person is ‘placed’ with an agency, the agency provides the service in line with their overall provision, ethos and policies. In reality it is common practice for other service users with similar needs who are already in the service to be provided with a new or enhanced service from the allocation along the new person. The Auditor Generals report highlights that ‘The risk with this approach is that the core funding allocation will over time become weakly linked to levels of identified need and as a result that funding may not always be targeted to areas of greatest need’.

This method of funding also means that the way the service is provided to the person is determined as much by the culture and ethos of the voluntary body as by the needs of the person. And, given the defined geographic areas in which agencies operate without competing alternative providers, the level of choice and control open to the person over the way services are delivered is determined by the modus operandi of the provider. Conaty characterizes these agencies as ‘hybrid’ organisations, being almost fully dependent on state funding while at the same time retaining their individual culture and ethos. He suggests that they present several challenges for effective performance management and

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815 See Health Service Executive National Service Plan 2012 Dublin, HSE (2012) p8 The national allocation to disability services was reduced by 3.7% in 2012.
accountability. In particular, the complexity of managing the multiple stakeholders relationships and the asymmetry in power among them, the tensions between the priority objectives of the independent agencies and the funders and clashes of culture between the two and the stress caused by the necessity and difficulty of forming and maintaining trust between the funders and the agency.818

In addition the independent nature of these agencies poses challenges in terms of monitoring. The Auditor General states that '[p]oorly-developed structures for monitoring, measuring and assessing performance levels in the context of statutory funding could, therefore, be said to exist.'819 At present there is no independent inspection system in place to monitor the quality of services provided by the disability agencies except in the areas of financial management and management of staffing numbers. Several agencies have adopted quality assurance systems820 but this has been on a voluntary basis and does not include monitoring by the HSE, which is the primary funder. The Health Information and Quality Authority published a set of standards for residential services for people with disabilities in 2009. In 2012 new draft standards for residential standards for children and adults with disabilities were published by HIQA for public consultation. Implementation and monitoring of these standards was delayed due to financial constraints, however, the current government has committed to their implementation.821

A significant feature of the system of service provision for PWID is, as noted, the lack of choice of provider available. The Auditor General reports that ‘... services to persons with disabilities result from a historical pattern of provision and are largely negotiated rather than the result of contested procurement.’822 As a result people are dependent for support on the single agency operating in their geographic area. This dynamic of dependency creates enormous difficulties in forming partnerships between disabled people and their families and the provider as the power relationship between them is skewed towards the provider which holds the purse strings. It can also mean that people are reluctant to complain about poor service and can be forced into an attitude of gratitude for what they

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818 ibid p305
820 For example Personal Outcomes Measures developed by the Council on Quality and Leadership in the USA or the Quality Assurance in Social Services Standards a European system
821 See Programme for Government 2011 p24
have, even if it is not meeting the person’s needs. Conaty observed that in relation to the case study he conducted ‘[t]his power asymmetry was characterised ... by the exclusion of service users, their carers or advocates from the strategic, control and decision making mechanisms of the organisation but more importantly from ownership and governance.’

In 2005 the Competition Authority was extremely critical of the method of selecting disability services suggesting that it is not necessarily cost-efficient, does not foster innovation in service delivery and can be harmful to service recipients by restricting their ability to switch providers. The Authority also expressed concern that there is no tendering mechanism and that contracts appear to be of indefinite length - although SLAs are agreed annually, they are usually with the same providers from year to year. Importantly, the Authority highlights the lack of access routes for new, and potentially more innovative, providers into the current system. They conclude that ‘...unbundling the delivery of investment and on-going services as well as introducing competition among service providers ... should be envisaged as a mechanism to deliver cheaper and better services, foster innovation and promote choice for the benefit of people with disabilities.’

8.10.4. Individualised Funding

There is no doubt that the availability of direct payment or individualized budgets could create the potential for people to exercise greater choice and control in their lives. Mechanisms for supporting people in managing their budgets and in personal planning would be required. Experience from the UK would indicate that most people who avail of direct payments are positive about their experiences. However, Clements suggests that the development of the personalization agenda in the community care sector in the UK, including the rolling out of Individual Budgets, displays conceptual naivety and that the research evidence about the effectiveness of individual budgets is, to say the least, weak. He contends that the New Right morality underpinning these developments seek to move responsibility for the provision of care and support away from the state, and

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824 Competition Authority Submission to the Department of Health and Children on the Strategic Review of Disability Services Dublin, Competition Authority (September 2005) p1
on to individual disabled people and families and that it appears to be, at least in part, about cost reduction. An additional concern about the personalization agenda in the UK is its failure to adopt a human rights framework. Chetty et al. suggest that ‘... the framework of rights ... has not been central to the development of personalisation as a key driver of public policy. As a consequence, much of the new autonomy proposed through personalisation has the feel of a set of “privileges” that can be variously afforded, denied or withdrawn by professionals acting on behalf of the state through the apparatus of local government.’

There are some predictable pitfalls to the individualisation of funding which need to be taken into account, in particular the associated costs and the vulnerability to financial cutbacks.

The question of costs associated with closing large institutions and the development of community-based services, including individualized services and direct payments, remains unclear. A key finding of Mansell’s Europe-wide report on deinstitutionalisation was that the costs of supporting people with high levels of disability are high whether in an institution or in the community, but the outcomes achieved in terms of quality of life are better in the community. Equally the costs of supporting people with lower levels of disability are the same or lower in community settings and that the outcomes achieved by individuals are better in the community.

Lemay’s review of the literature on deinstitutionalisation in the UK and the USA concludes that generally community living for PWID appears to be less expensive and more cost-effective than care in institutions.

Research by Felce and Emerson also found that the contention that smaller scale residences will be more expensive that larger institutions is unfounded. They suggest that diseconomies of scale are only likely to occur where three people or less are accommodated together, and that these diseconomies occur at a point where the specific support needs of residents (such a need for over night staffing) can no longer be reduced in a manner

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proportionate to the number of residents.

In the Netherlands the demand for personal budgets rose steeply between 2002 and 2010 with costs increasing at a rate of 23% per year form €0.4 billion to €2.2 billion in this period.\textsuperscript{831} The increased demand, which appears to be derived from children and adolescents with intellectual disabilities and autism, prompted the Minister of Health to halt new applications for personal budgets in 2010.\textsuperscript{832} Whether there was also a decrease in demand for traditional services and a consequent decrease in the resources required for these services is not clear. As evaluation of the costs of individual budgets in the UK reported little difference in the costs to the State between individual budgets and traditional services, noting that ‘...[o]ver the full sample, IBs (individual budgets) funded a mean of about £280 of support per week compared with an estimated mean weekly cost of about £300 for support packages for people receiving standard mainstream services. This difference was not statistically significant, but it is likely from this evidence that IBs would be at least cost-neutral\textsuperscript{833}’. They suggest that IBs have the potential to be more cost-effective than standard care and support, particularly in relation to people with mental illness or younger people with physical disabilities. The issue of cost and cost-effectiveness, however, is far from clear-cut. Demos\textsuperscript{834} suggests that in the UK cost savings can be up to 45% and are on average about 10%. They also highlight the long-term savings to be made in avoiding the costs of residential and health care for people who are supported to remain living at home and have self-directed services. Van Ginneken et al suggest that ‘[t]he UK government must also recognize that personal budgets can create new demand. The Dutch experience shows that they raise expectations of people who previously were unable to find appropriate care. This may take some time to become apparent.’\textsuperscript{835} Experience from the province of British Columbia, Canada, which was one of the pioneers in the rolling out of individualized budgets paid directly to PWID, would appear to indicate a marked lack of enthusiasm on the part of potential beneficiaries. In its 2011/12 Annual Report Community Living BC – the crown corporation charged with delivering services to PWID – indicated that out of a total of 14,214 service

\textsuperscript{831} Van Ginneken, E, Groenwegen, P and McKee, M. ‘Personal healthcare budgets: what can England learn from the Netherlands’ (2012) 334(e1383) British Medical Journal

\textsuperscript{832} ibid


\textsuperscript{835} Van Ginneken, E, Groenwegen, P and McKee, M. ‘Personal healthcare budgets: what can England learn from the Netherlands’ (2012) 334(e1383) British Medical Journal
users only 314 people availed of individualized funding.\textsuperscript{836} An additional concern about the introduction of individualized funding or direct payments is the consequences for workers in this sector. Direct payments or individualized funding where people employ their own personal assistants would inevitably create demand for a greater pool of workers in the private market. Experience from Italy, Austria and France demonstrates that those employed as personal assistants are invariably lower paid, less qualified, often immigrant, women who often operate outside of the strictures of labour and social security regulations.\textsuperscript{837} Rivas, referring to personal assistants in the American context, states that ‘... the women who take these jobs ... work in private households, where they are socially isolated, with little potential for collective voice and few prospects for job mobility. There is no formal training, no career ladder and no hope for advancement...... Personal attendants rarely receive health benefits, vacation time or sick leave. They can be fired at will, without notice.’\textsuperscript{838} This is an issue requires attention because as Shakespeare suggests ‘It would be deeply unfortunate if the liberation of disabled people from dependency contributed to the exploitation of another disempowered section of the population.’\textsuperscript{839}

In the Irish context it is arguable that there are already considerably higher levels of funding to disability services than elsewhere and that this funding needs to be used differently. The recent \textit{Value for Money and Policy Review of Disability Services in Ireland}\textsuperscript{840} envisages a move towards the individualisation of services and supports within existing (and more than likely decreasing) budgets. The new policy direction proposal includes provision of individualized supports, which are primarily directed by the person and are provided on a one to one basis rather than in group settings. It also includes the development of individualized budgeting approaches and the implementation framework for the report proposes the development of demonstration projects to pilot the new model.\textsuperscript{841}

In addition to the question of the costs to the state arising from Direct Payments,
recipients of such payments are particularly vulnerable in time of economic recession and budgetary cutbacks. In the UK local authorities provide direct payments to people based on assessed level of need on a continuum from low to critical need. In response to cutbacks an increasing number of councils have changed their eligibility criteria and in 2012 some 83% of councils were only funding people in ‘substantial’ or ‘critical’ need while 2% were funding those in ‘critical’ need only.\footnote{Association of Directors of Adult Social Services, *Budget Survey 2012* (June 2012) \url{www.adass.org.uk/images/stories/Press12/ADASS_BudgetSurvey2012Summary.pdf} Accessed 6/9/2012} This confirms the finding from a Demos survey indicating that between 2010 and 2011 there was an increase from 109 to 123 councils moving to ‘substantial’ and ‘critical’ need only.\footnote{Wood, C., Cheetham, P. and Gregory, T. *Coping with the cuts* London, Demos, (2011) p50} Council cutbacks in adult social care budgets to individuals have been successfully challenged in the Courts,\footnote{See *Birmingham City Council v M, G and H* [2011] EWHC 1147 (Admin) and *Isle of Wight Council v JM and NT* [2011] EWHC 2911} nonetheless these cases serve to highlight the problem that where individuals are in receipt of support payments to them personally, the means of challenging cuts rests with the person. For many people with intellectual disabilities this is a route which is especially difficult given the acknowledged problems this group has in accessing the justice system. It demands that there be an individual who is willing and able to take a case and that they have the support and resources to do so. At the least a system based on direct payments must have strong advocacy structures so that individual people in the community do not become isolated from each other and face the negative impacts of reductions in support funding alone.

8.11. Conclusion

The Irish legislative framework contains many of the elements necessary to enable disabled people to live independently in the community. At the same time there are some major obstacles in the legislation which must be addressed if this is to be made a reality. The long overdue LC legislation will hopefully adopt a universalist approach and accord to disabled people their right to hold and exercise all rights including the right to IL.

There is a clear evolution in housing legislation towards inclusion not only for disabled people, but also of other marginalized groups including elderly people.
and homeless people. The most recent Housing Act and the subsequent Social Housing Assessment Regulations are important steps in proactively opening up mainstream social housing and housing supports to disabled people. This along with the provision that housing authorities can reserve a section of their housing for particular classes of people means that people inappropriately housed in congregated settings could be accommodated in mainstream housing. Of course there are resource implications in this and housing authorities must take account of all of the people on their waiting lists. Nonetheless, if the state is serious about addressing the situation of people living in residential institutions the legislation supports this.

Irish Equality legislation is recognized as being well framed to address discrimination in the provision of goods and services and the work of the Equality Tribunal has illustrated that it can have a real impact. However, this legislation cannot address the situation of people in segregated housing or residential institutions as support provided in such settings does not appear to fall within the definition of a service ‘... available to the public generally or a section of the public ‘ under the Equal Status Act. It is also difficult to identify a suitable comparator and the barriers in accessing the justice system for people in these settings are enormous.

At present there is no legal provision for individualized funding of personal support services directly to disabled people, and whether block funded agencies are able or willing to provide individualized services is dependent on the agency in question. As highlighted by the IHRC report ‘... it is not apparent that the Health Acts create any individualised entitlement to health or personal social services, such that they must be provided to a particular person in need of same,’\textsuperscript{845}

The other significant aspect of the current system is that disability service providers are usually the sole public provider of services in their geographic area. This appears to arise from the way the legislation has historically been interpreted and applied rather than from anything specifically therein. The Health Acts allow the State to sub-contract service provision to independent agencies on its behalf, but there is nothing in these Acts which limit the State in its decisions about which agencies should provide services or where. The practice of funding

the same agencies in defined geographic areas year on year is not dictated by the legislation, but is rather a system which has evolved from historic roots whereby voluntary or religious bodies were the sole provider of services in defined areas. The limitation of peoples choices which results from the fact that there is usually only a single provider in each area, raises a question about whether this practice is in breach of Competition legislation. The Competition Act 2002 prohibits and renders void ‘... all agreements between undertakings, decisions by associations of undertakings and concerted practices which have as their object or effect the prevention, restriction or distortion of competition in trade in any goods or services in the State or in any part of the State.’[^846] The introduction of competition into this area could be greatly beneficial both in terms of providing choice to disabled people and in improving the quality and cost-effectiveness of services.

A broader question which needs to be considered is the location of personal support funding within the health services. The type of supports which most people with intellectual disability require in order to live independently are social and personal in nature, and cannot be described as health services. The entangling of the two types of support in health budgets makes it extremely difficult to identify which aspects are for social or personal support and which are for health-related supports. In addition as suggested by the Centre for Disability Law and Policy, NUI Galway the current system ‘... makes the adoption of a truly social model approach much more difficult that it needs be. Health services are, by definition, medically orientated. When social support services are incorporated as part of a health service, the influence of the overall medical/health philosophy will undoubtedly have an influence on those services, regardless of efforts to instill social model values.’[^847]

The HIQA standards for residential services for people with disabilities will be important in ensuring quality. While this is welcome it must be acknowledged that in general, grouped residential services specifically for disabled people fall short of the ideals of Independent Living. Unless people have freely chosen these arrangements, and are not living there because of a lack of alternatives or because of lack of access to personal supports in the community, these settings cannot conform to the core elements of independent living.

[^846]: Competition Act 2002 Part 2, Section 4(1)
To achieve independent living it is essential that people have access to support in their own homes. At present support to elderly people to remain living at home is provided by the HSE through Home Care Packages and Home Help Services. These services are provided either directly by the HSE or by voluntary or private providers. Having access to this type of support would greatly enhance the ability of people with disabilities to live in their own homes. However, these services are currently unregulated and there is no independent inspection or monitoring of quality. The Law Reform Commission recommended that standards for professional home care providers be developed and monitored by HIQA and that a register of providers by established each of which would require changes to Health legislation. Importantly the Commission also recommends that ‘...a guiding principle of the proposed legislative framework should be the principle of independent living.’

We know that the many people with intellectual disabilities remain living at home with their families well into adulthood and that a very small percentage achieve independent living. The provision of in-home support in an individualized way, as is currently provided for elderly people, would be a significant step on the road to opening up access to independent living. It is important that these services be regulated and monitored and that there are in-build robust and fully accessible complaints mechanisms.

Opinions vary as to the likelihood of legislative change on any significant scale resulting from the ECHR Act. There would appear to be a reluctance on the part of the State and its agencies to fully embrace the Act reflected in its decisions to appeal each of the three cases where Declarations of Incompatibility have been granted. The option of amending the particular pieces of legislation without recourse to the Supreme Court was open, thus avoiding the long delays in resolving the issues. Cormac O’Dulachain, Senior Counsel, suggests that the governments reaction to ECHR Act gives ‘...clear impression of a State that has found itself with a “foundling law” placed at its backdoor and arriving by circumstances rather than invitation, an Act whose potential scope and effect has yet

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848 Law Reform Commission Legal Aspects of Professional Home Care, Report (2011) LRC, Dublin p105
849 See Health Research Board, National Intellectual Disabilities Database Annual Report 2011, Dublin, HRB (2011) Table 3.2 ‘Main Residential Circumstances by Degree of Intellectual Disability and by Age Group’ p37 indicating 74% of 20 – 34 year olds live at home, 39% of people between 35 and 54 years live at home and 17% of people aged 55 years and over live at home.
850 ibid Table 3.2 ‘Main Residential Circumstances by Degree of Intellectual Disability and by Age Group’ p37. Indicates that 6% of adults are living in independent circumstances i.e. with no or minimal support.
The cases discussed above give some hope that the rights-based obligations of Article 8(2) in relation to public housing in Ireland may be progressed by the incorporation of the Act, albeit it slowly. O’Connell is somewhat optimistic in his conclusion that ‘It remains to be seen whether the jurisprudence on state’s positive obligations under the ECHR will help to unlock the positive obligations which are implicit in Irish constitutional rights. In so far as the ECHR adds to rights whose textual foundations may appear fragile this potential cannot be underestimated.’ At this stage it is probably too early to assess full the impact of the Act in Irish law, however, what can be said with some certainty is that the human rights outlined in the ECHR have a greater likelihood of being realized with incorporation than without.

The Disability Act provides the framework for the delivery of services to disabled people and in many ways, especially in terms of access, it serves this purpose well. However, there are important parts of the Act which in effect hinder the achievement of IL. Specifically the needs assessment and service statement processes are heavily medically orientated and extremely bureaucratic. This may be because, to date, only young children have been included in the process, but it also derives from the provision in the Act that only health and educational needs related to the disability can be considered. The lack of a right to services and the internal nature of the complaints and appeals procedures are also problematic. It is debatable whether people should have a right to services given the resource implications and the service needs/rights of other groups in the population. However, it is worth considering whether enshrining a right to independent living and community inclusion in law would be worth pursuing.

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Chapter 9: Conclusions: Where to from here?

9.1 Introduction

Human rights apply equally to all members of the human family. As declared in the Universal Declaration of Human Rights ‘All human beings are born free and equal in dignity and rights.’ This must be the starting point for any exploration of how the right to Independent Living can be realised for all disabled people. This research set out to explore what is required to realise the right to independent living for people with intellectual disabilities in Ireland.

The research sought to answer the question of what Ireland needs to do in order to realise the right to independent living (IL) for people with intellectual (PWID) in a way that is fair to everyone – PWID themselves, families, society and all other groups who experience marginalisation. The focus of the work was on the legal supports needed to create the conditions necessary for this. The approach taken was to establish a generally applicable philosophical basis for the realisation of human rights for all. Thereafter it was necessary to settle on a conception of disability which is consistent with inclusive societies, and could be seen to be generally applicable – not only to disabled people but to all members of society in all circumstances. Having established this theoretical framework, the research then examined the law applicable in Ireland to ascertain the extent to which it supports the core element of the right to IL and identify where the blockages are and the possible solutions. This involved looking firstly to the United Nations human rights treaties to which Ireland has acceded and to the CRPD, which it is expected Ireland will ratify. The core elements of the IL right are to be found in the mainstream human rights instruments and drawing on these instruments, an attempt was made to identify the minimum core obligations of Article 19 of the CRPD which all member states are duty bound to fulfil. The case law of the European Court of Human Rights and the legislation emerging from the EU each have a direct impact on the law in Ireland. Both of these institutions were examined in order to determine their potential to further the right to IL in Ireland. Finally, relevant Irish legislation was analysed - in particular the Constitution, equality law, human rights law, disability law, housing law, health law and legal capacity law – in an attempt to discover the extent to which these laws support a universalist approach to disability and support the right to IL.
The research was confined largely to the law as it impacts on the right to IL and only briefly enters into the area of policy. IL spans a vast area of law and in order to make the work manageable it was decided to concentrate primarily on this. This clearly is a limitation of the research as the role of the law is a limited one. The cultural, social, political and economics beliefs and circumstances of any society could be said to be equally influential on how disabled people are perceived and treated. Yet the law can be both an influence on and reflective of society, and where certain practices are enabled or prohibited by the law they have a level of acceptability and an authority, which are not intrinsic to other less concrete societal norms. Of course the law is only effective if it is implemented and it is in this area that policy comes into play - for if the policies and practices are not compliant with the law and are not sanctioned for this, then the law is worthless. Nonetheless, unless that law itself mandates or prohibits certain behaviours, then challenging these behaviours becomes extremely problematic. Therefore, getting the law right and providing a firm foundation in law is essential if we are serious about enabling the right to IL for people with disabilities in Ireland.

A second limitation of this research is that it did not consult with PWID themselves or seek their views on how the law could help or hinder the right to IL. This was a deliberate decision taken early in the research process for a variety of reasons. In particular, a perception that any information given by respondents with ID could be unreliable and would require a much higher degree of validation than respondents without ID – the cultural belief that one cannot fully rely on what PWID say and that this must be checked and confirmed by others is deeply embedded in our society. Secondly, gathering information from people with poor verbal communication skills would have meant using alternative methods of communication, which would have been a time-consuming and possibly expensive process. Finally, a study focused on gathering what could be considered reliable data from PWID, would be an adjunct to legal research. This work aimed to discover what the law says about the research question and what are the barriers to IL in the law, rather than seeking to ascertain the opinions of stakeholders on the question. Involving PWID in looking at this question could be fruitful area of research in the future, but was beyond the scope of this work.
9.2 Summary of findings

What is important at the outset is to establish a political or philosophical foundation upon which human rights can be based. This foundation must be inclusive of all people in all circumstances and it must hold the potential to garner universal acceptance. That is, it must be a philosophical position which everyone could find acceptable and to which everyone could aspire.

I have argued that Rawls’ Principle of Justice provide such a foundation, that the principles of equal basic liberty, equal opportunity and the difference principle could hold widespread politically acceptability, and that they support a universal approach focused on the inclusion of all. This implies that a universal approach applies, not just to disabled people who may have particular support needs to enable rights realisation, but to all marginalised groups, who may also have specific needs which must be addressed in order to realise rights.

One of the basic problems which has beset disabled people has been their singling out as different and unusual and the consequent development of all manner of segregated ‘special’ services and facilities to meet their perceived ‘special needs’. These special services span the spectrum of large institutions to group homes and include special schools, special transport and special day services - none of which are available to other, non-disabled, people. A universalist approach takes the opposite view. It holds that disability is an inherent part of the human condition, that we are all more alike than we are different, and that we are more likely than not to experience some form of disability at some point in life. This should be taken into account in how we design and operate the structures of our society. These structures must, therefore, focus on being as inclusive as possible of all members of society, thus mandating universally accessible services and institutions along with the provision of supports to enable full access for those who remain excluded from any given environment. A Universal approach encompasses all groups and individuals who experience exclusion because of current or historic factors affecting the group to which they belong. Thus members of ethnic minorities who have been discriminated against, or who currently experience discrimination because of their group membership, should equally be included when designing societal structures and have the benefit of targeted supports to enable access if this is required. For if people are excluded
on whatever basis, they can never be said to have equal opportunities and thus will never be able to participate on an equal basis with others.

Rawls’ principles are, I suggest, a good basis upon which to base this approach as they provide a framework for universal inclusion and for positive measures to enable access to the equal basic liberties and equality of opportunity. They provide a basis for a substantive equality which mandates pure procedural equality along with positive actions to compensate for past or current inequalities. In this sense they are good principles upon which to build inclusive societies. However, the argument that Rawls’ Theory of Justice does not include people with impaired capacity, or indeed other marginalised groups, must be addressed. I believe the position that the principles of justice do not apply to people who do not possess the two moral powers – and hence the capacity to participate in agreeing the principles of justice - is not essential to the basis of the theory. Indeed defining who has, or does not have, the capacity to develop the two moral powers becomes problematic for the theory. For how can this be decided and on what basis? Capacity is impacted by many different factors including intellectual impairment as well as by personal, social, psychological and environmental factors. I argue that there is no need to define who has the requisite capacity to participate and that what is required is what Wong calls ‘enabling conditions’ to facilitate all to develop the two moral powers i.e. a universal approach with specific supports if needed to enable inclusion. Enabling conditions may be required for many reasons and may be required by many different groups or individuals.

The right to IL is, at first glance, only applicable to PWD as it appears in no other human rights instruments save for the CRPD which only addresses the rights of disabled people. In developing the IL right in the CRPD the negotiators recognised that many disabled people across the globe are denied the right to choose where and with whom to live and are obliged to live in ‘special’, often very inferior, living arrangements. So this issue has an especial relevance to the situation of people with disabilities and thus calls for a clear delineation of the right to specifically address the widespread denial of its basic elements. I argue that this right should be equally applicable to all people because it is a reality that many people are denied choices about where they live and with whom. For example, in Ireland alone, it is possible to point to the situation of asylum seekers who have no choice but to live in State provided accommodation with others with whom they have not
chosen to live, and are severely hindered in their ability to participate in the community because of regulations prohibiting them from working and extremely limited income. There are of course many other examples across the world where this right is also denied on the basis of membership of a particular group. A universalist approach would suggest that the right to IL then should be applicable to all people regardless of their membership of a particular group. The core elements of the right to IL are personal autonomy, choice and control, access, support and a right to participate in community. Each of these elements is to be found in other mainstream human rights instruments which apply to all people. There is a strong case to be made for extending the right to IL to all and making it specific in the case of other groups.

The CRPD embodies a universalist approach which aims at the realisation of rights for all disabled people regardless of type or degree of impairment. However, the development of a human rights instrument specifically for disabled people holds the danger of their further singling out for different or ‘special’ treatment. This argument can equally be made for other group-specific instruments and there is a valid argument that what is required is not single identity instruments, but an expansion or explication of what is required to realise rights for particular groups within the general comments of the mainstream human rights committees. Treating each group separately and according each a human rights instrument particular to their situation, could encourage society to continue to think of each as separate and different from each other and from the rest of the population. In reality people's identities are formed from many different sources including their gender, nationality, ethnic origin, religion, sexual orientation, disability, culture etc. Where people are asked to primarily identify with one aspect of their identity in order to claim protection from discrimination or to assert their human rights, this is a false premise and fails to take account of the full reality of people's lives. The proliferation of group-specific instruments has also lead to an increasingly complex system of reporting in the United Nations system and could indeed to said to be a hindrance in the monitoring of human rights protections. Nonetheless, in an environment where group-specific instruments are increasingly the manner in which rights are being explicated, it is important that people with disabilities are part of this move.

Article 19 poses the challenge of ensuring that PWD have the same opportunities to choose where they live and with whom, are not obliged to live in any particular
living arrangements, have equal access to all services available to the general population and have the supports they require to participate in their communities. Where is Ireland in realising these elements of Article 19 for our citizens with intellectual disabilities? The analysis of the current situation of PWID in Ireland reveals that we still have a long way to go. The pattern has deep historic roots and remains embedded in the ways in which we treat disabled people. Ireland has a long and sorry history of excluding people who did not fit a very narrow conception of the acceptable member of society, and the response to many perceived social misfits was institutionalisation. As noted, at one point in the 1960’s Ireland had the highest rate of institutionalisation in the world. Those who were subject to institutionalisation included not only disabled people, but also unmarried women with children, women who were seen to be morally wayward, people with mental illnesses, children whose parents were unable to look after them for family reasons and people who were simply too poor to provide for themselves.

For PWID today the housing pathways are, in general, strikingly different from that of the rest of the population, with various forms of segregated group-based housing being the predominant option open to people once they leave the family home. It is clear from the analysis that PWID are in general failing to access ordinary housing options once they leave home – which they do at a much later age than their peers. This pattern is more pronounced the higher the level of disability and the older people are. Within such group-based accommodation the ideals of IL are extremely difficult to achieve, regardless of how well intentioned the agencies or staff providing services are. This is especially true where people are living in the larger residential institutions, which are still prevalent despite a concerted move towards smaller settings in recent years. Whether people living in group homes or in institutional settings have chosen or consented to live there is open to question. Also open to question is the extent to which people in these settings have a choice about whom they live with. It is the case that people are placed in these settings by the HSE - or agencies on its behalf - and while some consideration may be given to the compatibility of residents with each other, it is more likely that people have little choice about who they will live with. For this reason it is not uncommon for people with challenging behaviour or people with severe or profound intellectual disabilities to be accommodated together in
grouped living arrangements - because of the perceived commonality of their support needs, rather than because of any choice on their part.

Even if it can be demonstrated that people have made an informed choice about living in grouped settings, the question remains as to whether this is, at least in part, influenced by the fact that there are few alternatives available to people, especially in the absence of a legal mechanism for PWID to access state support to live in their homes.

Within Irish law it is notable that the definition of what constitutes an ‘institution’ appears not in housing legislation, but within the Health Acts. Clearly the provision of residential accommodation to disabled people, among others, was perceived as a health issue, rather than a housing issue. This remains the case today although the most recent Statutory Instrument giving effect to the social housing needs assessment provisions of the Housing (Miscellaneous Provisions) Act 2009 marks a significant change in this. This Statutory Instrument encompasses the housing needs of people with disabilities living in institutions and people with a housing need arising from a disability. This denotes an important shift in how the housing needs of PWID are perceived and dealt with in Irish legislation. The new Housing Strategy for People with Disabilities, under which local structures to integrate the social support and housing needs of disabled people will be established, should greatly assist in aligning disabled people’s housing needs with those of the rest of the population. It is to be hoped that issues such as the ineligibility of people living in HSE-funded accommodation which includes residential supports, for rent support will also be dealt with as part of the strategy.

All signatories to UN human rights treaties are duty-bound to fulfil at least the minimum core obligations of each of the articles of the specific instrument. Ireland has not yet ratified the CRPD and as such is not yet bound by its articles. However, based on the assumption that the Irish government will ratify after the enactment of the long-overdue legal capacity legislation, it is worth considering the extent to which we are currently meeting the minimum core obligations in relation to Article 19. In some areas Ireland has made some considerable progress particularly in relation to anti discrimination and equality legislation and more recently in the development of progressive plans to open up pathways to mainstream housing and close the larger institutions, proposals to individualise
disability support funding and the establishment of a national advocacy service for people with disabilities. It is to be hoped that the proposed legal capacity legislation will adopt a universal approach to capacity as this is one of the building blocks needed to enable independent living.

The Irish legal framework is subject to the influence of both the European Union and the Council of Europe. At EU level the Framework Employment Directive (FED) which is applicable in national law, has had a major impact in outlawing employment-based discrimination for the protected groups. It remains to be seen what impact the provisions of the Lisbon Treaty will have particularly the enhanced legal status of the Charter, accession to the ECHR by the EU and the ratification of the CRPD. The FED is a multi-ground instrument and this has been one of its most important features. As discussed PWD have often been singled out for ‘special’ treatment – both good and bad – by society. This is at the heart of many of the problems faced by disabled people and is directly contrary to a universalist approach which acknowledges the universality of disability and impairment. It appears that the proposed Equal Treatment Directive prohibiting discrimination in the provision of goods and services on several grounds is unlikely to be adopted and that a disability-specific directive could be adopted instead. This would be an unfortunate development as it is likely to contribute to the identification of disabled people as a special group requiring special measures, while what is needed are general measures to combat discrimination against all groups. In order for disabled people to be conceived of as an inherent part of the human family they must be treated in the same way as all other members of the human family. This does not preclude particular actions to support them, but it does mean that their needs cannot be addressed at the expense of others who have equally pressing needs. If disabled people wish to be treated as truly equal citizens, then the same rules, obligations and benefits must in general apply to them as to everyone else. If these rules, obligations or benefits are unfair or contribute to inequality, then the rules must be adapted to the situation of whichever group is unfairly advantaged or disadvantaged. But this must happen within a general framework which applies to all, not within a specific framework applicable only to one particular ‘special’ group. In the short term this may slow progress for PWD, but in the longer term it holds the potential to reap much greater benefits for disabled people. On an immediate practical level one action which could be taken by the EU is the use of the structural funds to support the
development of community-based alternatives to institutional care and the prohibition of the use of these funds for the building of new residential institutions for disabled people, or indeed for other groups.

The European Convention on Human Rights and the rulings of the European Court of Human Rights have the potential to be a positive influence on the evolution of the right to IL in Irish law, but the processes involved are slow and arduous for all applicants to the court. With the incorporation of the ECHR into Irish law these processes should be more easily navigated. However, to date the Irish government has shown a marked reluctance to fully embrace the tenets of the ECHR Act and to respond to the Declarations of Incompatibility handed down by the Irish Courts. Nonetheless the rulings of the European Court must be taken into account by the Irish courts and there is evidence that this is happening. In this regard the decisions of the European Court in cases dealing with disabled people particularly in relation to Article 5 and Article 8 of the ECHR, which are most relevant to the IL right, are very pertinent. The Court has given quite detailed direction in relation to PWD on the deprivation of liberty, legal capacity and, most recently in Stanev, on the need to disentangle the need for support from the need for accommodation - stating that the need for social support should not automatically lead to institutionalisation. Although this most recent case referred to a country where large-scale institutions are the main way of dealing with disabled people in need of support, the rulings have a relevance in Ireland. In particular the Court has ruled that a person may be considered to have been deprived of their liberty even where they did not resist - or did not have the capacity to consent to - their detention and that where people are subject to supervision and control by staff and cannot leave of their own free will, they have been deprived of their liberty in contravention of Article 5. While PWID in Ireland are not legally detained in group homes or in residential institutions, several of these conditions exist. Most people, whether or not they resisted their placement or did not have the capacity to fully understand the implications of their placement in such settings, often comply. And most cannot leave of their own free will - often because of a lack of ability to manage without the support available in such settings and a lack of alternatives. Another issue is that the majority of people in group homes and in residential centres do not have any security of tenure, which is one of the hallmarks of adequate housing. In reality this means
that people can be moved from their place of residence for reasons that have little or nothing to do with their wishes.

While ECHR Article 5 directly addresses the issue of institutionalisation, Article 8 is at the heart of the idea of independent living. For without respect for the private life of individuals with disabilities, achieving IL is impossible. The Article 8 case law has, however, so far been disappointing. The crux appears to be a reluctance on the part of the Court to enter into areas of national policy which are beyond the ambit of the Court and which could have large resource implications for COE member states. There has been a singular failure by a succession of applicants to convince the Court firstly, of the existence of a direct link between the measure sought and the applicants’ private life. Secondly, even where the direct link is acknowledged, the need to strike a fair balance between the needs of the individual and the community as a whole, and the wide margin of appreciation allowed to states in deciding on national economic and social priorities has proven to be a stumbling block for the Court. This gives little grounds of optimism. However, it is worth considering DeSchutter’s proposal that future applicants could consider arguing that where the direct link is clear, that what is required is reasonable accommodation for the particular individual, not wholesale policy change for all disabled people. This could indeed be a more successful strategy but it also limits the effectiveness of Court decisions in levering policy or legal changes. On the other hand, as with reasonable accommodation generally, such decisions could serve as examples of how people with disabilities can be included on a case-by-case basis and provide examples of flexibility and innovation which in the longer term could bring about attitude changes. There is as yet the untapped potential to prove that institutionalisation represents a breach of Article 8 akin to the famous Olmstead judgement in the United States. The Olmstead judgement has driven widespread changes in policies in all of the states across America and has seen a move away from institutional accommodation for PWID and people with mental illness towards community-based housing. Although the applicants in Stanev and Kedzior each sought to make this argument, the Court did not consider it on the basis that the substantive issues had been addressed under other Convention Articles. While this was disappointing, and was criticised in two dissenting judgements in Stanev, it means that this route has not been closed off and remains as an area where progress can be made.
There are many aspects of Irish legislation which enable the realisation of the core elements of the right to IL, while at the same time it also presents some barriers. The placing of residential accommodation and personal supports for PWID primarily within health legislation is one of the major obstacles to the achievement of IL and indeed to a universalist approach to disability. A universalist approach supporting IL dictates that all environments and all structures should seek to be inclusive of all – and this includes not only housing, but all other environments as well, which spans all legislation, policies and structures. As long as personal support funding remains bound up with health funding, a move towards a rights-based or social model or universalist approach will be unnecessarily problematic. And in reality most PWID are not sick, are not patients and are in no greater need of health services than the rest of the population. In addition there is a lack of legal clarity about what constitutes personal social services for PWD which compounds the difficulty. The supports people need to achieve IL are primarily social and personal - rather than health-related - in nature and why these continue to be delivered by our health system is an important question which needs to be addressed. The health framework will almost inevitably have a decisive influence on how social supports for PWID are conceived and delivered and this must change if people are to be enabled to realise their right to IL.

Equally important is the mechanism used by the state to fund disability support services – primarily via annual block grants to voluntary agencies (albeit almost 100% state-funded) which provide services in specified geographic areas under the terms of an agreed Service Level Agreement. This mechanism has a legislative basis in the Health Acts, but the awarding of grants to the same agencies year on year in defined geographic areas is not an essential part of the legislation. And in fact the Competition Authority has criticised the process because it severely limits the choices open to PWID, stifles innovation and is not necessarily cost-efficient. So long as services are provided by a single provider in any given area, PWID can have little or no choice about the type of support they receive or only to the extent to which the provider is willing or able to be flexible in how they deliver support services. Where support services are provided by a particular agency primarily in grouped residential settings, then this remains the only option open to PWID. Choosing where and with whom to live and not being obliged to live in any
particular living arrangement as dictated by Article 19, is well nigh impossible in these circumstances.

The proposal that funding for personal support services be paid directly to disabled people so that they would have greater choice and control over how they live, is gaining ground. This would require legislative change. The most recent policy on disability services from the Department of Health foresees the development of a mechanism to individualise funding within the block grants along with the development of the structures needed to provide direct payments. Both of these methods are often hailed as essential in realising IL and both have been introduced in several countries with mixed results. Experience in the United Kingdom would indicates that while most recipients of direct payments are relatively happy with their experience, older people and people with more complex needs do not express the same satisfaction. Clements points out that the research evidence supporting the effectiveness of individual budgets is scant. British Columbia, Canada, which was one of the pioneers in offering individualised funding, has seen a very slow take up of individualised funding options. What also remains unclear is the costs involved in providing direct payments or individualised budgets to PWID - with predicted cost-savings resulting from the rolling out of individual budgets in the UK ranging from 10% to 45%. On the other hand the Netherlands has seen a large increase in the funding required to meet the demand for individualised payments, arising mainly from children and adolescents with ID and autism. There is, however, clear evidence that people do better in community settings than in institutions, especially where these institutions accommodate large numbers of people together. What we know then, is that people have better lives in communities than in institutions. What we do not know is how important having individualised budgets or direct payments is in enabling PWID achieve the basic elements of IL and an improved quality of life. Perhaps the key is that people have the facility to direct their own services within the available resources, rather than necessarily having control over the money.

Individual budgets or direct payments would entail the development of a workforce to meet the demand for personal assistants. Experience internationally paints a picture of a largely female workforce, many of whom are from immigrant backgrounds, with poor working conditions and who often operate outside of employment and social security protections. As Shakespeare suggests it would indeed be unfortunate if the empowerment of disabled people contributed to the
disempowerment or exploitation of an equally vulnerable section of the population.

Individualised budgets or direct payments would require a complex administrative system which would see each applicant undergoing some form of needs assessment, a methodology for the allocation of resources to individuals and each accounting in some way for the resources they receive. The use of individual service planners and independent brokers form part of these systems in the UK. It is widely acknowledged that the needs assessment process currently operating under the Disability Act is ill-equipped to serve the purpose of needs assessment required for individual budgets. Legislative change would be required to establish new systems to provide for individual budgets and for direct payments and would involve system-wide change.

The process of introducing individualised budgets or direct payments is fraught with difficulties especially if it entails wholesale systems change and needs to be approached with care. However, in order to enable disabled people to have a degree of choice and control over where and with whom they live it must be available as a manageable option.

Ireland's equality legislation has been lauded as well fitted to protect disabled people and the other listed groups from discrimination. This, along with the work of the Equality Tribunal established under the legislation, has contributed greatly to the increased unacceptability of unfair discrimination against PWD and others on the areas of employment and the provision of goods and services. However, it appears that people living in group homes or residential centres cannot have recourse to the Tribunal to make a case of discrimination in the provision of residential or support services. This appears to be because such services do not fall within the definition of a 'service' generally available to the public or a section of the public under the Act. It is arguable that specialist accommodation only available to PWID, the mechanisms by which people access this type of accommodation and the lack of needed supports in other housing options represent discrimination.

For disabled people the Disability Act has been a mixed blessing. The access provisions of the act have seen the development of sectoral plans by several government departments to increase the accessibility of their services and the National Disability Strategy has had some success. Initiatives such as the
Disability Access Certificate for buildings from the Department of the Environment are directly attributable to the NDS and the department’s sectoral plan. However, the assessment of needs and service statement processes have not done anything to improve services for people with disabilities. This appears to have resulted from the narrow focus of the needs assessment process and the fact that pre-school children are, so far, the only group to have been brought within its ambit. The lack of a right to service was heavily criticised by disability advocacy groups prior to the enactment of the Act. However, whether the inclusion of a right to service is desirable or sustainable in an environment with limited resources, is questionable. The suggestion by DeWispelaere and Walsh, that a Right to Challenge the statement of need arising from the needs assessment process is worth considering further.

Irish housing legislation is also reasonably well structured to include disabled people, particularly with the recent passage of the Statutory Instrument concerning social housing needs assessment and the National Housing Strategy for People with Disabilities. It remains to be seen if the structures envisaged in the housing strategy can open up access to mainstream housing for PWID, especially given the growing demand for social housing from other sections of society who have equally pressing needs.

The legal capacity legislation currently in force in Ireland is widely recognised as representing a major obstacle to the achievement of IL. It is to be hoped that new legislation, which is due to be enacted in 2013, will adopt a universal approach to legal capacity and will provide a basis for the provision of supports to enable people develop and exercise their legal capacity. There is a symbiotic relationship between legal capacity and independent living, without one the other is almost impossible and vice versa.

9.3 Implications of the research findings for the law in Ireland as it impacts the right to Independent Living

This research has highlighted the positive aspects of law in Ireland which support the right to IL. These include an increasingly accessible social housing system with the support of the National Housing Strategy for People with Disabilities, robust anti-discrimination legislation and those aspects of the Disability Act,
which have seen attention focused on access to public services. As well the incorporation of the ECHR into Irish law must be seen as a positive development. Although the government has been slow in its responses to the Declarations of Incompatibility handed down by the Courts, the fact that the Courts are routinely taking account of the judgements of the European Court of Human Rights can only be beneficial.

The research has also focused on the areas where change is required to further this right. Some of the changes needed are beyond the scope of the law, particularly cultural conceptions of PWID. It is possible to hypothesise that the only way fundamental changes in perceptions will come about is by people actually doing things differently, regardless of what the law says. So that to achieve IL people must actually go out and do it – for it is only when we see everyday examples of PWID living the lives of their choosing in places of their choosing that we may be able to believe that it is possible. However, there are some important legal changes which need to be made before people can do this and, equally importantly, unless some of these changes occur people will remain locked in a system which limits their access to ordinary housing and ordinary communities.

The most obvious areas where change is required are firstly, the placing of social support for PWID within the health legislative framework and secondly, in the area of legal capacity.

Institutions for disabled people are dealt with in the Health Acts, thus clearly placing responsibility for the provision of residential accommodation and supports for people living in these settings with the Department of Health. First and foremost then, the housing needs of PWID who need personal support rests outside of mainstream housing systems. Although the social housing system is beginning to open up to PWID, this is relatively new, and most people are confined in a separate system operated and funded by the health services. The framing of the housing needs of PWID within health has major implications, particularly as it is primarily in housing provided by the health services that people can access the supports they need to live. This system requires a fundamental alteration which would enable people to access support in the homes of their choosing within the ordinary systems. This should include the option of receiving direct payments to purchase the supports needed. However, it is more important that people are
enabled to direct their own support services, because the most important aspect of the IL right is that people can choose where and how to live, not that they manage the money allocated to them to do this. If people are enabled by legislation to decide how their supports are configured to best support their choices, then it is of secondary importance who manages the money needed to fund the supports. As a first step for this to happen all group homes and residential centres for PWID need to come within the ambit of housing legislation. This is already envisaged in relation to HSE operated community residences accommodating people with mental illness as part of the Implementation Framework for the National Strategy for People with Disabilities. Along with this support services in group home and residential centres should come under the ambit of either a distinct unit in the Department of Health or preferably with the Department of Social Protection. All residents of group homes and of residential institutions could then be offered tenancies in these settings or offered alternative social housing options. Along side this the opportunity to have support provided in mainstream housing settings should be provided and this would be much more likely to be practicable where the housing and support costs are dealt with by separate agencies. This should include an option for people to receive direct payments instead of through a disability service provider - but this should be an option, and not become compulsory as is the trend in the UK. If all of the residents of a group home then decided to rent private accommodation – possibly with rent support – the challenge would be for the support provider to re-configure the support so that this is possible. This does not preclude the possibility of existing providers – including the large voluntary bodies or the HSE – from continuing in this role, but it would mean significant changes in how their support is organised and structured. The possibility of commissioning new providers in each geographic area should also be considered as this would provide greater choice for users. This may require additional resources, especially at the beginning. But we simply do not know how well people would do in these scenarios because, where people have not been give the opportunity to live their lives in the community, their skills in independent living are likely to be under-developed. And without the opportunity to experience ordinary life, they will never develop these skills - and the reality may well be that we have actually over-supported PWID because of our assumptions about their incompetence. Legislative change would be required to re-place residential accommodation within the Department of the Environment and local authorities and social support within the
Department of Social Protection. The provision of direct payments would also require legislation change and the establishment of administrative structures to support this.

The issue of legal capacity is intimately linked to the idea of independent living. If people’s right to make decisions is not respected in law then it becomes almost impossible for them to exercise their right to IL. And if people are denied opportunities to have independent lives, how then can they develop the skills or acquire the experience they need to make good decisions and develop independent living skills. There are numerous examples in Irish law of the denial of the capacity of people to make decisions on their own behalf. These include the prohibition on sexual relationships with PWID under the Criminal Law (Sexual Offences) Act, the regulations granting control over the use of the Disability Allowance to agents for indefinite time periods and, most obviously, the current capacity law – the Lunacy Regulations dating back to 1871 under which the Ward of Court system operates. There is no debate about the necessity to introduce new legal capacity legislation and the government has published the Scheme of Mental Capacity Bill. The Scheme however, falls short of what is required to implement the aim and purpose of the Article 12 of the CRPD and the 2012 Oireachtas hearings on it give rise to the hope that it will be amended. To create the conditions necessary for the realisation of the right to IL for all disabled people it is essential that new legislation adopt a universal approach to legal capacity, and this would be mandated strongly by a universal conception of disability. This would entail an assumption that everyone has legal capacity, that everyone can exercise their capacity and that where supports are required to enable people develop and exercise their capacity these should be put in place. The role of the courts then, would be to determine whether the necessary supports are in place and whether they are effective in enabling the individual exercise their capacity. If people are unable to make decisions because their intellectual disability is too severe, only then should the legislation provide for some form of substitute decision-making. And substitute-decision making in these circumstance would have to be based on what is known about the person’s preferences and their wishes. Overall though we know that people’s capacity to decide develops when given the chance to live in communities and make everyday decisions. And despite the presence of legal obstacles to the exercise of capacity, it is eminently
possible within the current framework to begin enabling people to acquire these skills.

Allied to this is the need to open up access to the justice system for PWID because the ability to resort to the courts to exercise rights is a core ingredient of anti-discrimination law. As it stands at present it is extremely difficult for PWID to pursue a case because of the question of capacity – and more often than not a parent or other family members will take a case on behalf of the person with ID. The courts have a powerful role to play in ensuring the upholding of the law and where this route is in effect barred, people are placed at a significant disadvantage. This is especially true for PWID living in large residential institutions, many of whom have poor contact with family, and therefore lack family advocates. In many instances their main support comes from staff members of these institutions. Where the issue concerns conditions or placement in the institution, these staff cannot realistically support the person because of a conflict of interest with their employer. The establishment of the National Advocacy Service for people with disabilities goes some way to addressing this issue, but legal capacity legislation recognising and supporting universal legal capacity is an essential element. In addition the National Advocacy Service cannot provide legal advise or legal representation.

As noted Sectoral plans developed by several government departments as part of the National Disability Strategy outlined how each proposed to enhance access to their services for PWD. These plans were due for review in 2012 and it is important that this work continue. Opening up access can be costly where physical infrastructural change is needed. But access to services does not necessarily entail large costs. Examples of ways of enabling access have been identified by the Equality Tribunal in relation to housing providers. These include the provision of information in accessible formats, identifying specific staff members to support access and the provision of reasonable accommodation. Accessibility is already supported by legislation and policies are already in place to enable greater access. What is required is an increased focus on promoting accessible services and a realisation that all members of the public, including PWID, are entitled to access services. At a minimum public services need to examine their systems to ensure that they are not inadvertently excluding PWID and take measures to include this population group. The proposal by Fredman among others – and as implemented in Northern Ireland with the Public Sector
Equality Duty – that public service providers pro-actively plan for the access needs of various groups is worth considering. This is an area which would require legislation in order to be effective, but it could help in the move towards more accessible services and a more substantive version of equality that currently exists.

9.4 Areas for further research

Creating the conditions in which IL is possible for PWID in Ireland will involve changes on many levels and the law is just one of these areas. Perhaps the most fundamental change needed, at a basic cultural level, is in the ways in which PWID are seen and valued as citizens of this state. This however, is a circular problem - until we see PWID living freely chosen lives in the community the perceptions of what they are capable of are unlikely to change. At the same time until we allow PWID begin to have real choice about how they live, we have no evidence upon which we can bring about change in attitudes and perceptions. Building reliable evidence on the ways in which PWID can achieve IL will be important in making it a realistic option for people themselves, for families and for policy makers. This would include gathering information about models of service and support which have been successful in other jurisdictions and testing these in the Irish context. For example, the Microboards first developed in Canada and Keyring Community Living Networks from the UK are well-established models which could be piloted and evaluated in this country and adapted as necessary. There is also a need to develop other models based on the tenets of IL particularly for people with more significant intellectual disabilities and complex needs.

An inherent part of research needed in this area is a focus on the costs and cost-effectiveness involved in enabling PWID to achieve IL. There is ample research to support the contention that people do better in smaller community-based housing than in institutions. There is little research however, about how well PWID do living in there own homes with the supports needed to achieve IL. This is a relatively new area and so is not surprising, but it will be important to have reliable research evidence as to the outcomes achieved by PWID living independently and the costs associated with this.
As noted, estimates of the cost-savings or the additional costs of individual budgets or direct payments vary widely. And while having access to direct payments is not essential in the achievement of IL, is one option which should be open to people. The research evidence in the UK on the effectiveness of individual budgets is slight. If Ireland is to embark on the development of the structures needed to support individualised budgets and direct payments – including needs assessment processes and resource allocation mechanisms - there is a need for strong research evidence as to the cost, cost-effectiveness and outcomes of each methodology. It would be unfortunate if, in attempting to achieve IL, the bureaucratic processes become overly intrusive or costly or complex for PWID or other disabled people. We know from the experience of the needs assessment and statement of needs processes currently operating under the Disability Act that this can happen, and it is essential that this be avoided.

This research did not include any direct consultation with PWID and this is certainly one its limitations. PWID as a group have been researched perhaps more than most others, often as objects of the research rather than as active participants. Including PWID as participants in research concerning them should, at least in principle, be a priority. This may make the work more time-consuming or expensive. Nonetheless it is suggested that as a general rule, especially in the testing of models of IL or the use of individual budgets or direct payments that PWID should be actively involved.

The most debilitating stereotype which we as a society impose on PWID is that of low – or no – expectations. In fact what we expect of PWID is that they will always be a drain on the resources of their families and of the state. We expect little of PWID, treating them like grown up children who are unlikely to ever achieve full adult status. We do not consider their potential to contribute, to take on normal responsibilities or to be fully active members of our society. And this stereotype is embedded in many of our laws and structures. The ideals of IL have the potential to begin to change this. If we can bring about the legal changes needed to enable IL and allow people the freedom to begin to live the lives they choose we may well be surprised at what PWID can actually do and be in the world. We need to get the law and the structures right and then perhaps, take a leap of faith.
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