

**Mental Health Legal Centre
Forum on Advance Directives
June 22, 2006**

Topic: Human Rights – self-determination and first-person voice

Speaker: David Webb

Hello everyone, and thanks for coming today. I'm delighted to appear on the program today as a member of *insane australia*, so I thought I should wear our fabulous t-shirt and introduce our mascot Batty to anyone who hasn't yet met her (or him– there is currently some dispute about Batty's gender). And also our motto for Batty, who we love dearly, which is "Batty Is Beautiful".

The program also identifies me as a member of the MHLC management committee, but I'm a very new member of the committee and still learning about the centre and how it runs. So I must be very clear and explicit that I am not representing the centre here today. All responsibility for the views expressed in my talk today rest entirely with me ... etc etc ... OK ...

Finally, by way of introduction, I must also mention the World Network of Users and Survivors of Psychiatry (WNUSP) where I'm a deputy to the board members for the Asia-Pacific region of WNUSP. I'll say a little more about WNUSP shortly.

I have three topics that I want to touch on today. The first is the urgent but neglected issue of human rights in mental health, a large and complex topic but one in which Advance Directives have much to offer. The second is to briefly mention my own research as a PhD student at Victoria University, and make some connections with that and Advance Directives. And finally, I want to take this opportunity here today to make my own personal Advance Directive before you all.

But before starting, I feel obliged, as the first speaker, to give some definition of our topic today. I'm no expert in Advance Directives – we'll hear from these people later – so I've taken a definition from a book currently being written that Merinda Epstein has been involved in. Here's a couple of paragraphs from this book, which I'll just read without comment, and then get on to my own topics ...

Advanced directives offer the opportunity for consumers to participate more fully in making treatment and other decisions during times of distress. The idea of advance directives is based on the assumption that people who have been diagnosed with mental illness know about their own lives and have the right to maximally participate in the decisions that are being made about them even when they are deemed to be 'very unwell'. Advance directives enable people with mental illness, particularly people with episodic mental illness, to document what they need if or when they become distressed or 'ill' again in the future. They are an exceptionally important mechanism for people who believe that it is likely that some time in the future they will be deemed to have lost decision making competence with the consequence of them being once again forcibly hospitalised and treated against their will.

Using advanced directives, people can record things that either assist or make worse their treatment. They can for example, document drugs that have, in the past, caused nasty side effects; who they do and do not want to come and visit them in hospital and opinions about Electro Convulsive Therapy (ECT). However, advance directives need not just be restricted to treatment decisions. They can also apply to essential mental health decisions like childcare, locking houses and flats and making sure they are secured, and the care of household pets.

While there is no legal backing yet in Australian jurisdictions for advanced directives, Victoria, New South Wales and the Act are exploring ways in which the concept of advanced directives might be implemented. Consumers are promoting the process of developing advanced directives as a way of encouraging family and treatment services to be sensitive to consumer rights, and a way of maximizing the opportunities for consumers to participate directly in their treatment decisions at a time when they are most disabled by their illness.

To begin then, in the last few years I've become involved in the disability rights movement, primarily through my association with WNUSP, who are the accredited NGO representing people with psychiatric disability at the UN Convention on the Rights of People with Disabilities. It is hoped that a final draft of this Convention will be achieved in New York this August, so right now is a critical time for people with disabilities. There's not time for me to say much about the Convention today – but perhaps our next speaker, Graeme Innes, who is an advisor to the Australian delegation at the Convention negotiations, will have something to say on it.

Within the wider disability community, people with psychiatric disability have been called the "forgotten cousins" of the disability movement. In Australia, even more than elsewhere in the world, there is remarkably little discussion of psychiatric difficulties from a disability perspective. This perspective, which follows a social,

rather than medical, model recognises environmental factors as a major contributor to a person's experience of disability. It also recognises human rights as *always* a central concern in any discussion of disability. These and other similar concerns are now established as core issues for the disability movement, but so far they have received remarkably little attention in any of the discussions around mental health in Australia. Which is a great pity, for we have much to learn from our disability cousins.

I'll give just a couple of examples of how our 'poor cousin' status contributes to the *institutionalised* discrimination, which is the most serious and damaging form of discrimination, against people with psychiatric disabilities – oh, and by the way, please do not call discrimination 'stigma'. The Victorian government has just passed its new Disability Act in which psychiatric disability has been explicitly excluded from its definition of disability, contrary to both national and international standards for the definition of disability. Their argument is that the Mental Health Act covers people with psychiatric disability, but this is plainly not the case, as my own circumstances make clear. I am not currently a consumer of any mental health services that come under the Mental Health Act. But I am still on the Disability Support Pension and I certainly experience discrimination as a consequence of my status as a person with a psychiatric disability. With this new Disability Act, I find myself feeling invisible again – reminiscent of how I felt when I was actively suicidal – in the face of such institutionalised discrimination from my government.

The other example comes from my brief time on Bronwyn Pike's Ministerial Advisory Committee on mental health. At every meeting I attended, I made a point of raising human rights as a critical issue for consumers and explicitly asked that it be put on the agenda for the committee to address sometime. And yet every time we were presented with a revised list of outstanding issues for the committee, somehow human rights had slipped off the agenda. I do not see any evidence that this government has any serious commitment to the human rights of people with psychiatric disabilities. We have *so* much to learn from our disability cousins.

What does this have to do with Advance Directives? One of the core issues still being debated at the UN Convention is that disability organisations are calling for the

Convention to endorse, as a matter of human rights, a ‘supported decision-making model’, as opposed to the prevailing substituted decision-making model that we find in most guardianship legislation. There are many complex and delicate issues around supported versus substituted decision-making, too many and too complex to go into here, such as involuntary treatment, genuine informed consent, and our legal capacity to make our own decisions. But 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 – any disability, including psychiatric – 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 – indeed they reinforce these rights and protect us against the violation of them that is all too common in mental health in Australia today.

The second topic I’d like to just briefly mention comes from my research as a PhD student at Victoria University. And if I may indulge myself, I’m delighted to be able to tell you that just two weeks ago I finally received the examiners’ reports, which were all really wonderful – I’m still in celebration mode, so please excuse the warm inner gloat that I’m currently enjoying.

Although my research was not about advance directives, or even mental health services, some of the key conclusions of my research I feel are relevant to the discussion today. I refer, in particular, to what I now call first-person research (a much more satisfactory term than ‘consumer’ research). My research clearly shows that the current systematic exclusion of the first-person voice from not only mental health research but also every aspect of mental health policy, education and service delivery, is neither rational nor scientific. Rather, this exclusion has to be seen as ideological, and a prejudice of those who assert objective, third-person knowledge as not only superior to subjective, first-person knowledge but, even worse, that it is the only valid form of knowledge. This is the rationale behind the current demand for

‘evidence based’ research, policy and practice, which comes primarily from medical criteria for testing new drugs and surgical procedures. But this narrow definition of what constitutes valid evidence is not appropriate for mental health research, policy and practice where we are dealing not with flesh and bone but with the feelings and emotions of the psyche or soul. No further research is needed to demonstrate the limitations and inadequacy of a solely third-person, objective approach to mental health – though the political challenge to this ideology that excludes the first-person voice will clearly be a major struggle.

There is, however, a major research challenge before us. This is how do we effectively bring the subjective, anecdotal, first-person data and knowledge into our understanding of mental health in a robust way? This is the most pressing need in mental health research today, but is still not currently acknowledged by those who control the research agenda.

The link here today is that Advance Directives represent a clear and concrete mechanism for bringing the first-person voice into better 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. Advance Directives, which have arisen from consumers campaigning for their voices to be heard, are an example of how we can have better mental health policy if we listen more carefully and more often to the first-person voice. Further first-person research is urgently required to bring this expertise into many other aspects of mental health research, policy and practice.

Moving on to my third and final topic, I now want to take the liberty of making my own personal Advance Directive – here, now, in this public forum. I admit that I’ve not given a lot of thought to what I might include in an Advance Directive for myself, but there are two specific ‘directives’ that leap to mind for me, which I can state in plain, unequivocal language to you now. I do this primarily to give you an illustration or example of the kind of directives that a consumer, such as myself, might want in an Advance Directive. But also, since we are talking about Advance Directives but don’t

yet have them, I call upon all of you to be the public witnesses of the directives I make now. Regardless of how crazy or suicidal I might get in the future, I make it clear to you all now that there are two things that I do **not** want to occur.

My first directive is that I do **not**, under any circumstances, want to take any psychiatric medications – no anti-depressants, no anti-psychotics of any kind, no so-called ‘mood-stabilisers’, no neuroleptics, no psycho-drugs of any kind – unless I give my explicit consent at the time.

My second directive is that I do **not**, under any circumstances, want to have any private, one-on-one, behind-closed-doors, consultations with any psychiatrist. If circumstances occur that I am required to have a consultation with a psychiatrist, then I insist that there be at least one witness present *of my choice*. Furthermore, in this directive I make the statement that if a witness of my choosing is not present then I will remain totally silent and not enter into any conversation with the psychiatrist.

These two statements are quite clear and I ask you all to bear witness to them. In my view, nothing more needs to be said in order to justify these directives and have them honoured, should the situation arise where they might be invoked. But in the context of today’s forum, I think it useful to elaborate a little on why these directives are important for me.

During my four years of madness in the late 1990s, my two serious suicide attempts occurred while I was taking a maximum dose of an anti-depressant and also a pretty heavy dose of an anti-psychotic. These drugs do not help me, they in fact made things worse. I never want to take these drugs again, OK. Next, during these four years, I had encounters with six different psychiatrists and in every single one of them I was in some way deceived, bullied, ripped-off or otherwise abused, sometimes in relatively minor ways but a couple of times in dangerously serious ways. If you go into a paddock six times and find a snake in the grass six times out of six, then you really don’t want to go into that paddock again. In late 1999, I made a personal promise to myself that I would never willingly be alone in a room with a psychiatrist ever again. So far, I have kept that promise, though it can be tricky at times, for instance if you are on the disability pension, as I am, and you’re called in for an assessment of your eligibility for the pension.

It's also useful to explain, I think, why my directive includes the statement that I would remain silent if there were no witnesses. Without this in the directive in advance of any circumstances that might invoke it, my silence at such a time would invariably be interpreted as either a symptom of some mental illness and/or evidence of incompetence, rather than a sound and rational decision based on past experience.

Finally, my Advance Directive requires that I identify some witnesses of my choosing. There are many who could fill this role, but for today I'll just mention a few. First of all, anyone in my immediate family – my twin brother, my three elder sisters, or my dad (and also my mum if she were still alive) – would all be suitable witnesses as they all know, respect and would support my wishes in this regard. There are also some people in this room, mostly fellow consumers, who I would be happy to have as witnesses, though today I can name only the two who I have already consulted about these directives and got their agreement to be named today. I have every confidence that my batty colleagues, Merinda Epstein and Cath Roper, know and understand my wishes in regard to these directives and that they would do their utmost to ensure that they were honoured, should they need to be invoked.

That's it – my Advance Directive – to which you are all now witness. Thank you.

And I thank you all for coming today and look forward to a lively discussion about this very important topic. If anyone has any questions or comments then I'd be happy to respond.