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**Advance directives and the translation of human rights principles in  
mental health law-towards a contextual analysis**

Dr. Penny Weller

In concert with international trends in human rights based reform in mental health law, interest in psychiatric advance directives<sup>1</sup> in Australia has amplified following the passage of human rights legislation in the ACT<sup>2</sup> and Victoria,<sup>3</sup> the anticipation of similar legislative programs in other jurisdictions and most importantly, Australia's participation in the drafting, and subsequent signing, of the United Nations *Convention on the Rights of Persons with Disabilities*.<sup>4</sup> In supporting the inclusion of advance directive provisions in revised mental health legislation, the current ACT review offers the opportunity to consider the application of advance directive mechanisms in closer detail than has yet occurred in

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<sup>1</sup> Psychiatric Advance Directives are documents that enable competent persons to dictate medical treatment choice in anticipation of future periods of incapacity. The terms psychiatric advance directives or PADS as is common in the American literature 'Advance Directives' and 'Living Wills'. are often used interchangeably. Other terms used in the literature included advance agreements, preference plans, consent-in-advance instruments, advance treatment authorisations or future treatment plans. Some commentators make a distinction between living wills as informal documents, and advance directives as legally binding instruments. The term 'Ulysses Agreements' or 'Ulysses contracts' generally refers to a specific type of binding advance directive and relates to debates about irrevocable advance directives.

<sup>2</sup> *Human Rights Acts 2004* (ACT);

<sup>3</sup> *Charter of Human Rights and Responsibilities Act 2006*(Vic) came into full force on 1/1/2008.

<sup>4</sup> United Nations Convention on the Rights of People with Disabilities. The draft convention was finalised at the Eighth Session (14 - 25 August 2006) and adopted by the general assembly on December 13th 2006. The convention opened for signature on 30th March 2007. Australia signed the convention in New York on 30<sup>th</sup> March 2007. <http://www.ohchr.org/english/press/newsFrameset-2.htm> access 2/3/07..

Australia.<sup>5</sup> The ACT review benefits from recent reviews in mental health legislation in other state and territory jurisdictions and from the broader general discussion about advance directives that has been largely generated by the advocacy of community based organizations. It is evident that there is a broad diversity of views in Australia about the appropriate scope and application of advance directives, and a range of concerns about the way in which general support for advance directives might translate into legislation. Beyond detailed consideration of scope and validity, full discussion about the most appropriate and effective legislative recognition of advance directives properly includes a comprehensive analysis of the legal and legislative context that surrounds and supports the contemplated legislative amendment, as well as consideration of the service delivery context upon which legislative innovation is intended to impinge. Consideration of the legal context should include (but not be limited to) analysis of the scope and orientation of the legislation in which the provision will be placed, analysis of the relevant common law, assessment of applicable guardianship and/or substitute decision making provisions, assessment of provision for refusal of medical treatment, and reference to the intersection of civil and criminal commitment provisions. International experience suggests that if these matters are not given proper consideration, and if inadequate provision is made for their introduction in terms of practical administration and the education of both mental health professional and consumers, the introduction of advance directives mechanisms may be disappointing. The consideration of international trends in the legislative recognition of advance directives in this paper is a necessarily limited contribution to a broad and complex debate. It is offered in the spirit of open discussion with a view to constructively extending the commendable discussion that has commenced during the ACT review.

### **The human rights legacy**

Anxiety about the impact of psychiatric advance directives extends from their controversial heritage. First mooted in the 1960s<sup>6</sup>, advance directives were envisaged as a legal mechanism that would enable patients to refuse extraordinary life sustaining measures. Their application to psychiatric settings, most famously promoted by Thomas Szasz<sup>7</sup>, is associated with the rise and influence of the anti-psychiatry movement<sup>8</sup>. Consumer advocates have continued to press for advance directives as a vehicle for securing the autonomy and self determination of people living with mental illness. Informed by the

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<sup>5</sup> Review of the Mental Health (Treatment and Care) Act 1994 Discussion Paper, August 2006; Review of the ACT Mental Health (Treatment and Care) Act 1994 Options Paper, 2007. p20-23, Review of the ACT Mental Health (Treatment and Care) Act 1994 Stage 2 Consultation: Report AEQUITAS Communications April 2008,

<sup>6</sup> Maclean, A (2007) 'Advance directives and the rocky waters of anticipatory decision-making' *Medical Law Review*, 16 Spring 2008 pp 1-22. The idea is attributed to America Lawyer Luis Kutner.

<sup>7</sup> Szasz 1982 The psychiatric will. A new mechanism for protecting persons against "psychosis" and psychiatry.: *Am Psychol.* 1982 Jul;37(7):762-70

<sup>8</sup> Thomas S. Szasz (1960) The Myth of Mental Illness *American Psychologist*, 15, 113-118; Szasz (1961) *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*, Hoeber-Harper New York .

continued development of the international human rights movement, the concept of advance directives has strengthened and deepened. In their contemporary guise advance directives are envisaged as encompassing a broad range of matters including the selection of appropriate medical treatment, the refusal of inappropriate or damaging treatment, the communication of information about triggers and therapeutic sequale not normally recognised in standard treatment assessments, recognition of and preparation for intermittent lapses of capacity, the nomination of preferred support persons, the nomination of proxy or substituted decision makers, and recognition and preparation for provision for unexpected periods of psychiatric hospitalisation or detention in terms of practical arrangements for the maintenance of ongoing social responsibilities such as employment commitments and carer responsibilities<sup>9</sup>. These ideas invest the concept of advance directives with the aspirations of affecting real change in the delivery of mental health services.

The principles of autonomy and self-determination espoused in both the early civil rights conception of psychiatric advance directives and reiterated in the links forged between the contemporary vision, the principles of human rights and their reflection in international human rights law, clearly positions the concept of advance directives within the ambit of a human rights approach in mental health law. Paradoxically, explicit recognition of advance directives has not featured in international instruments that seek to guide human rights approaches to mental health legislative reform<sup>10</sup>. Nevertheless, advance directives are widely recognised as a strategy that may give effect to the principles of non-discrimination, participation, acceptability and accessibility in mental health care<sup>11</sup>. It is significant from the Australian point of view that in other Commonwealth jurisdictions<sup>12</sup> where human rights legislation has been adopted the advance directives debate is well advanced and has resulted in legislative reform<sup>13</sup>. The human rights context of Commonwealth experience is particularly pertinent for the ACT. It suggests that the inclusion of advance directives in mental health legislation must be considered as part of a broader shift toward the general recognition and entrenchment of human rights. The explicit human rights context that surrounds advance directives also reinforces the argument that advance directive provisions must be understood within the applicable legal context in its broadest terms and extends the necessary legal analysis to encompass human rights law.

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<sup>9</sup> Community Forum on Advance Directives, Hotel Y, June 22nd, 2006

<sup>10</sup> United Nations Principles for the Rights of Person with Mental Illness and for the improvement of mental health care (1991); Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993); WHO Mental Health Legislation and Human Rights (2003).

<sup>11</sup> General Comment 14.(2000) The right to the highest attainable standard of health E/C.12/2000/4

<sup>12</sup> Both the legal and health care systems in Commonwealth jurisdictions such as New Zealand, the United Kingdom<sup>12</sup>, Scotland and Canada have developed with sufficient uniformity to provide particularly instructive in international comparisons. Although directly applicable, the experience of the United States is also highly pertinent. At the time of writing analysis of the Canadian provisions is insufficiently developed to include in this paper.

<sup>13</sup> *The Human Rights Act 1993(NZ)*; *Human Rights Act 1998(UK)* ; and *Canadian Human Rights Act 1985*.

Expansion of the advance directive movement is reflected in the development of the common law which has solidified its recognition of the principles of autonomy and self determination particularly in terms of bodily integrity, the right to informed consent to medical treatment and the right to refuse medical treatment. In principle the common law recognises advance directives for all persons who are able to make medical decisions about their own health care. In practice, relevant case law is inconsistent and ambiguous<sup>14</sup>. Continued controversy about the scope of the rights that the common law recognises, and legal status of common law advance directives in both general medicine and psychiatry has lead to a range of legislative responses. Before turning to a consideration of these international trends, a review of the development of policy debate regarding advance directives in Australia assists in identifying the characteristics of the international developments that are of most relevance to the Australian context.

### **Australian consideration of Advance Directives**

Long standing international concern for the human rights of people living with mental illness<sup>15</sup> was given specific expression in 1991 with the United Nations Principles for the Rights of Person with Mental Illness and for the improvement of mental health care (1991)<sup>16</sup>. Australia's engagement with international developments at that time is reflected in the rights focus of the National Mental Health Plan (1992) and the tenor of the Burdekin Report in 1993 which described in detail the dimensions of the human rights violations experienced by people living with mental illness in Australia.<sup>17</sup> Recognition of the need for urgent legal reform translated into a commitment to develop legislation in all States and Territories that was consistent with the UN Principles by 1998.<sup>18</sup> In 1994 the Center for Health Law Ethics and Policy developed Model Mental Health Legislation to facilitate the national reform process<sup>19</sup>. A preferred strategy adopted by the new conservative Federal government was to conduct a quantitative audit of compliance with the UN principles using an audit tool<sup>20</sup>. The goal of recognition of

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<sup>14</sup> See Maclean (2007) at f/n 7; Biegler P, Stewart C, Savulescu J and Skene L, "Determining the Validity of Advance Directives" (2000) 172 *MJA* 545; Willmott, White, Howard ' Refusing Advance Refusals: advance directives and life sustaining medical treatment, [2006] *MULR* 7.

<sup>15</sup> The Declaration on the Rights of Mentally Retarded Persons was Proclaimed by General Assembly Resolution 2856 (XXVI) of 20 December 1971; 1981 International Year of Disabled Persons was declared in 1981; Declaration on the Rights of Disabled Persons Proclaimed by General Assembly resolution 3447 (XXX) of 9 December 1975; Principles for the protection of persons with mental illness and the improvement of mental health care was Adopted by General Assembly resolution 46/119 of 17 December 1991; Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by General Assembly resolution 48/96 of 20 December 1993.

<sup>16</sup>; 'Principles for the protection of persons with mental illness and the improvement of mental health care' Adopted by General Assembly resolution 46/119 of 17 December 1991, Office of the High Commissioner for Human Rights, <http://www.unhchr.ch/html/menu3/b/68.htm> access 28/4/08.

<sup>17</sup> Burdekin, B (1993) 'Human rights and mental illness', Report of the National Inquiry into human rights of people with mental illness', *Human Rights and Equal Opportunity Commission*, AGPS, Canberra, A.C.T.

<sup>18</sup> National Mental Health Plan (1992)

<sup>19</sup> Rees, Craze, (1994) Model Mental Health Legislation, Newcastle University

<sup>20</sup> A "Rights Analysis Instrument" was developed by the Commonwealth Attorney-General's Department in 1996 to measure compliance by state and territory mental health legislation with the UN

advance directives was not included in either of these approaches to mental health law reform. This omission reflects the stilted development of international debate at the time which has since benefited from a closer engagement with concerns to consumers.<sup>21</sup> In 1999 the Human Rights and Equal Opportunity Commission called for submissions in response to its discussion paper on 'Living Wills'.<sup>22</sup> Supportive submissions were received from several advocacy groups. Acknowledgement of at least some aspects of the emerging debate resulted in the formal inclusion of Medical Treatment Plans in the Victorian *Mental Health Act (1986)* in 2003.<sup>23</sup> The Victorian Medical Treatment Plans provide for the formal recording in the patients medical record of their preferred treatment choices.<sup>24</sup> Anecdotal evidence suggests that in practice the plans are poorly executed and tend to record standard medical treatment plans without reference to consumer preferences or aspirations.<sup>25</sup> Despite obvious consumer support and persistent advocacy around the issue, consideration of advance directives in policy and legislation has remained muted. Comprehensive reviews of state and territory mental health legislation over the last five years<sup>26</sup> have resulted in new legislation in New South Wales and the Northern Territory, neither of which include provision for psychiatric advance directives<sup>27</sup>. In the jurisdictions that have commenced review there is little direct comment about advance directives although all give consideration to the issue of consent and involuntary treatment.<sup>28</sup> The South Australian review has

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Principles. Watchirs, H (2005) 'Human rights audit of mental health legislation-results of an Australian pilot' *International Journal of Law and Psychiatry* 28(2005) pp 99-125.

<sup>21</sup> The critical lit.

<sup>22</sup> HREOC Discussion Paper: Living Wills, paper and submission available at [http://www.humanrights.gov.au/disability\\_rights/hr\\_disab/Wills\\_DP/wills\\_dp.html](http://www.humanrights.gov.au/disability_rights/hr_disab/Wills_DP/wills_dp.html) accesses 27/408.

<sup>23</sup> s19A *Mental Health Act 1986* (Vic) inserted by *Mental Health (Amendment Act) 2003* came into effect 6 December 2004. see related documents at <http://www.health.vic.gov.au/chiefpsychiatrist/treatment-plan.htm>

<sup>24</sup> See evaluation 2006 Chief Psychiatrist forum "Treatment plans can we do better?" at

<http://health.vic.gov.au/chiefpsychiatrist/treatmentplan/forum-feedback.pdf>

<sup>25</sup> Merinda Epstein, Presentation, 'Advance Directives', Hotel Y, June 22nd, 2006

<sup>26</sup> ACT: current evaluation of the Mental Health Strategy & Action Plan 2003-2008. Responses and submission closed in December 200; Queensland: The *Mental Health Act 2000* commenced on 28 February 2002. An independent conducted by Mr Brendan Butler AM Sc released its final report in 2006 "Promoting balance in the forensic mental health system" available at <http://www.reviewmha.com.au/>; South Australia: an Issues paper was published in 2004, following by a Final Report '*Paving the Way*', Bidmeade, I (2005) at [www.dh.sa.gov.au/mental-health-unit/publications.asp](http://www.dh.sa.gov.au/mental-health-unit/publications.asp). The proposed Mental Health Bill (SA) 2007 is available for public comment . . . <http://www.health.sa.gov.au> accessed 20/12/08; Tasmania: the final report of a review of mental health services '*Bridging the Gap*' recommends improved administration of the Mental Health Act. New South Wales: the *Mental Health Act 2007* (NSW) commenced operation on 16th November 2007; NT: The NT review commenced in 2003 resulting in the passage of the *Mental Health and Related Services Act Amendment Act 2007*

<sup>27</sup> NSW: The Mental Health Act (NSW) 2007 does not include provision for advance directives or treatment plans. The 'Statement of Rights' included in Schedule 3 of the Act states: "Can I be treated against my will? The facility staff may give you appropriate medical treatment, even if you do not want it, for your mental condition or in an emergency to save your life or prevent serious damage to your health. The facility staff must tell you what your medical treatment is if you ask. You must not be given excessive or inappropriate medication."

<sup>28</sup> For example the 2003 Report of the WA Review '*The way forward*' includes the following discussion: "...no jurisdiction in the world that can offer model legislation in this area that addresses all of the competing interests and principles. UN Principle 11(6) states that a plan of treatment may be given to a patient without their consent if (a) the person is an involuntary patient; (b) an independent

recommended the recognition of psychiatric advance directives be included in planned legislation to recognise general advance directives<sup>29</sup>.

In a recent address to the Mental Health Review Board, Neil Rees included advance directives as an area of possible reform in Victorian mental health law<sup>30</sup>. Rees argued that careful consideration must be given to the test for capacity at the time the directive is made, the identity of the person who attests to the person's capacity, the means by which an advance directive is drawn to the attention of relevant clinicians, the scope of the directives, the circumstance in which an advance directive may be overridden, and the identity of the person or body that may be invested with the power to override the advance directive<sup>31</sup>. He suggests further that successful resolution of these questions will depend upon a thoughtful balancing of competing rights principles<sup>32</sup>. The ACT review provides an opportunity to engage with this emerging debate.

The review of the Australian Capital Territory Mental Health (Treatment and Care) Act 1994 Options Paper supports the inclusion of advance directive provisions in legislation. It is envisaged that the provisions will clearly set out the status, development, use and review of advanced statements. The recommendations of the Stage 2 Consultation Report also support the inclusion of advance directives in the revised legislation but recommends that full consideration of advance directives be deferred until a clearer understanding of the definition of capacity to be included in the Act has been achieved. While the definition of capacity to be adopted in the legislation will have bearing on the ultimate form of advance directives, additional questions of principle identified in the review, such as the definition of mental illness and the relationship that is set between voluntary and involuntary treatment provisions will also have significance. It is also important that consideration be given to the links and interactions with other pertinent legislation prior to the drafting stage. For example, the *Medical Treatment (Health Directions) Act 2006* (ACT) provides the withholding or withdrawal of medical treatment in the ACT. The principal objective of the *Medical Treatment (Health Directions) Act 2006* is to protect the rights of

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authority is satisfied that the patient lacks the capacity to consent or unreasonably withholds consent; and (c) the independent authority is satisfied that the treatment is in the best interest of the patient's health needs. UN Principle 7 allows, as an alternative, for a guardian to give consent; and UN Principle 8 allows for emergency psychiatric treatment without consent. It is clear, therefore, that the WA Act is presently inconsistent with the UN Principles, a fact given great prominence in submissions received from consumer groups and non-government organizations. The review was urged to consider sections 55-57 of the NT Act concerning tribunal reviews of treatment and section 18 of the Victorian Mental Health (Amendment) Act 2003 concerning the insertion of new section '19A. Treatment plans' into the Vic Act."

<sup>29</sup> Bidmeade, I (2005) 'Paving the Way'. Recommendation:12.1 Advanced directives by consumers to cover the times when they are temporarily incapacitated should be given legal recognition by the planned Advanced Directives Act. The Mental Health Bill 2007(SA) includes provision for treatment plans at s37-39.

<sup>30</sup> Rees, N, Chairperson, Victorian Law Reform Commission. "Learning from the past, looking to the future: is Victorian mental health law ripe for reform?" Address to the Mental Health Review Board of Victoria 20<sup>th</sup> Anniversary Conference, 6th December 2007, Melbourne.

<sup>31</sup> Ibid at 9-10

<sup>32</sup> Ibid p10.

patients to refuse unwanted medical treatment while ensuring that their right to receive relief from pain and suffering is also honoured.<sup>33</sup> The Act provides for the refusal or withdrawal of medical treatment through the making of a 'health directive'<sup>34</sup>. Persons for whom a guardian is appointed under the *Guardianship and Management of Property Act 1991* or who have impaired decision making capacity are not permitted to make a health direction<sup>35</sup>. One approach to addressing the recognition of psychiatric advance directives in the ACT may be to broaden the scope of the *Medical Treatment (Health Directions) Act 2006*. In the Australian context this suggestion raises a number of complex issues about the content and scope of advance directives in general medicine, their applicability in the psychiatric arena, and more problematically the relationship that would arise between potentially conflicting pieces of legislation. The latter example provides a useful entry into discussion on international trends because this general approach, the extension of advance directive mechanisms to include people living with mental illness, has been adopted regarding advance directives in the United Kingdom.

### **Advance directives in the community- the United Kingdom**

The *Mental Capacity Act 2005(UK)* introduced legislative enabling statutory advance directives in the United Kingdom. The UK Act enabled people with capacity to make directives about their future care. Persons are regarded as lacking capacity if they are unable to make decisions because of an impairment of, or a disturbance in the functioning of, the mind or brain at a material time. The Act stipulates that a lack of capacity cannot be established merely by reference to the person's age or appearance, or to a condition or aspect of behavior, which might lead others to make unjustified assumptions about capacity<sup>36</sup>. The breadth of the *Mental Capacity Act 2005(UK)* provisions enables the formulation of psychiatric advance directives. Many mental health services and consumer organizations in the United Kingdom provide information about the formulation and use of advance directives. For example, the Derbyshire Mental Health Services NHS Trust has produced advance directive guidelines for service users<sup>37</sup>, and the Mersey Care NHS Trust has introduced advance statements for its mental health service users which include information about medication preferences and a range of practical issues. Several voluntary organizations have also produced clear factsheets for service users about advance directives and statements, including the Mental Health Foundation, Mind and Rethink<sup>38</sup>

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<sup>33</sup> s5 *Medical Treatment (Health Directions) Act 2006 ACT*

<sup>34</sup> *Ibid*, s7

<sup>35</sup> *Ibid* s7(3)

<sup>36</sup> s2 *Mental Capacity Act 2005(UK)*

<sup>37</sup> (Derbyshire MHST, 2004).

<sup>38</sup> Sainsbury Centre for Mental Health (SCMH) 2006 *Choice in mental health care* at [www.kingsfund.org.uk](http://www.kingsfund.org.uk) . See also [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk); [www.mind.org.uk](http://www.mind.org.uk); [www.rethink.org](http://www.rethink.org);

The development of the *Mental Health Capacity Act 2005* (UK) followed the comprehensive review of the *Mental Health Act 1983* (UK) which commenced with the appointment of an expert committee of inquiry in 1988<sup>39</sup>. The Richardson Report was released in July and included recommendation for the provision of advance directives for people living with mental illness<sup>40</sup>. The review process resulted in the passage of the *Mental Health Act 2007* (UK) which amends the 1983 Act. The principle features of the *Mental Health Act 2007* (UK) relevant to the present discussion are the inclusion of the principle of recognition and respect for the past and present wishes and feelings of patients<sup>41</sup>, provision for making independent mental health advocates available to detained person<sup>42</sup> and provision for compulsory psychiatric treatment in the community. Provision for compulsory community treatment proved to be highly controversial in the United Kingdom<sup>43</sup>. In their final form the community provisions recognize the validity of advance directives in relation to authorized involuntary community treatment provided the directives are made in accordance with the *Mental Capacity Act 2005*. The same recognition is not accorded to advance directives in relation to involuntary treatment in a facility. A shift in the perceived relationship between detention and treatment can be discerned in the new criteria for detention in the *Mental Health Act 2007*. In the new provisions patients may not be compulsorily detained or their detention continued unless medical treatment which is appropriate to the patient's mental disorder is available to that patient. The UK provisions thus reflect a limited recognition of advance directives in psychiatric settings<sup>44</sup>.

### **Advanced directives for all mental health orders -Scotland**

The *Mental Health (Care and Treatment) (Scotland) Act 2003* (the Act) includes recognition of advance directives within an integrated approach to securing new rights and safeguards for people living with mental illness<sup>45</sup>. The Act provides for the involuntary confinement of persons with mental illness<sup>46</sup>, and includes detailed provision for advance directives that are applicable to all the mental health orders authorized by the legislation. The Act gives patients the right to make and withdraw written statements

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<sup>39</sup> Coinciding with the introduction to the *Human Rights Act 1998* (UK)

<sup>40</sup> Richardson Report p160-166. available at <http://www.dh.gov.uk/> accessed 15/4/08

<sup>41</sup> s8 *Mental Health Act 2007* (UK)

<sup>42</sup> Ibid.s30

<sup>43</sup> Bindman, Maingay, Szmukler. 'The Human Rights Act and Mental Health Legislation' *British Journal of Psychiatry*, (2003), 182, 91094.

<sup>44</sup> See Richardson, G 'Balancing Autonomy and risk: a failure of nerve in England and Wales?' *International Journal of Law and Psychiatry* 30 (2007) 71-80 for a discussion of the anticipated interaction between the *Mental Health Capacity Act 2005* and the revised *Mental Health Act 1983*.

<sup>45</sup> *Mental Health (Care and Treatment) (Scotland) Act 2003* came into effect on 5 October 2005. available at [http://www.opsi.gov.uk/legislation/scotland/acts2003/asp\\_20030013\\_en\\_2#pt1-11g1](http://www.opsi.gov.uk/legislation/scotland/acts2003/asp_20030013_en_2#pt1-11g1) Accessed 24/2/2008.

<sup>46</sup> The *Adults with Incapacity (Scotland) Act 2000* provides for decisions about the adult's property or financial affairs, or about their personal welfare, including some comment on medical treatment decisions to be made on behalf of adults who lack legal capacity to do so themselves because of mental disorder or inability to communicate. The Act does not contain advance directive provisions as does the equivalent UK Act.

that include information about how they would wish to be treated and how they would not wish to be treated, in the event that they become unable (due to their mental disorder) to make their views known about care and treatment at a future date<sup>47</sup>. The Act requires the Tribunal<sup>48</sup>, persons authorized to give medical treatment under the Act and designated medical practitioners, to have regard to the wishes expressed in advance directives.<sup>49</sup> If such persons, tribunals or treating medical practitioners make decisions that conflict with the advance statement, they are required to provide a statement in writing that sets out the reasons why a conflicting decision has been made. The decision must be communicated to guardians and advocates and a copy placed on the patient's medical record<sup>50</sup>.

The advance directive provisions are supported within the overall structure of the legislation by a number of important features that enhance the ability of people with mental illness to participate fully in their treatment decisions. First, the guiding principle of the Act set out in Part 1 obliges persons discharging functions under the Act to have regard to a range of matters. These include the past and present wishes and feelings of the patient, the views of the patient's 'named' person, carers, guardian, and welfare attorneys. The Act also requires consideration of the following: the importance of the patient participating as fully as possible in all decisions; , the importance of providing such information and support to the patient as is necessary to enable the patient to participate; the range of options available; the importance of providing the maximum benefit to the patient; , the need to ensure that, unless it can be shown that it is justified in the circumstances, the patient is not treated in a way that is less favourable than the way in which a person who is not a patient might be treated in a comparable situation; and the patient's abilities, background and characteristics, including the patient's age, sex, sexual orientation, religious persuasion, racial origin, cultural and linguistic background and membership of any ethnic group<sup>51</sup>. Second, the Act requires that written information be provided to all patients regarding the following matters: the reasons why the patient is being detained; the effect and consequences of relevant orders; the powers that the patient's responsible Medical Officer and the Tribunal have in relation to revoking that provision; the patients right to make an application, or appeal, to the Tribunal; the powers that are exercisable by the Tribunal; how the patient may exercise any such right; and how the patient may obtain legal assistance as respects any such right.<sup>52</sup> Assistance is to be provided if the patient has difficulty in communicating or generally communicates in a language other than English<sup>53</sup>. Third, the Act gives special recognition and status to a person who is formally

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<sup>47</sup> s275 *Mental Health (Care and Treatment) (Scotland) Act 2003*

<sup>48</sup> *Ibid* s276.

<sup>49</sup> *Ibid* s276(3)

<sup>50</sup> *Ibid* s276 (8)

<sup>51</sup> Section.

<sup>52</sup> s260 *Mental Health (Care and Treatment) (Scotland) Act 2003*

<sup>53</sup> *Ibid* s261

nominated by the person with mental illness.<sup>54</sup> Where a person is not nominated, is not able to be nominated, or declines to be nominated, the Act recognises the primary carer as the named person or in the event that the carer decline, the nearest relative<sup>55</sup>. Fourth, the legislation establishes the right of every person with mental disorder to have access to an independent advocate<sup>56</sup>. Additional provisions aimed at supporting the participation of the patient, are the inclusion in the detailed provision for compulsory treatment in Part 7 of patient participation in the provisions for treatment plans. A treatment plan is required in all cases, and is separate to the provision for advance directives. Similarly, Part 18 provides the protection of review for persons who are detained informally<sup>57</sup>. In summary the legislative scheme suggests a concern to address the communicative barriers that limit the opportunity of people living with mental illness to receive appropriate mental health care. In doing so the Act maximizes the participation of persons in the medical decisions that affect them, thereby recognizing the most fundamental element of self-determination for people negotiating care in health settings, particularly mental health settings. The Scottish legislation came into effect in 2005. Consumer organizations in Scotland remain cautiously optimistic about the capacity of the legislation to improve mental health services in Scotland<sup>58</sup>.

### **Incorporating rights – New Zealand**

New Zealand's approach to the recognition of advance directives links the general recognition of advance directives to the *Mental Health (Compulsory Assessment and Treatment) Amendment Act* 1999 (NZ) through the requirement that persons authorised under the Act must take consumers' wishes into account, must consult with patients and their families, and must make treatment decisions with proper recognition of the patient's beliefs<sup>59</sup>. Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992 (NZ) issued by the Ministry of Health April 2000<sup>60</sup> note that the concept of 'best interests' is the recognized principle underpinning clinical responsibility in the Act. The Information

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<sup>54</sup> Ibid s250. s255 requires the mental health officer to ascertain who the relevant person is. Subsequent section set out the responsibilities of the named person under the Act.

<sup>55</sup> Ibid s251 the meaning of "nearest relative" is set out in s254

<sup>56</sup> s259 The onus is on the service and Health Board to ensure the patient is assigned an independent advocate.

<sup>57</sup> The person, or others on behalf of the patient (including anyone having an interest in the welfare of the patient), may apply to the Tribunal for an order requiring the hospital managers in which the patient is being unlawfully detained to cease their detention. These provisions reflect the decision of *HL v the United Kingdom* by the European Court of Human Rights,

<sup>58</sup> SAMH at <http://www.samh.org.uk/frontend/index.cfm?page=223> access 24/2/2008;

<sup>59</sup> s7A & s5: See Minkowitz T, *No force advocacy for users and survivors of psychiatry*, 2006 Mental Health Commission, Wellington, NZ; *Te Tāhuhu: Improving Mental Health 2005-2015: The second New Zealand Mental Health and Addiction Plan*, June 2005 [http://www.moh.govt.nz/mental health](http://www.moh.govt.nz/mental%20health) accessed 23/7/06.

<sup>60</sup> <http://www.moh.govt.nz> pp19-20 accessed 16/4/08

[http://www.moh.govt.nz/moh.nsf/0/BA365913B5EA0E334C2568AF001733A6/\\$File/GuidelinesCAT92.pdf](http://www.moh.govt.nz/moh.nsf/0/BA365913B5EA0E334C2568AF001733A6/$File/GuidelinesCAT92.pdf)

considered relevant in determining the best interests of the patient includes consideration of any advance directives the patient or proposed patient may have made. The general right to make an advance directive appears in the Code of Health and Disability Services Consumers Rights<sup>61</sup>. The Code of Health and Disability Services Consumers' Rights was incorporated into New Zealand on 1 July 1996 as a regulation under the *Health and Disability Commissioner Act 1994* (NZ).<sup>62</sup> Advance Directives are also recognised in the National Mental Health Sector Standard<sup>63</sup>, and in the provisions for Enduring Powers of Attorney under the *Protection of Personal and Property Rights Act 1988* (NZ). In practice, advance directives in New Zealand are required to be drafted in collaboration with a treating practitioner<sup>64</sup>, thereby avoiding some of the practical and legal dilemmas associated with advance directives by ensuring practitioner knowledge of, and commitment to treatment decisions. Criticism of this model questions whether the requirement of therapeutic supervision or practitioner oversight fundamentally undermines the independence of treatment decisions, having the effect that it ensures that practitioner preferred, rather than consumer preferred, options are included in the document<sup>65</sup>.

### **Exclusion of people living with mental illness- Australia**

Advance Directives are recognised at common law and have been regarded as valid in some circumstances, although notably not in relation to the provision of psychiatric treatment and care<sup>66</sup>. Each of the jurisdictions discussed have extended common law and/or general legislative recognition of advance directives to the mental health sector. In Australia legislative recognition of advance directives in general medicine remains limited<sup>67</sup>. Where legislative provision is made, people living with mental illness are generally excluded from the ambit of such legislation by the requirement that persons making advance directives be 'of sound mind'<sup>68</sup>. Common law principles enable people living with mental illness to express their treatment preferences either verbally or in written document, to discuss treatment choices with their treating practitioner, to request that the information be kept in their medical file or communicate their wishes to a friend, relative or advocate who may make either formal or informal contribution to medical decision making on behalf of the consumer. Some people living with mental illness in Australia report that have prepared informal advance directives, have successfully negotiated support for their future treatment choices with their treating practitioners, and expect that

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<sup>61</sup> Article 5 'Every consumer may use an advance directive in accordance with the common law', <http://www.hdc.org.nz/theact/theact-thecodedetail> accessed 16/408.

<sup>62</sup> <http://www.legislation.govt.nz/act/public/1994/0088/latest/DLM333584.html>

<sup>63</sup> section 16 of NZ S81434:2001.

<sup>64</sup> Community Forum on Advance Directives', Hotel Y, June 22nd, 2006.

<sup>65</sup> Merinda Epstein, Community Forum on Advance Directives', Hotel Y, June 22nd, 2006.

<sup>66</sup> McClean at f/n 2

<sup>67</sup> Biegler P, Stewart C, Savulescu J and Skene L, "Determining the Validity of Advance Directives" (2000) 172 MJA 545.

<sup>68</sup> Medical Treatment Act 1994 (ACT), s 6; Natural Death Act 1988 (NT), s 4; Consent to Medical Treatment and Palliative Care Act 1995 (SA), s 7; Medical Treatment Act 1988 (Vic), s 5.

these informal documents will be honoured in the event of a future mental health crisis<sup>69</sup>. It is commonly asserted that verbal advance instructions or informal, self initiated documents have little or no legal significance in the psychiatric context. While a full discussion of the status and legal significance of common law expression of advance directive is beyond the scope of this paper, the general assertion that patient communications regarding treatment have no legal significance misunderstands the principles of medical law and underestimates the potential application of human rights law, particularly in jurisdictions with human rights legislation. The noted difficulties that people living with mental illness face in accessing legal advice and assistance and bringing matters before either domestic or international courts and tribunals limits the opportunities for relevant jurisprudence to develop both in the domestic and international area. Nevertheless, provided there was sufficient cross sectoral support, it is possible to imagine advance directive practice flourishing in the absence of legislative provision.

### **The service context**

In addition to a critical analysis of the full legal context in which advance directive provision might appear, consideration must be given to the relevant service context, both in terms of the specificity of service capacity and administration in each jurisdiction and in terms of broad trends in service delivery for people living with mental illness. In Australia the under resourcing of the introduction of community based services in preference to institutional care has profoundly altered the quality and availability of mental health services. This has created new difficulties and compounded old ones. The '*Not for Service*' report by the Mental Health Council of Australia<sup>70</sup>, published in 2005, documents serious systemic neglect in the mental health sector. The report found that across all State and Territory jurisdictions there were inadequate resources, insufficient early intervention especially for young people, failures to address issues of dual diagnosis, inappropriate facilities for children, insufficient emergency services and insufficient community support resulting in unwarranted reliance upon the criminal justice system.<sup>71</sup> In 2006 the Senate Select Committee on Mental Health also identified a range of problems in its two part report entitled '*A national approach to mental health – from crisis to community*'<sup>72</sup>. Hazelton has argued that the shift to community care has coincided with the emergence of risk management as a dominant theme in institutional care, resulting in a palpable hardening of the institutional ethos to create environments less likely to respect the expressed preferences of people

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<sup>69</sup> MHLC research project

<sup>70</sup> With the Human Rights and Equal Opportunity Commission and the Brain and Mind Research Institute

<sup>71</sup> Ozdouski S 2005 'Outcry and silence : the social implications of asylum closure in Australia' in Savy P, Collyer F, Schofields T (eds) *Closing asylums for the mentally ill : social consequences*, Australian Sociological Association, Sydney.

<sup>72</sup> First Report, 30 March 2006; Final Report, 28 April 2006.

living with mental illness<sup>73</sup>. That the balance and relationship between community and institutional care is of profound importance is also illustrated by the European studies that demonstrate that the most important criteria for admission to psychiatric institutions is the availability of alternative care. Thus in practice consumers who sought to refuse treatment or who were without community support were more likely to be admitted involuntarily to European institutions<sup>74</sup>. The implementation of advance directives within fraught service contexts will have an impact on their acceptability to clinicians, and their efficacy for consumers.

### **Implementation –developments from the United States**

The extensive experience in the United States with legislative provision of advance directives, and the emergence of a body of empirical research about the benefits, effect and application of advance directives, has resulted in the development of strategies to overcome evident problems and difficulties in implementation. Although less directly applicable to the Australian context because of significant differences in the law and in health service delivery, the critical evaluation of advance directive practice in the United States highlights some crucial issues. Widespread State legislative provisions for advance directives followed the introduction of the federal *Patient Self Determination Act (1991)*. The Act requires that patients admitted to federally funded hospitals be informed about their right under state law to prepare an advance directive. The hospital is obliged to inquire and document whether the patient has executed an advance directive, is obliged to respect the documents, and is obliged to educate health care providers regarding their use.<sup>75</sup> Twenty five States have passed legislation enabling competent individuals to consent to or refuse future mental health treatment during decisional incapacity, either by mental health advance directives or by proxy decision making. All States permit competent adults to use health care law to make at least some psychiatric choices in advance- typically through a health care power of attorney<sup>76</sup>. Empirical research indicates that consumers are slow to take advantage of advance directive options but have a strong and consistent commitment to their use<sup>77</sup>. Barriers to wider use include lack of ready access to them in a crisis, a lack of clinician familiarity<sup>78</sup>, and legal uncertainty about their application<sup>79</sup>. Strategies to improve crisis access have included the use of

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<sup>73</sup> Hazelton (2006) in Savy P, Collyer F, Schofield T (eds) *Closing asylums for the mentally ill : social consequences*, Australian Sociological Association, Sydney.

<sup>74</sup> Lorant, Depuydt, Gillain, Guillet, & Dubois (2007) Involuntary commitment in psychiatric care: what drives the decisions? *Social psychiatry & Psychiatric Epidemiology* (2007) 42:360-365

<sup>75</sup> Swartz, M & Swanson, J (2007) 'Psychiatric Advance Directives and Recovery-Oriented Care', *Psychiatric Services*, September 2007, 58:9, pp 1164.

<sup>76</sup> MacLean, opcit note 6 at page 5 re *C (Adult Refusal of Treatment)* [1994]1. W.L.R. 290

<sup>77</sup> Swanson, Swartz, Ferron, Elbogen, Dorn (2006) 'Psychiatric Advance Directives Among public Mental Health Consumers in Five US Cities: prevalence, demand and correlates'. *Journal American Academy Psychiatry & Law*, 31:43-57, 206

<sup>78</sup> Swanson, Swartz, Elbogen, (2006) 'Facilitated psychiatric advance directives' *American Journal of Psychiatry* 163, pp 1942-1951

<sup>79</sup> Szmukler, G (2006) 'Advance statements in psychiatry' *Psychiatry*, 6:2 pp 49-51

crisis cards which may state preferences or specify persons to be contacted in a crisis<sup>80</sup>, and more recently, the development of electronic registers. For example, a national electronic directory, the U.S Living Wills Registry is currently being developed. The registry will provide online storage and secure access to care planning documents<sup>81</sup>. Strategies to address legal uncertainty and improve clinical compliance with advance directives have included the use of trained facilitators to assist consumers in the development of effective instruments, collaborative formulation of directives with the clinical team, and formal joint crisis planning that involves the consumer, treating clinicians, the health service, independent clinicians and independent advocates in the formulation of a crisis plan<sup>82</sup>. Strategies to improve clinician familiarity with advance directives focus on professional education and include the MacArthur Foundation supporting a new National Resource Centre for Psychiatric Advance Directives<sup>83</sup>. As the Stage 2 Consultation report notes, it is critical that the planned introduction of advance directives be accompanied by appropriate resourcing, training, community education and professional development<sup>84</sup>.

## Conclusion

This brief introduction to international trends in implementation of psychiatric advance directives shows that Australia lags well behind international practice. It is commendable that the ACT review has included active consideration of psychiatric advance directives and invited broad stakeholder discussion about the possible ambit of the new provisions. This paper has argued that careful consideration of the broad legal and service delivery context is necessary to ensure the crafting of effective legislative recognition of mental health consumer autonomy and self determination. The objective of tailored law reform that is informed by relevant international comparisons should not be to achieve conformity with international trends, but to work toward enhancement of the human rights of people living with mental illness in the ACT.

Penny Weller

17/4/2008

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<sup>80</sup> Sutherby & Szmukler (1998) Crisis cards and self-help initiatives, *Psychiatric Bulletin* 22, pp4-7.

<sup>81</sup> Swartz & Swanson *opcit* note 55.

<sup>82</sup> Szmukler. *Opcit* note 59 at p49

<sup>83</sup> *Ibid*, p50

<sup>84</sup> Page 30.