

Massey University Disability in Education
Conference

Progress Through Partnerships

3-5 September 2001
Albany, New Zealand

Wednesday 5 September 2001

Keynote address

Arana Pearson, B.A.
Consumer Advisor
Mental Health Commission

P O Box 12-479, Thorndon, Wellington, New Zealand
apearson@mhc.govt.nz

Mental Health Commission vision statement

Our vision is for New Zealand to be a place where people with mental illness have personal power, full participation in their communities and access to a fully developed range of recovery-oriented services

Mental Health Commission mission statement

To take a lead, through advice, monitoring and promotion, to build a country where people with mental illness, the services they use and the communities they belong to, are able and willing to contribute to their recovery

ABSTRACT

Critical issues for people with a mental illness pursuing higher education

Mental illness is projected to become the second largest cause of disability within the next twenty years. Yet current experience suggests students with experience of mental illness are not readily accessing support to participate in higher learning. The most likely the reason for this is the stress and distress of disclosure within an environment of pervasive negative discrimination, alongside the financial pressure of living costs associated with student life including the personal costs of academic study with associated burden of student loan. For those people who do request supports from institutions of higher learning, there are some practical support strategies that can be made. The challenge in terms of partnership is for the education sector to work with the mental health sector, and for the mental health sector to work with the education sector and for both sectors to attempt partnerships with psychiatric survivors in the true spirit of "nothing about us without us".

1.WHAT IS THE NATURE OF MENTAL ILLNESS?

If we explore the 'illness' model, then it understands that just as there are a variety and range of physical illnesses along with specialty service delivery, so there are many kinds of experiences of mental illness, each differing in its effect on people's lives. Some illnesses are less intrusive through a persons overall life span, others are extremely debilitating in peoples life and long term functioning. As former mental health commissioner Julie Leibrich noted:

Some people have a single episode of illness, some have episodes throughout their lives, and for others the illness is ongoing.

(Leibrich, 1999, p. 7)

Mental illness in all its forms is part of society. It affects people of all cultures and classes. Mental illness is significantly different from physical illness, in that physical health needs are mostly 'visible' or at least able to be empirically evidenced through accepted diagnostic tools. According to the World Health Organization and the World Bank (1996), depression will be the second leading cause of disability in the world by 2020.

Historically medical professionals have assumed the right to define the problem when people search for meaning and help. And from the medical viewpoint the problem resides in individuals (Ballard 1994 p 18). In the medical paradigm, the notion of health and health promotion is defined as an absence of symptoms. The experience people with mental illness have of services is that they focus upon their perceived deficiencies, on what is 'wrong'. And this experience is couched within the spectre and threat of forced treatment.

The Mental Health (Compulsory Assessment and Treatment) Act 1992 empowers the state to force treatment on individuals. The threat of compulsory treatment may influence an individual's willingness to seek assistance. Once 'sectioned' under the act, a person's ability to take up opportunities in their life including those aspirations for higher education may be diminished. The Mental Health (Compulsory Assessment and Treatment) Act 1992 defines "Mental Disorder" as meaning

"Any person with an abnormal state of mind (whether of a continuous or an intermittent nature), characterized by delusions, or by disorders of mood or perception or volition or cognition, of such a degree that it a) Poses a serious danger to the health or safety of that person or of other; or b) seriously diminishes the capacity of that person to take care of himself or herself".

The process of diagnosis alluded to here requires more of a personal judgement call than objective empirical tests. And what is not often appreciated about the use of the Mental Health (Compulsory Assessment and Treatment) Act, is its application is often reduced to an exercise in public accountability to communities about risk assessment and management for that community. Therefore the use of the act may contribute to a person's vulnerability instead of supporting someone into better health. Therefore, from a 'mental health service user' perspective, there are largely unacknowledged risks to the person being diagnosed and sectioned under the act. Increasingly it is being acknowledged the risks to a person being diagnosed with mental illness may include 'sexual, financial, occupational or family exploitation; financial mismanagement; serious neglect of self-care; and serious social embarrassment (Ministry Of Health 1998 Pg 18). And the identifiers of these risks may include being sectioned under the Mental Health (Compulsory Assessment and Treatment) act (1992) and the use

of the Protection of Personal and Property Rights Act 1998 (welfare guardianship) (Ministry of Health 1998).

What then is the effect of mental health service labelling and diagnosis on people? When people enter mental health services they assume the role of 'consumer', 'client' or 'service user'. These labels define them person as passive receivers of a service. This is in addition to their psychiatric diagnosis, which has a major effect on their identity (Deegan, Patricia, 1990). So, added to these depersonalised roles of 'consumer', 'client' and 'service user' are layered more labels such as "schizophrenia" or "manic depression". Diagnosis is a medical procedure intended to be helpful however, words such schizophrenia have taken on a life of their own within popular culture. These roles and labels denote that person's inability, and the inability of their community of family and friends, to find answers to their problems. In these roles people leave behind their active citizenship and become passive clients; their abilities and attributes no longer acknowledged. The focus becomes their illness, their perceived deficiencies. John McKnight (1995), American analyst and defender of community, articulates clearly the effect of this idea on communities:

*When the capacity to define the problem becomes
a professional prerogative, citizens no longer exist .
(p 49)*

This effect of this loss of citizenship in the face of a diagnosis of mental illness can be expressed as stigma and its inevitable accompaniment, negative discrimination.

2. RESPONSES TO STIGMA AND NEGATIVE DISCRIMINATION

After over one hundred years of mental health patients' rights and consumer rights activity, the general community is still largely untouched in their understanding and attitudes towards people labelled with major mental illness. (Clinton, & Olsen, 1998). The Mason Report (Mason, Ken; Johnston June, & Crowe, Jim (1996) noted.

*There is no doubt that the feeling of alienation created by stigma
is one of the significant reasons cited for loss of hope and relapse
by those who experience mental illness. (p 163)*

The Mason Report (Mason, Ken; Johnston June, & Crowe, Jim (1996) led to the establishment of the Mental Health Commission, with monitoring responsibility with respect to the development of mental health services, workforce development, and the reduction of stigma and discrimination associated with mental illness.

The Mental Health Commission researched discrimination, (Thompson & Thompson 1997), and subsequently published, "*A Travel Guide, for people on the journey towards equality, respect and rights for people who experience mental illness*" The Guide looked at causes of discrimination, the interplay of behaviour and attitudes, and how change might occur. It points to seven destinations necessary in order to achieve zero tolerance for discrimination in Aotearoa/New Zealand.

1. A country in which people with mental illness have personal power to gain equality respect and rights
2. A health sector which values people with mental illness and treats them fairly
3. Laws and practices which uphold the rights of people with mental illness
4. Public organisations which are accessible and fair for people with mental illness
5. Private organisations which are accessible and fair to people with mental illness
6. Communities which behave fairly and inclusively towards people with mental illness
7. He Ara ki te Ha o Te Tangata: a country that treats Maori with mental illness fairly.

Alongside this work, the Ministry of Health funded the national Like Minds, Like Mine project and network of twenty-nine regional providers working to a national plan of action to the year 2003 (June 2001).

However, many in the field agree this work is just scratching the surface for social inclusion of people with experience of mental illness. There is yet to be agreed best approaches that work for people. For example, the topic of disclosure as related to acceptance into educational institutions and employment may be straightforward for the 'visible' disabilities such as for people with vision or mobility impairment but not so for people labelled with the 'invisible' disabilities. The American experience with including people with Mental Illness in the American Disability Act (ADA) suggests that issues of disclosure within the environment of negative discrimination can make the issue of gaining employment more difficult for the person involved (Sayce, 2000). Concomitantly, difficulties arising from disclosure of one's mental illness are similar in other areas of people's life such as education.

Perhaps what needs acknowledging up front is the oxymoron inherent in the descriptor "Mental Health Service" when clearly the purpose and focus of these services is the business of mental illness (Skynner/Cleese, 1993). However there is an emerging debate challenging the deficiency base of medical 'mental health' service diagnostic process about the promotion of mental health. Alongside this is a growing acceptance that mental well-being is an essential component of general health (Ministry of Health, July 2001). In this way, discrimination is being challenged in the form of alternative paradigms in which to understand the nature and cause of 'mental illness'. A key concept in this debate is the relatively new notion about the nature of resilience. The word resilience originates from the Latin root '*resilere*' meaning, "to jump back". From

a spiritual paradigm, resilience is transforming adversity into wisdom. Or from a biological view it is about evolution and adaptation to survival. Resilience is a dynamic process and not just an absence of pathology. It is the ability to cope with adversity, stress, risk and deprivation: the human capacity to face, overcome and to even be strengthened by the experiences of adversity (Deveson, 2001). The key concept here is to support people in coping and to work with people's strengths rather than identifying their weaknesses.

Resiliency is not just a concept that is individually based, although that tends to be the perspective most studied in a western framework. We need also to look at the resiliency of communities. Mental health is inextricably tied up with community and to see mental illness only as residing in individuals is to miss a large part of the interactive relationships between 'the self' and 'community' that create and describe 'unhealthy-ness'. There have been attempts to demonstrate these community inter-relationships by the design of a resilience framework (Karol L. Kampfer 1999). An holistic view of the nature of people underlies most paradigms of health and similar expressions are mirrored within the New Zealand/Aotearoa Maori concept of "Te Whare Tapa Wha" or the four cornerstones in the house of health: spiritual, mental, physical, and family Durie, Mason (1994, 1988).

However, not everyone agrees the concept of resilience is a better approach than the medical diagnostic method Howard B. Kaplan (1999). And the medical paradigm certainly prevails for those who are diagnosed with a major psychiatric label.

3. WHAT CAN BE DONE: REASONABLE ACCOMODATIONS TO SUPPORT HIGHER LEARNING

It needs to be acknowledged upfront most students struggle to support themselves financially and are vulnerable to stresses associated with debt incurred to pay for education. These realities are heightened for people who have experienced major illnesses. Given that people with an experience of mental illness find their rights to education, community living and employment are regularly violated, what role has the tertiary sector in working to change this reality?

Three characteristics of mental illness are important to consider when working out how best to support students.

1. The effects of 'mental illness' are often less cognitive than emotional (or affective) so may not impair a persons ability to think and study.
2. As in physical illness, there is a great variety of individual experience
3. Mental illness is mostly episodic.
4. The experience of 'mental illness' is essentially an 'invisible' experience, and disclosure is fraught with personal danger, so identification of people who would benefit from supportive strategies

may be difficult, given the cultural environment of stigma and negative discrimination

How then can tertiary institutions of learning support students and researchers in their aspirations for higher learning? .

1. Work to reduce the fear of disclosure so students can safely declare their challenges and seek help. This can be done in a variety of ways: when asking about support needs, mental illness can be seen as one of a number of needs students have; put up posters from the Like Minds campaign; employ people with an experience of mental illness to support others; work with the student union on ways they can support students with a mental illness; have articles in student magazines on the successes of people with an experience of mental illness (staff or students) who are willing to 'come out'.
2. Educators can learn to recognise needs. For example, some significant indicators of a possible 'mental illness' include a marked personality change over time, prolonged severe feelings of depression or apathy, feelings of extreme highs or lows, heightened anxieties, fears, anger, or suspicion; blaming others; social withdrawal, substance abuse; thinking or talking about suicide. Educators may notice significant changes in their students such as consistent late arrivals or frequent absences; low morale; disorganization in completing assessments or in study habits; drowsiness (a side effect of medication), lack of cooperation or a general inability to communicate with others and problems concentrating.
3. For people who are already 'diagnosed' and receiving treatment in the form of medications, then there are a variety of strategies that can be helpful in the classroom, which the Boson University has usefully listed on a web site (1997). For example medications can produce side effects such as dry mouth, blurred vision, and restlessness. Typical classroom accommodations would therefore include beverages being permitted in class and preferential seating by a door, regular pre-arranged breaks to allow people to move, tape recording of lectures, the use of note takers or the photocopying of others notes, assignment assistance during hospitalisation, text books on tape.
4. Course planning. Stressors can be reduced by advance notice of assignments for people to anticipate and plan workload; along with regular 'check in' for early alerts to the need for flexibility in the workload.
5. Typical administrative accommodations may include providing modifications, substitutions, or waivers of courses on a case-by-case basis, flexibility in determining "full time" status for purposes of financial aid, assistance with selecting classes and course load. It may be that disclosure of the 'mental illness' situation occurs after

key administrative milestones have lapsed, and the ability to individually plan for a recovery of the study plan would be helpful.

6. Examination accommodations include permitting exams to be read orally, dictated, scribed or typed; Increase frequency of tests or examinations; permit exams to be taken individually, including in hospital; segmented by dividing the exam into parts and allowing the student to take them in two or three sessions over one or two days to help reduce the effect of fatigue; change the test format, for example from multiple choice to an essay format may help students demonstrate their knowledge more effectively; delay in assignment due dates to accommodate hospitalisation and medication reviews.
7. Disability Co-ordinator and Student Advisor roles have the training to be conversant with paradigms of 'mental health' and public health promotion (strengths based 'resilient' model) service delivery. They should also have established networks of 'mental health' service users and services to effectively liaise among.

4. FUTURE DIRECTIONS

As the twenty-first century has begun, one of the notions we have that differs from one hundred years ago is that it is possible to recover from mental illness. As noted by Tessa Thompson (2000), "work to promote social inclusion is fundamental to recovery ...(it) is not a sideline to mental health services - it is the heart". And this heart of recovery needs to be expressed within the academic community also for:

Community connections bring a double benefit: promoting mental health for labelled people, and reducing the stigma and discrimination, through the people contact that has been shown to be so effective.

Business Research Centre report,

(1997)

As well as supporting individual students there is another way universities can play a large contribution to social change. Universities have roles in both research and teaching. In tertiary institutes ideas are debated and new approaches mooted – they are often in the forefront of social change. The very nature of mental illness, often debated as being a social construct, needs to be fully explored. Innovative approaches to community change and supports need to be developed and supported with research, preferably by people with an experience of mental illness themselves.

Tertiary institutes can give people with an experience of mental illness the opportunities they need to begin exploring and developing their own perspectives on their experiences. As McKnight has said

Revolutions begin when people who are defined as problems achieve the power to redefine the problem (1995, p 16).

When supports enable success, tertiary education can be empowering. Once people with an experience of mental illness are visible in tertiary institutes in large numbers and are enabled to contribute their perspective and experiences, effective changes in the ways we view and support people may begin at last.

Closing song "I'm just a little mad" (Ferreiro, Flinter-Leach, and Searle, 1999)

REFERENCES.

Ballard, Keith (ed) 1994 Disability, Family, Whanau and Society. Palmerston North, New Zealand: Dunmore Press

Boston University (1997) Center for psychiatric rehabilitation website:
<http://www.bu.edu/cpr/>

Business Research Centre (1997). Public Knowledge Of, and Attitudes to, Mental Health and Mental Illness. Wellington, New Zealand: Business Research Centre.

Clinton, Michael & Olsen, Anne (1998). 'Collaboration for Mental Health' Australia: keynote address at the 8th Annual TheMHS Conference 1998.

Deegan, Patricia, (1990). Spirit Breaking: When the Helping Professions Hurt. The Humanistic Psychologist, volume 18, Number 3, 1990.

Deveson, Anne (August 2001). Resilience and Mental Health, Keynote Address, The Mental Health Services Conference of Australia and New Zealand (TheMHS) Wellington.

Durie, Mason (1994, 1998). Whaiora: Maori Health Development. Oxford University Press, Auckland,.

Kaplan, Howard B (1999) Toward and understanding of Resilience: a Critical Review of Definitions and Models from "*Resilience and Development: Positive Life Adaptations*", edited by Glantz and Johnson. Kluwer Academic/Plenum Publishers, New York, 1999

Kumpfer, Karol L (1999) Factors and Processes Contributing to Resilience: The Resilience Framework from "*Resilience and Development: Positive Life Adaptations*", edited by Glantz and Johnson. Kluwer Academic/Plenum Publishers, New York, 1999

Leibrich, Julie (1999). A Gift of Stories: discovering how to deal with mental illness. New Zealand: University of Otago Press/Mental Health Commission.

Mason, Ken; Johnston June, & Crowe, Jim (1996). Inquiry Under Section 47 of the Health and Disability Services Act in Respect of Certain Mental Health Services. New Zealand: government (commonly known as The Mason Report)

McKnight, John (1995). The Careless Society: Community and Its Counterfeits. United States: Basic Books.

Mental Health Commission (1997). A Travel Guide for people on the journeys towards equality, respect and rights for people who experience mental illness. Wellington, New Zealand: Mental Health Commission.

Mental Health Commission website: <http://www.mhc.govt.nz>

Mental Health (Compulsory Assessment and Treatment) Act 1992.
New Zealand legislation.

Ministry of Health (July 2001). Building on Strengths a springboard for action: A new approach to Promoting Mental Health in New Zealand/Aotearoa. Consultation document. New Zealand: Government

Ministry of Health (1998). Guidelines for clinical risk assessment and management in mental health services . New Zealand: Government

Ministry of Health (June 2001). National Plan 2001-2003 Project to Counter Stigma and Discrimination Associated with Mental Illness. New Zealand: Government
website: www.likeminds.govt.nz

Ferreiro, Flinter-Leach, and Searle (1999). C.D. "I'm just a little mad" recorded by Arana Pearson and published by the Serious Fun 'n Mind Trust (2000). E-mail SeriousFunNMind@xtra.co.nz

Sayce, Liz (2000). From psychiatric Patient to Citizen: Overcoming discrimination and social exclusion London: Macmillan Press Ltd.

Skyner Robin & Cleese, John (1993). Life and how to survive it London, Great Britain: Methuen.

Thompson, Tessa (2000). The power of stories in a movement towards social inclusion. Paper presented at the UK Mind Conference, New Zealand: Mental Health Commission

Thompson & Thompson (1997). Discrimination Against People With Mental Illness Wellington, NZ: Mental Health Commission.

World Health Organization and the World Bank (1996). The Global Burden of Disease: A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020 CJL Murray and AD Lopez (eds) Global Burden of Disease and Injury Series, Vol 1. Harvard School of Public Health on behalf of the World Health Organization and the World Bank.