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Advance Directives for Mental Health

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Society as a whole will benefit from a more efficient, cost-effective health care system in which the rate and duration of hospitalisation is reduced, due to informed clinical decision making and care planning.

Consumers of mental health services eager to explore options to ensure that their wishes are respected have often prepared documents that articulate their wishes. Unfortunately, these documents are often ignored because they are not legally enforceable in Victoria. Because of this discrepancy between utility and unenforceability, people with mental health issues are keen for law reform to occur in this area. The Mental Health Legal Centre is also keen to advance this reform.

In June 2006, the Mental Health Legal Centre (MHLC) convened a forum about Advance Directives. This was in response to consumers' concerns about the lack of say that people have in the medical treatment they receive from mental health services. The message that came through loudly and clearly from speakers at the forum was that Advance Directives, with some legal force, would mean a vast improvement in the recognition of their rights.

This paper provides an overview of Advance Directives; it describes their benefits for consumers and third parties and documents the experiences of Forum participants who have developed and applied Advance Directives.

What are Advance Directives?

An Advance Directive is a document that a person completes while they are well. The documents are widely used and respected in general health settings where they are sometimes called advance care or treatment plans. In a general health setting, the document is used to inform clinicians about preferred treatment in the event that the person becomes unwell at a later date. In a sense, the Advance Directive becomes the voice of the person at a time when they may not be able to convey their preferences. An Advance Directive can articulate the person's preferences or nominate another person to make particular decisions. The document may state the negative effects of particular treatments and the reasons that other medications are preferred. Advance Directives for people with a mental illness aim to extend beyond medical treatment to all aspects of the person's life. For example, as well as articulating support and treatment preferences, the Advance Directive may also be used to set in place a number of arrangements that need to be carried out in the event of an emergency. These arrangements may include notifying a trusted other of a wide range of practicalities including the need for children to be picked up from school and outstanding bills to be paid.

The benefits of Advance Directives are numerous not only for the person receiving better treatment but also for those they may rely upon in times of stress, e.g. carers, clinicians and society as a whole.

For people with mental health issues, the main benefit of writing an Advance Directive is the better clinical outcomes that come about when a person is genuinely involved in their own treatment. Better clinical outcomes are also facilitated if the person knows that practical measures are being taken care of while they receive treatment.

For carers, Advance Directives are an excellent reminder to assist them to act in accordance with the person's wishes. Preparation of the documents may encourage and facilitate discussion between parties and avoid uncertainty and tension in the event that the person becomes unwell. Advance Directives may also reduce the likelihood that the carer will have to make a decision based solely upon speculation.

For clinicians, Advance Directives allow a decision to be informed by the lived experience of the patient. This experience will alert clinicians to what has worked and what hasn't in terms of medications and other treatments and thus provide for better clinical outcomes. It also invites a conversation that gives the clinician the opportunity to respectfully understand the consumer's views and interests.

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What do people have to say about Advance Directives?

Board member of the World Network of Survivors of Psychiatry and co-founder of Insane Australia David Webb

strongly advocates a shift away from the impersonal, supposedly more scientific approach to mental health research and service provision. In its place he calls for greater acknowledgment to be given to the first-person voice. He believes that this fundamental shift will encourage a transition from substituted decision making to supported decision making in which Advance Directives can play an important role:

'The essential feature of the supported decision-making approach is that every effort must always be made to ascertain the wishes of a person with a disability, including psychiatric disability, and furthermore, that these wishes must then at all times be respected without exception.'

'Advance Directives are a clear, concrete and practical example of supported decision making in practice. Unlike substituted decision-making, which is inherently contrary to human rights principles, Advance Directives are a mechanism that not only offers better responses to consumers in critical times, but does so in a way that is consistent with the basic principles of human rights.'

'Advance Directives bring the first-person voice into mental health practice. Advance Directives, by definition, hear and respect the first-person voice. They respect our human rights, in particular the right to self-determination and the basic civil and political rights of control over our own bodies.'

A senior consumer consultant also emphasises the need to prioritise the knowledge possessed by the person as opposed to the speculation of third parties:

'I actually feel it's important, because I know "me" better than somebody who's never met me. For example, if I get caught up in the public system on the weekends, somebody who's never met me, they don't know my history—I know "me" a lot better than they know me so why shouldn't my decisions about what works for me come before what they have to say? And I'm not

asking for people to agree with my choices. What I'm asking them to do is to respect them, and I think there's a difference. In general health, we may not agree with a "do not resuscitate" or "don't give me a blood transfusion" but we do respect it.'

Consumer academic at the Centre for Psychiatric Nursing Research and Practice at University of Melbourne Cath Roper suggests that the very notion of Advance Directives marks a shift in the emphasis of mental health services – from clinician driven to consumer-driven services – and the priority of mental health services – from maintenance to empowerment:

'People are starting to be seen as the experts of their illness and condition and are able to plan for a crisis in advance. Developing Advance Directives helps to reduce the stress

caused by an admission to hospital and helps a person to establish an empowering, therapeutic relationship with health and social-care professionals from day one of their admission. Advance Directives are an important way to maximise the self-determination of the consumer and to uphold the right of the consumer to be involved in their own care.'

The importance of Advance Directives goes beyond matters relating strictly to medical treatment preferences. Advance Directives can also be used to ensure that practical arrangements are taken care of in an emergency. These practical arrangements are often just as important to the person receiving treatment as the treatment itself. Merinda Epstein published author, activist and consumer advocate at Our Community describes a situation when a consumer

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was unable to communicate their needs to mental health services, whom in turn, had no way of finding out what they may be:

'One of them was a story that was told to me by a clinician in a mental health service in Melbourne about a woman who was admitted as an involuntary patient to a unit in which she was kept for approximately a month. She was taken by the police to the unit, and during that time no-one realised that they had left her house completely unlocked. So she had been in there for a month, vandals had gone totally through the house, her dog had escaped; it had remained unfed. And the service felt terrible afterwards because no-one had thought to ask, because that's not what mental health services necessarily do, so she went back to her place that had been totally destroyed.'

'Now in that instance, an Advance Directive, if it had been available to staff on the unit, would have given an instant indication that this person lives on her own, has no relatives in Victoria and has a dog for which she is responsible – do you know what I mean? That information would have been there, clearly articulated for people to have a look at and the whole thing could have been solved fairly easily.'

Overseas Research

Countries such as the US and the UK have progressed much further than Australia in taking up Advance Directives as a means of increasing the autonomy and self-determination of consumers of mental health services. What is clear from overseas studies is that, contrary to the fears of carers and clinicians that legal Advance Directives would be a license to refuse all treatment, consumers resoundingly use Advance Directives as a means of receiving better treatment.

Findings from two recent studies reveal that people who complete Advance Directives do so in a manner that ensures they firstly receive treatment that is applicable to their circumstances and needs, and secondly, receive treatment that incorporates the vast knowledge they possess about their own illness.² In addition to this, Amering states that consumers are very much aware of the importance of requesting the kinds of treatment that could reasonably be provided by their mental health treatment team.

Much thought was given to ensuring that the Advance Directives were feasible and that preferences fell reasonably within the range of options of the mental health system. Participants were intent on not compromising mental health professionals with neither the content nor the style of the directive.³

Typically, a consumer's reluctance to receive treatment is interpreted as confirmation of a person's illness. What research from the US shows is that people are reluctant to receive treatment in a system that completely undermines their autonomy, not treatment per se.⁴

The Mental Health Legal Centre Advance Directives Project

In response to the concerns of Victorian consumers of mental health services, the Mental Health Legal Centre has recently commenced the Advance Directives Project. The Project, funded by the Reichstein Foundation, aims to understand the difficulties that some consumers face when attempting to assert their own preferences in their own treatment. Under the guidance of consumers, the Project aims to develop a proforma that will assist consumers to develop Advance Directives that are comprehensive and will be respected and adhered to by those they wish to inform. It is hoped that discussion with consumers will allow the Centre to better understand the barriers to effective implementation and thus inform us to make recommendations about necessary support and law reform.

▶▶▶ **FIND OUT MORE.** For Further information about Advance Directives or to participate in the Mental Health Legal Centre Project please contact Project Worker Martin Thomas by email at Martin_Thomas@clc.net.au or by telephone on 03 9629 4422.

References

- ¹ Speech given at Advance Directives Forum, Hotel Y, Melbourne, June 2006. All other quotes in this section are from the same Forum.
- ² Amering, M., et al, 'Psychiatric Advance Directives: qualitative study of informed deliberations by mental health service users', *British Journal of Psychiatry* (2005), 186, 247–252.
- ³ Backlar, P, et al, 'Consumer, Provider, and Informal Caregiver Opinions on Psychiatric Advance Directives' *Administration and Policy in Mental Health*, Vol 28, No. 6, July 2001. Above n 2 at p 249–250.
- ⁴ Gallagher, E.M., 'Advance Directives for Psychiatric Care: A Theoretical and Practical Overview for Legal Professionals' *Psychology, Public Policy and the Law*, Vol 4 (3), September 1998, 746–787.