

**Department of Justice
Parliament House, Melbourne
December 8, 2005**

Rights of Persons with Disabilities: Action in Development

Topic: Economic, Social and Cultural Rights of People with a Disability in the Future Development of Australian Society

Speaker: David Webb

Around Australia today, about a thousand people will think seriously about killing themselves and roughly a hundred of them will make a medically serious suicide attempt. Of these, six or seven will succeed and die. Most of these will be men. About four times as many men than women die by suicide, though curiously this ratio is almost reversed for non-fatal suicide attempts. Some commonly cited indicators for suicide are mental illness, substance abuse and trauma of all kinds. But the strongest indicator is a previous suicide attempt.

This is just a sample of the data and evidence that I've learned about suicide doing a PhD at Victoria University, in which I've had to do a thorough study of the academic and professional discipline known as suicidology. Suicidology describes itself as the *science* of self-destructive behaviour. As a science, suicidology talks of the need for 'observable objects', data that can be measured and counted, in order to develop an evidence base to inform suicide prevention policies. At the conclusion of my PhD, I now call this data third-person data, and the knowledge derived from it third-person knowledge.

But there is another kind of data and knowledge that can also help us understand suicide better, and I have some familiarity with this knowledge too.

I have known what it feels like to want to die. I can recall the unbearable pain of not wanting to be me. I know what it is like to draw the curtains in the motel room with no intention of ever leaving that room alive. And I have known the horror of being revived in hospital, furious that I was such a total failure that I couldn't even kill myself. I knew all this back in 1979 when I got these accidental burns after a deliberate overdose. And I knew it all again nearly twenty years later when the wish

to die dominated my life for four years. Thankfully, I also now know about my own inner peace so that suicide is no longer the only option.

This knowledge is first-person knowledge – the subjective knowledge of direct experience. It is to know something ‘from the inside’. We are all familiar with first-person knowledge. It is to know the inner feeling of a lived experience. It is the intimately personal knowledge of what an experience *means to those who live it*. But the data of first-person knowledge are not observable objects. First-person data are the lived experiences themselves, what they mean to us, the sense we make of them and the stories we tell about them. And if we share these stories with others, then the opportunity arises for finding more meaning in them and more first-person knowledge is created. Only this time it is the first-person plural of collective, *intersubjective* knowledge rather than individual, *subjective* knowledge. This, very briefly, describes the foundations of first-person research.

I make this distinction between first-person and third-person knowledge because it lies at the very heart of our topic today. First-person knowledge is what people like Frank and I, and many others, have to contribute to economic, social, and cultural development. And economic, social and cultural inclusion is about including the first-person knowledge of people with disabilities in policy development – especially, but not only, policies that directly effect us.

But the reality today is that we are still largely excluded from effective participation. In mental health we hear a lot of rhetoric about consumer participation but the reality is just the opposite. The clearest example of this is that the Victorian government claims that greater consumer participation is one of its six Key Directions in mental health. But in this year’s budget, where we saw a \$180 million increase in mental health spending, not a single dollar was allocated specifically for consumer participation.

It is almost a cliché these days that policy must be informed and guided by evidence based research. But if we look at mental health research and the criteria used for what constitutes valid evidence, we find that it is almost exclusively third-person evidence. Mental health policy in Australia and Victoria is primarily determined by advice from

the medical profession, where the ‘quality of evidence’, as they call it, is defined by strictly third-person criteria.

These criteria may be appropriate for researching and testing new surgical procedures and new drugs, but they are not appropriate for mental health research. Unless, that is, you assume that mental health is entirely to do with the biology of the brain. And when we look at disability – a social issue, not a medical one – this very narrow definition of what constitutes valid evidence is even more inappropriate.

The medical colonisation of what it is to be human that we find in our current mental health policies, rests almost entirely on the false claim that the only valid evidence is third-person evidence. So the next time you hear the ‘evidence based’ cliché, I urge to ask these questions: whose evidence, what criteria are they using, and in particular, what other evidence is being excluded by these criteria?

To illustrate this, I’m currently working on a project looking into Consumer Delivered Services, which includes things like peer-support groups. We’re looking at what makes peer support effective from the consumer – that is, the first person – perspective. The words that repeatedly come up are things like empathy, respect, and compassion, all of which are invisible to the third-person radars of medicine. Mental health consumers though, as first-person human radars, are capable of detecting and working with this important first-person data.

Another illustration of the exclusion of the first-person voice can be seen in a report by the World Health Organisation on Promoting Mental Health, which had its world launch a month or so ago here in Melbourne. One of the reasons it was launched here is that two of its three editors are Melburnians. This report was a major project of three years work with over 100 contributors from all around the world. Not one of these contributors was a mental health consumer or spoke from the first-person perspective. When I queried this, I was told that the report was about mental health not mental illness.

In today’s forum, where we are talking about the contribution people with disabilities can make to society, I simply say to the WHO that understanding madness much better than we currently do has a great deal to teach us about what it is to be human.

I have no criticism of good third-person science, on the contrary. I am merely asserting the relevance and importance of first-person knowledge and the validity of first-person data and evidence. First-person and third-person ways of knowing are not in any conflict or competition. Rather, they complement each other, adding depth and balance to two *equally* valid perspectives. But either form of knowledge – *by itself* – will always be partial, incomplete and inadequate. And policies based on research and advice from only one source of knowledge will be similarly partial, incomplete and inadequate.

My criticism then is with a hardline third-person science that denies the validity of the first-person voice and excludes it altogether. This is not rational, nor is it good science. The hardline scientist argues that first-person data are unreliable, unworkable, unmeasurable and so on. This is really an admission of the limitations of their exclusively third-person research methods. In fact in many areas of the human sciences, such as teaching and learning, parenting, gender and identity studies and so on, research into first-person questions has made enormous progress in recent decades, with many significant benefits. Perhaps the outstanding example of this is feminist research, which has brought the lived experience of being a woman onto the research agenda – and changed the world forever, I think for the better.

Given this trend in most other human sciences, I find it peculiar that in psychiatric disability – or mental health – the trend is in quite the opposite direction. Mental health is being increasingly medicalised. So much so that even the President of the American Psychiatric Association has admitted – and I quote – “We have allowed the biopsychosocial model to become the bio-bio-bio model.”

Before finishing, I must briefly mention the World Network of Users and Survivors of Psychiatry, which is the international voice of people with psychiatric disability at the UN Convention on the Rights of People with Disability [that Frank has talked about]. WNUSP supports a social model of psychiatric disability, and strongly opposes the medical colonisation of mental health. Our motto is Nothing About Us Without Us, which is also the motto of the Australian Mental Health Consumer Network. Note how this motto immediately speaks of the first-person perspective. Note too that it is also a political slogan, not unlike the feminist cry of ‘the personal is political’ (and

note again the first-person voice here). WNUSP and its many member organisations around the world is therefore a social change, human rights organisation in the tradition of civil rights, feminism and Gay Pride.

Last week I spoke with Tina Minkowitz, a Co-chair of WNUSP and the leader of our delegation at the UN, and I mentioned, almost in passing, the recently released draft of Victoria's new Disability Bill. In drafting this bill, various definitions of disability were canvassed and it was decided to adopt the definition used in Commonwealth legislation. Minus one word – psychiatric. If this bill is passed, mental health consumers will no longer be recognised in Victoria as people with disabilities. This flies in the face of not only current Victorian and Commonwealth laws, but also all human rights institutions such as our own HREOC and the United Nations. Tina was stunned to hear this and asked for details that she could pass on to the UN Special Rapporteur on Disability. The only other place where she knew of such discrimination against us was Kenya.

To move forward on these issues, we can look to the UN's 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities'. Although not binding international law, these Standard Rules do represent a strong moral obligation on countries that ratify them, as Australia has. They identify the key issues for including people with disabilities in economic, social and cultural development, in particular the need for strong grassroots consumer organisations to ensure effective inclusion and participation. But mostly, the key message in the Standard Rules is the message I want to leave you with today – Nothing About Us Without Us.

I'll finish with some words that, for me, succinctly capture the first-person wisdom of Al Alvarez, the author of *The Savage God*, perhaps the best book ever written on suicide.

We must at all times remember, that the decision to take your own life is as vast and complex and mysterious as life itself.

I'd like to thank the Department of Justice for this forum today, and the Mental Health Legal Centre for inviting me to speak. And thank you all for coming. Thank you.

Nothing About Us Without Us.