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# **ADVANCE DIRECTIVES IN MENTAL HEALTH CARE: HEARING THE VOICE OF THE MENTALLY ILL**

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## **Abstract**

Advance directives or “living wills” are statements by competent adults setting out their wishes in anticipation of future incapacity to make decisions. The capacity to make independent choices and decisions may be impacted by mental illness, making advance directives of relevance to mental health law. Advance mental health directives allow competent individuals to specify their treatment preferences in advance of an incapacitating mental health crisis. Advocates believe that they can enhance autonomy and empower persons with mental illness to participate in their future treatment decisions. Opponents believe that they present a wide range of legal and ethical problems, making them unworkable in practice. The potential therapeutic, economic and human rights benefits demand their consideration in the Irish mental health context.

## **Introduction**

Advance directives are the subject of debate in contemporary mental health care. The concept has gathered momentum in the first decade of the twenty first century and is increasingly recognised internationally. The inclusion of advance directives in mental health settings is part of an international impetus towards the recognition and entrenchment of human rights for people with mental illness.<sup>1</sup> The main theoretical

rationale behind advance directives is the enhancement of patient autonomy, but the mechanism also has the potential to ameliorate some of the negative consequences of mental illness. Advance directives were originally developed to allow decisions regarding end-of-life care.<sup>2</sup> The “living will” was then extended to the mental health context, allowing treatment choices to be expressed in advance of incapacity. Traditionally, individuals with mental health difficulties have not been afforded the opportunity to become involved in their treatment decisions.<sup>3</sup> Many patients still have little influence over their destiny during a mental health crisis and are excluded from participation in many life decisions once deemed incapable. Advance directives offer a novel solution to this dilemma by enabling treatment choices to be asserted during periods of decision-making capacity. Preferences can be expressed through instructional directives which provide directions regarding treatment or proxy directives where the authority to make decisions is given to an appointed person in the event of incapacity.<sup>4</sup> Advance directives are increasingly recognised as one of the “strategies for giving people with mental disorders more say in the management of their treatment and their lives”.<sup>5</sup> This article explores the issues surrounding the mechanism and seeks to establish whether legislation providing for advance mental health directives should be enacted in Ireland.

### *Development*

Thomas Szasz initially suggested the notion of a “psychiatric will” in the early 1980s.<sup>6</sup> This involved taking a patient’s express refusal or consent to future psychiatric treatment into account. The first reported Court decision occurred in the United States in 1991, when a New York Court denied the authorisation of electroshock therapy in the case of *Rosa M.*<sup>7</sup> The Court referred to the prior

competent wishes of the patient expressed in a brief signed statement. It was held that the hospital must respect a patient's competent rejection of certain medical procedures even after they lose capacity in the absence of an overriding State interest. The mechanism has since been widely recognised in the United States. Phrases used to describe advance mental health directives include: psychiatric advance directives (PADs); Ulysses directives; advance statements; advance decisions; self binding directives and psychiatric wills.

#### *Advance mental health directives v End-of-life directives*

Advance mental health directives can be distinguished from end-of-life directives in two ways. Firstly, persons executing end-of-life directives are usually making decisions regarding treatments they may have never experienced. Mental health patients, in contrast, are often dealing with a chronic illness which is episodic in nature and are therefore more likely to have prior experience of treatment. The goal of general advance directives is usually to increase dignity and autonomy at the end of life, whereas the objective of an advance mental health directive is often to maximise recovery while minimising unwanted intervention and treatment.<sup>8</sup> The end-of-life directive is only used once, whereas a mental health directive may be used many times.<sup>9</sup> Backlar describes the distinction succinctly, “one directive attempts to guarantee for those who so desire, a good death; while the other endeavours to secure, for a specific population of individuals a good life”.<sup>10</sup>

#### *Types of Advance Mental Health Directives*

Advance directives can take varying forms, enabling different decisions to be made.<sup>11</sup> A valid advance directive must be executed by competent persons and clearly express

their wishes.<sup>12</sup> The measure takes effect with the onset of an incapacitating episode of mental illness. Advance mental health directives usually include personal treatment choices but can also include information regarding other life management issues, e.g. household finances. A directive can be either positive or negative in that it includes advance consent or refusal of treatment. Some directives are legally binding while others are accorded due respect and consideration. A Ulysses directive provides for anticipatory consent through a self binding contract which can be used to override refusals in advance of future episodes of mental illness.<sup>13</sup> The directive is named after the Odyssey, in which Ulysses directed his crew to tie him to the ship's mast and keep him bound regardless of subsequent pleas.<sup>14</sup> The attraction of the directive is that it enables people to manage their illness in advance of a psychiatric episode when they know they will refuse treatment. Many patients self-bind to avoid deterioration and the need for involuntary detention. Minnesota was one of the first US States to provide for Ulysses directives.<sup>15</sup> Self-binding directives are now available in a number of US States and Canadian provinces.

### **Autonomy**

The moral and legal validity of advance directives is based on the patient's right to autonomy. Autonomy derives from the Greek words "*auto*" and "*nomos*" meaning self law or self control<sup>16</sup> and is considered one of the foundational principles of Western society.<sup>17</sup> It can be used to make choices and to resist choices others make on our behalf, including the right to make decisions which others may not agree with or understand.<sup>18</sup> The unenumerated right to autonomy was first recognised in Ireland in *Re a Ward of Court (No.2)*.<sup>19</sup> Denham J. outlined factors to which the court had regard when determining the "best interests" of an incapable patient, including the

constitutional right to autonomy.<sup>20</sup> The right has recently been reaffirmed in *Fitzpatrick & Ryan v F.K. (No.2)*<sup>21</sup> when Laffoy J. noted the existence of the right of autonomy protected by Art.40.3.1 and Art.40.3.2 of the Constitution.<sup>22</sup> The principle of autonomy is also recognised under Article 8 of the European Convention on Human Rights.<sup>23</sup>

The general principle of the law requires consent to medical treatment.<sup>24</sup> In the absence of an advance directive, treatment may be administered to a patient incapable of consenting if it is in their “best interests”. Advance directives are an extension of the principle of autonomy for incapable patients, allowing them to express autonomous choices regarding future medical treatment.<sup>25</sup> The exercise of prior autonomy is of increased significance in mental health due to fluctuations in capacity and the invasive nature of psychiatric treatment.<sup>26</sup> The denial of autonomy is normally justified on the basis of harm to the patient themselves or others. Mental health legislation frequently over-rides the right to autonomy and provides for involuntary treatment in certain circumstances. In the case of involuntary patients in Ireland, consent to treatment is required, except where, in the opinion of the consultant psychiatrist, it is necessary to safeguard the life of the patient, to restore their health, to alleviate their condition, or to relieve their suffering, and by reason of their mental disorder the patient is incapable of consenting.<sup>27</sup> The patient must be capable of understanding the nature, purpose and likely effects of the proposed treatment in order to consent.<sup>28</sup> The limitation placed on autonomy during mental illness has been criticised by human rights campaigners.<sup>29</sup> The Richardson Report found that the principles governing mental health care should be the same as physical health care wherever possible.<sup>30</sup> Discrimination still exists between the provision of advance

directives in physical and mental health care. After filing a legal challenge for differential treatment in *Hargrave v Vermont*,<sup>31</sup> Nancy Hargrave asserted “it seems fundamentally unfair that I choose or refuse chemotherapy which is saving my life, but I don’t have the same right to choose or refuse psychiatric medication”.<sup>32</sup>

Proponents of autonomy have always accepted that the right is not absolute. However, the possibility of harm does not justify a total disregard for autonomy. Involuntary treatment should be proportionate to the danger posed by the patient and in accordance with the least restrictive alternative.<sup>33</sup> Research indicates that the increased risk of harm posed by people with mental illness is relatively low and violence occurs very rarely.<sup>34</sup> The psychological effect of the loss of autonomous control and the non-consensual invasion of the body during involuntary treatment is significant.<sup>35</sup> Autonomy is not just about independence, it can help improve therapeutic relationships, enhance communication and facilitate the sharing of ideas to make realistic choices.<sup>36</sup> Advance directives enable such autonomous choices to be made during incapacitating periods of mental illness.

## **The Value of Advance Mental Health Directives**

### *Therapeutic Benefits*

The broader therapeutic impact of the law is apt when considering the adoption of advance directives in mental health care.<sup>37</sup> Advance directives offer a myriad of benefits in the mental health context, including the potential to motivate adherence to treatment plans, improve continuity of care, mobilisation of resources and enhanced management of crises.<sup>38</sup> Winick lists a number of therapeutic benefits including the facilitation of preventative care, patient empowerment, the prevention of future

incapacity, the reduction of stress and anxiety, enhanced self esteem and decision making capacity, improved negotiation with clinicians and increased compliance.<sup>39</sup> Some commentators believe that the major benefit of advance directives is that they force psychiatrists to listen to their patients.<sup>40</sup> A survey of 536 service users by the National Service Users' Executive found 58 per cent of users felt listened to and 43 per cent felt their views and wishes were given priority.<sup>41</sup> The importance of listening and the development of trust were highlighted in a recent Irish study on recovery in mental health.<sup>42</sup> The study found that,

service users should be encouraged to talk at length, narrate their story, voice their concerns and aspirations towards recovery and participate in a dialogue with service providers.<sup>43</sup>

Advance directives provide a forum for this to occur. The perception of respect for patient choice can lead to a sense of empowerment.<sup>44</sup> One service user in Australia asserted:

I was denied any participation in my own treatment ... to be able to sit down and discuss things, has actually not only improved my own situation, it's improved my level of health.<sup>45</sup>

Other patients felt nobody really listened to them and decisions were made in their "best interests".<sup>46</sup> Psychiatric institutions foster dependency, incompetency, learned helplessness, and a form of institutionalisation that is inconsistent with community readjustment and recovery.<sup>47</sup> Patients who participate in their own treatment are more



likely to achieve successful outcomes. International experience suggests that recovery enables people to become active participants in their own care.<sup>48</sup>

### *Reduced Involuntary Detention and Treatment*

Advance mental health directives are at the forefront of contemporary measures to reduce involuntary treatment.<sup>49</sup> Winick argues that advance directives have therapeutic value, making patients more responsive to treatment and self compliant, thereby reducing the need for involuntary detention.<sup>50</sup> The pattern of repeated hospitalisation and coercion can be minimised by the availability of non-coercive treatment options. The MacArthur Research Network studies show that patients who believe they have a “voice” experience less coercion during the hospital admission process.<sup>51</sup> Henderson et al. found decreased use of mental health legislation and reduced readmission rates for the group who used joint crises plans (a form of advance directive) in the UK.<sup>52</sup> A significant number of mentally ill people are averse to the depersonalisation and loss of control that accompanies the involuntary detention process rather than being totally opposed to treatment itself.<sup>53</sup> Coercive treatment can be anti-therapeutic, negatively impact on self esteem and induce feelings of apathy, distrust, submissiveness, dehumanisation and frustration.<sup>54</sup> Advance directives give patients a sense of informed consent,<sup>55</sup> thereby reducing resistance to treatment. Non-voluntary admissions accounted for 11 per cent of all admissions to Irish psychiatric hospitals in 2008.<sup>56</sup> The rate has decreased by 29 per cent since the mental health tribunals were established but a high rate of non-voluntary hospitalisation still persists.<sup>57</sup> The mechanism provides an opportunity to redefine the coercive model of treatment to one of collaboration, reducing the need for involuntary detention and treatment.

### *Economic Benefits*

A recent report found that mental health problems cost the Irish economy over €3 billion per year.<sup>58</sup> Advance directives have been shown to decrease costs and reduce hospital readmission rates in mental health care.<sup>59</sup> The potential economic benefits resulting from the therapeutic impact of advance directives is significant. An economic valuation of joint crisis plans found a 78 per cent probability that they were more cost effective than standard service information in preventing admissions.<sup>60</sup> The “revolving door syndrome” describes the pattern of repeated involuntary hospitalisation, subsequent noncompliance and decompensation experienced by many mental health patients.<sup>61</sup> The role of advance directives in reducing involuntary readmission rates was demonstrated in a UK study.<sup>62</sup> The measure has also been shown to reduce hospitalisation lengths.<sup>63</sup> Readmissions accounted for 70 per cent of the 20,752 admissions to Irish psychiatric units in 2008.<sup>64</sup> A study on Irish readmission rates in 2001 showed that 37 per cent of patients were readmitted at least once more during the following five years.<sup>65</sup> In addition to increased costs, a high rate of readmissions can block the admission of new patients and impact on the quality of care.<sup>66</sup> At a time when the Irish health care system is under resourced, advance directives can have significant economic benefits in mental health care.

### *Collaborative Decision-Making*

Advance directives provide a way of harnessing patient expertise and improving decision-making quality in mental health care. The instrument has the potential to transform relationships and foster strong therapeutic alliances traditionally lacking in psychiatry and mental health law.<sup>67</sup> Evidence suggests that the presence of a mental health professional during the execution of an advance directive empowers patients,

promotes a healthy therapeutic relationship and reduces anxiety during future medical crises.<sup>68</sup> A recent Irish study highlighted the need for support in formulating patient needs.<sup>69</sup> Under the recovery approach, the use of medication should be based on shared decision-making between service users and providers.<sup>70</sup> Advance directives can only gain currency if they are supported by all parties. Lack of information amongst patients, professionals and other community members is a major barrier to implementation.<sup>71</sup> Educational campaigns which alleviate fears and promote usage are crucial. Advance mental health directives should involve “mutual understanding and collaboration between clinicians and patients” rather than being viewed as “adversarial documents designed to protect patients from doctors”.<sup>72</sup>

### *Patient Preferences*

Advance directives are not only used to refuse treatment but to proceed to certain agreed treatments. Some jurisdictions provide for positive advance directives which allow patients to consent to certain treatment choices in advance of incapacity. The law does not provide for the right to a specific intervention in any jurisdiction so the right to request treatment is a power to consent rather than a power to compel.<sup>73</sup> Researchers at Duke University examined patient preferences for psychiatric advance directives.<sup>74</sup> Seventy four per cent of patients were interested in making an advance directive through a power of attorney for health care. In another study almost three-quarters of patients expressed a preference for advance refusal of electroconvulsive therapy (ECT), while antipsychotics were the most refused form of medication.<sup>75</sup> The perception of respect may be the most important factor in advance mental health directives, regardless of clinical outcomes.

Exploratory research by Amnesty International Ireland into advance decision-making amongst people who have experienced impaired capacity in the mental health context found a strong consensus in favour of advance directives.<sup>76</sup> Individuals expressed a preference to set out in advance their treatment choices, including refusal of certain treatments and the opportunity to state “what works” for them. A preference for legally binding directives was also expressed. It was suggested that medication preferences be negotiated with the individual’s mental health professional. Participants also suggested that directives include other life management issues. In a recent Irish study on mental health recovery, participants felt self determination played a major role.<sup>77</sup> The need for dialogue and support with professionals in designing recovery rather than treating patients as passive recipients of medication or other therapies was emphasised. Forcing somebody to do something against their will was perceived as traumatic and slowed down reconnection with life.<sup>78</sup> Other factors which hindered recovery were lack of somebody to talk to, medication side effects, being treated as a disease rather than a person, long stays in hospital and hostility and stigma in the wider community.<sup>79</sup>

### **International Framework**

The principles of autonomy and self determination place advance directives in the ambit of a human rights approach to mental health law.<sup>80</sup> While advance directives are not explicitly acknowledged in international instruments relating to mental health, they are widely recognised as vehicles for the principles of participation, non-discrimination, acceptability and accessibility.<sup>81</sup> The mechanism is seen as implicitly promoted in new human rights legislation and policy.<sup>82</sup> According to Atkinson, the Convention on the Rights of Persons with Disabilities (CRPD)<sup>83</sup> can be interpreted as

promoting various forms of supported decision-making including advance directives.<sup>84</sup> The evolving human rights framework implies that persons with mental health disabilities have equal dignity and freedom to make their own decisions.<sup>85</sup>

The CRPD provides human rights campaigners with a new foundation for challenging established standards in mental health care.<sup>86</sup> The reclassification of mental health rights to the realm of disability rights will give persons with mental illness an equal opportunity to participate in their future care. The non-discrimination principle requires that capacity is maximised with appropriate support.<sup>87</sup> The autonomy and self determination principles require that wishes are recognised and given equal validity.<sup>88</sup> Advance directives can facilitate collaboration, respect and reduce discrimination in mental health care provision.<sup>89</sup> The mechanism provides the opportunity to realise the social model of disability and embed values such as equality, participation, autonomy and inclusion for persons with mental illness. Any country which ratifies the CRPD consents to be bound by its provisions and is obliged to promote and realise the rights set out in it. Ireland signed the CRPD in 2007 but has not yet ratified its terms. Ratification of the CRPD will be instrumental in furthering the use of advance directives in mental health care.

The Council of Europe has built on Recommendation No. R 99 (4) concerning the legal protection of incapable adults<sup>90</sup> to include self determination mechanisms such as advance directives and powers of attorney.<sup>91</sup> Advance directives and continuing power of attorney are recognised as the principal means of self determination for capable persons anticipating future incapacity. The Recommendation concerning continuing powers of attorney and advance directives for incapacity<sup>92</sup> is designed to

encourage further development in this area. While the recommendations are not legally binding, the move signifies the European direction in regard to the use of advance directives for incapable adults. The Recommendation reinforces the need for a legislative framework for advance directives in Ireland.

### **Advance Mental Health Directives in the Irish Context**

The legal status of advance directives in general and mental health care is uncertain in Ireland. While there is no law prohibiting a person from expressing their treatment wishes, the absence of a legal framework means these may or may not be enforced. The authority as to whether an advance directive will be respected remains with the High Court under the *parens patriae* jurisdiction, which obliges the Court to act in the “best interests” of the individual. This jurisdiction was exercised in *Re a Ward of Court (No.2)*.<sup>93</sup> The right to refuse medical treatment was recognised by the Supreme Court when O’Flaherty J. stated that:

consent to medical treatment is required in the case of a competent person ... and, as a corollary, there is an absolute right in a competent person to refuse medical treatment even if it leads to death.<sup>94</sup>

The reasoning in the case suggests that advance directives would be respected by an Irish court.<sup>95</sup> O’Flaherty J. asserted that while he found it

impossible to adapt the idea of the ‘substituted judgment’ to the circumstances of this case and, it may be, that it is only appropriate where the person has had the foresight to provide for future eventualities.<sup>96</sup>

While it is likely that an Irish court would uphold the terms of an advance directive, a statutory framework detailing the conditions and limitations of the mechanism would ensure that the wishes of the individual are properly recorded and applied.<sup>97</sup> The courts may be willing to recognise advance directives but the law remains ambiguous in relation to the recognition of advance directives in mental health care.

### *Law Reform Commission*

The Law Reform Commission proposed a statutory framework for the provision of general “advance care directives” in a Consultation Paper in 2008.<sup>98</sup> Psychiatric advance care directives were specifically excluded from its scope due to the complexities involved. The Commission published a report setting out its final recommendations on advance care directives, together with a draft Mental Capacity (Advance Care Directives) Bill intended to implement these recommendations in September 2009.<sup>99</sup> The Commission recommended that the appropriate legislative framework for advance care directives should be enacted as part of the reform of the law on mental capacity under the Scheme of a Mental Capacity Bill 2008.<sup>100</sup> The recommendations include the use of negative advance care directives involving refusal of treatment only.<sup>101</sup> The report also recommends that the proposed legislative framework should not apply to advance care directives in mental health care.<sup>102</sup> A separate review was recommended for this area which would include an assessment of the impact of the Mental Health Act 2001 and the work of the Mental Health Commission.

### *Scheme of the Mental Capacity Bill 2008*

The main purpose of the Scheme of the Mental Capacity Bill 2008<sup>103</sup> is to introduce a modern statutory framework governing decision-making for people who lack capacity in Ireland. The new proposals will reform the existing Wards of Court system and replace the Lunacy Regulation (Ireland) Act 1871. The Scheme proposes to provide greater protection for people who suffer from impaired decision-making ability, including those with mental illness. The foundational human rights principles include respect for dignity, bodily integrity, privacy and autonomy.<sup>104</sup> While the Scheme does not contain a specific framework for advance directives, the principles implicitly support advance decision-making. Advance directives are promoted through the principle that the past and present wishes of the person must be taken into account.<sup>105</sup> The “best interests” provisions of Head 3 also require that any written statement made prior to incapacity be taken into account.<sup>106</sup> Amnesty International submits that Head 1(g) and Head 3(1) (iii) should require the approval of the Court of Protection or other body where it is proposed to depart from a person’s express wishes.<sup>107</sup> Capacity is defined as the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is made.<sup>108</sup> When a person is found to lack capacity, those acting for them must do so on the basis of the person’s “best interests”.<sup>109</sup> This includes, as far as practicable, allowing the person to participate, or improving their ability to participate as fully as possible in any act or decision.<sup>110</sup> Recent decisions interpreting the “best interests” provisions of the Mental Health Act 2001 signify a paternalistic approach by the Courts.<sup>111</sup> This further emphasises the need for autonomy-preserving mechanisms such as advance directives in mental health care.



### *Enduring Power of Attorney*

An enduring power of attorney is a form of advance directive which enables a competent person to delegate decision-making powers to an appointed person in the event of incapacity. The current Power of Attorney Act 1996<sup>112</sup> applies to property and finance decisions and to limited personal care decisions but specifically excludes health care decisions. The Scheme of the Mental Capacity Bill 2008 extends the current enduring power of attorney to health care.<sup>113</sup> The proposed law may enable an enduring power of attorney for decisions in the mental health context provided that the person is capable at the time of execution and it is not superseded by the involuntary provisions of the Mental Health Act 2001. Amnesty International Ireland submits that substitute decision-makers such as donees of an enduring power of attorney should be recognised in mental health legislation in order to maximise the autonomy of persons with mental health problems.<sup>114</sup> It is crucial that the proposed law adopts an enforceable rights-based approach to people lacking capacity, particularly in the area of mental health.<sup>115</sup>

The capacity framework may provide a suitable location for a specific provision for advance mental health directives. The “Bazelon Centre for Mental Health Law” advocates providing for psychiatric advance directives with general legislation rather than in specific provisions which may discriminate against persons with mental illness.<sup>116</sup> A number of factors need to be considered prior to their introduction, including the legal, social and policy context, analysis of the relevant common law, legislation, assessment of applicable capacity legislation and substitute decision-making, provision for the refusal of medical treatment and the intersection between criminal and civil commitment provisions.<sup>117</sup> An assessment of the attitudes and

perceptions of various stakeholders may be critical.<sup>118</sup> Educational campaigns are also crucial to implementation. International experience suggests that advance directives may have a limited impact if these issues are not considered. Advance directives need to be accessible, easily executable and include appropriate support from professionals, family and advocates in the mental health context.

### *Mental Health Legislation*

The Mental Health Act 2001 marked a shift towards a rights-based approach to mental health law in Ireland. In making a decision regarding the care or treatment of a person under the Act,

the best interests of the person shall be the principal consideration with due regard being given to the interests of other persons who may be at risk of serious harm if the decision is not made.<sup>119</sup>

All decisions made under the Act should have due regard to “the need to respect the right of the person to dignity, bodily integrity, privacy and autonomy”.<sup>120</sup> The Act appears to be respectful of autonomy but a paternalistic approach has been emerging in a number of recent decisions by the Irish Courts.<sup>121</sup> According to Donnelly, the protections afforded to the rights of autonomy, bodily integrity, and privacy are not sufficient under the Act.<sup>122</sup> The use of advance mental health directives could alleviate some of these problems by allowing patients to express their autonomous wishes in advance of incapacity and reduce the need for involuntary treatment.

### *Irish Mental Health Policy*

A “Vision for Change” provides a national mental health policy framework over a 7 to 10 year period.<sup>123</sup> The strategy proposes significant changes and improvements for Irish mental health services, including important recommendations for empowerment, advocacy, and recovery.<sup>124</sup> The framework provides for a holistic, patient-centred recovery approach where the need for hospital admission is greatly reduced. Self determination and control are seen as key components of recovery.<sup>125</sup> The therapeutic impact of advance directives can help patients gain a sense of control over their treatment, build self esteem and support recovery. A “Vision for Change” explicitly supports the use of advance directives and states that:

a person centred approach to the delivery of care will both highlight and moderate these conflicting rights, offering measures such as advance directives that can be put into effect at times when the user may not be well enough to make informed decisions.<sup>126</sup>

The report explicitly refers to participation as a principle of service delivery and to the use of advance directives and enduring powers of attorney in mental health services for older people.<sup>127</sup> The involvement of service users and their families at every level of service provision are seen as the next steps in the development of services.<sup>128</sup>

While the policy is supportive of advance directives in mental health care, there has been little progress in implementing the strategy. The continued lack of a recovery ethos in Irish mental health services was highlighted by the Independent monitoring group in 2009.<sup>129</sup> A recent study provided evidence that depersonalised and pessimistic attitudes often dominate over a person-centred approach.<sup>130</sup> The vital

importance of patient input into care was emphasised.<sup>131</sup> The introduction of advance directives can contribute significantly to the recovery ethos and person-centred care espoused in the policy framework.

### **Advance Mental Health Directives in other Common Law Jurisdictions**

Advance directives are aligned to the common law which recognises autonomy and self determination in relation to medical treatment. In principle, the common law recognises the validity of advance directives for persons who are capable of making decisions regarding their own healthcare, although this has not been extended to the mental health context. The debate on advance directives in mental health has advanced in other common law countries and resulted in legislative reform in some cases.<sup>132</sup> Many jurisdictions have provided for advance mental health directives through extended common law or legislative provisions. Comparative analysis shows that Ireland lags behind other comparable jurisdictions in providing for advance directives in general or mental health care.

#### *Scotland*

Scotland has a specific provision for advance directives under mental health legislation. The Mental Health (Care and Treatment) (Scotland) Act 2003<sup>133</sup> recognises the concept of advance mental health directives through a provision for non-binding advance statements. The Act provides a comprehensive framework for advance statements which can only be overridden by the clinician after reasons have been provided to the patient, the patient's guardian, legal representative and the Mental Welfare Commission.<sup>134</sup> The Act aims to encourage the use and development of advance directives by requiring mental health professionals and tribunals to have

regard for their content.<sup>135</sup> An advance statement cannot bind a doctor or member of the care team to provide or withhold specific medicines or treatments, but a competently made advance statement is a strong indication of a patient's wishes regarding their treatment.<sup>136</sup> The Scottish legislation includes a comprehensive set of ethical and human rights principles which promote good practice. The Act has received widespread general approval and provides a useful model for the use of advance statements in mental health care.

### *United States*

Advance mental health directives are widely recognised in the United States and are commonly referred to as psychiatric advance directives or PADs. Twenty five states have statutes explicitly authorising psychiatric advance directives or proxy decision-making and nearly all the others permit them through health care advance directives or power of attorney statutes.<sup>137</sup> Minnesota was the first State to legislate for psychiatric advance directives in 1991. All of the legally enforceable statutes can be overridden by mental health professionals without civil liability.<sup>138</sup> None of the statutes allow patients to use directives to avoid emergency involuntary detention.

### *England*

Advance mental health directives are accorded limited recognition in England and Wales. The Richardson Report included a recommendation for the provision of advance directives for people with mental disorder.<sup>139</sup> The review process resulted in the Mental Health Act 2007,<sup>140</sup> which provides for recognition of the past and present wishes and feelings of the patient.<sup>141</sup> The 2007 Act however, failed to give statutory recognition to advance directives in its amendments. Advance decisions were

accorded the status of good practice despite the inclusion of advance refusals under the Mental Capacity Act 2005. While advance refusals are given statutory force under the 2005 Act, treatment deemed necessary for the health and safety of the patient or others is excluded under the Mental Health Act 2007. “Concern over public protection outweighed concerns about patient autonomy”.<sup>142</sup>

### **Challenges in Practice**

A range of legal and practical issues accompany the use of advance directives in the mental health context. Opponents argue that the legal and ethical status of advance directives is ambiguous, making them unworkable in practice. The issues that require consideration include the assessment of capacity, the circumstances in which they can be overridden or revoked, the right to refuse treatment, involuntary treatment, the right to request treatment and collaborative decision-making.<sup>143</sup> Other issues include awareness, accessibility, patient preferences and legislative provision.

Many of the objections to general advance directives are weaker in the mental health context. Individuals with mental illness usually have a diagnosis before formulating an advance directive, making it easier to predict treatment choices. The directive is less likely to be drafted in vague or ambiguous terms if the executor is familiar with the condition and range of treatments. The argument that a competent person lacks experience of life as an incompetent person is diminished, as many individuals with mental illness display personal insight into their incapable selves and the effects of expressing anticipatory treatment preferences. Reports show that people suffering from mental illness develop an in-depth knowledge of “what hurts and what helps” during a crisis.<sup>144</sup> The reflection process involved in creating an advance directive can

help identify beneficial interventions and a personal crisis strategy.<sup>145</sup> This can lead to a change in personal convictions and the motivation to assert oneself.<sup>146</sup>

### *Refusal of Treatment*

Some mental health professionals fear that patients may refuse all treatment if given a choice. Studies have shown that the availability of advance mental health directives rarely leads to refusal of all treatment.<sup>147</sup> Bartlett found that there were few outright refusals of treatment in Ontario despite the existence of the legal right.<sup>148</sup> Backlar similarly found that none of the patients in his study refused all treatment.<sup>149</sup> Many patients view medication as helpful when their concerns and preferences are taken into consideration.<sup>150</sup>

### *Overriding an Advance Directive*

The circumstance in which an advance directive may be overridden is more complex in the mental health context. Advance directives are generally overridden if a person is a danger to themselves or others and is subject to involuntary detention. Appelbaum suggests that civil commitment will, and should always, trump an advance refusal of treatment.<sup>151</sup> The law varies as to whether a person detained under mental health legislation automatically loses the right to refuse treatment. The Bazelon Centre for Mental Health Law urges that psychiatric advance directives operate in the same way as other advance directives, subject only to legitimate emergency situations.<sup>152</sup>

### *Capacity*

Capacity assessment is pivotal for executing, invoking and revoking an advance directive.<sup>153</sup> The validity of a directive depends on whether the person was capable at

the time it was executed, as it only becomes operational when the person is deemed incapable. The functional approach, which focuses on a person's ability to make a particular decision at a specific point in time, has been accepted in most jurisdictions under modern capacity legislation.<sup>154</sup> Mental illness is often characterised by fluctuating capacity and accurate assessments are notoriously difficult to conduct. In some jurisdictions, the directive has to be witnessed at the time of execution and revocation to confirm capacity. Incapacity has traditionally been equated with mental illness and refusals of treatment.<sup>155</sup> The MacArthur Treatment Competence Study<sup>156</sup> demonstrated that although decision-making abilities were compromised in some patients with mental illness, more than half had capacity levels similar to their counterparts in physical health care. The European Court of Human Rights recently held that the existence of a mental disorder alone cannot justify a finding of incapacity.<sup>157</sup> Valid and reliable instruments for capacity assessment and review mechanisms are necessary for advance directives to work effectively in the mental health context.<sup>158</sup> Irish mental health legislation currently lacks a review mechanism for capacity determinations which are made by the treating consultant psychiatrist.<sup>159</sup> Research by Amnesty Ireland showed a strong preference amongst participants for a neutral party to conduct capacity assessments.<sup>160</sup> The adverse psychological effects of being deemed incapable<sup>161</sup> can be replaced by a sense of empowerment through the use of advance directives.

## **Conclusions**

Advance directives can have significant economic, therapeutic and human rights benefits in the Irish mental health context. The mechanism offers an unprecedented opportunity to retain the maximum degree of control during the most disabling



episodes of mental illness.<sup>162</sup> Advance directives serve “to restore the voice and control of the individual in crisis at a time when they are most needed and yet most often disregarded”.<sup>163</sup> The principles and rights laid down in the Irish legislative and policy framework are largely supportive of advance directives in mental health care. Exploratory research also suggests a strong consensus in favour of their use amongst service users.<sup>164</sup> The inclusion of advance directives in the legislative framework requires a significant paradigm shift in the conceptualisation of mental illness and how it is treated. The National Disability Authority asserts that the

legislative and policy context provides significant opportunities to realise the social and human rights model of disability and embed values such as equality, participation, quality and inclusion within policy, provision and wider Irish society as part of an integrated social change agenda.<sup>165</sup>

A legislative framework for advance mental health directives can help embed these values and promote an attitudinal change to people with mental health problems in Ireland. While issues around legalisation and implementation exist, these problems do not justify the exclusion of advance directives. Advance mental health directives merit a specific legislative provision through capacity or mental health legislation or through a standalone measure. The enactment of new capacity legislation, the ratification of the CRPD, the new Council of Europe Recommendations and implementation of the national mental health policy provide the perfect backdrop for the consideration of advance mental health directives in Ireland.

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