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Changing the Paradigm: reflections on experiences in workshops to reduce stigma and discrimination in mental health services.

A thesis submitted
in partial fulfilment of the
requirements for the degree
of Master of Philosophy
at Massey University,
Auckland, New Zealand.

Ruth Gerzon, December 2001
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ABSTRACT

One of the key objectives of the national Like Minds, Like Mine project against stigma and discrimination associated with mental illness is to work with the mental health sector to change attitudes and behaviour through education and policy development. This action research thesis examines the effectiveness of workshops aimed at reducing the stigma and discrimination within mental health services.

Most hospital based mental health services were developed within the 'medical model' based on professional power. Non-discriminatory services are seen to be those that support a 'recovery model', as promulgated by the Mental Health Commission, which is based on partnership and participation by service users. For many services this requires a change in their culture. This research examines the effectiveness of workshops designed to support such cultural change, facilitated by people with experience of mental illness. Observation, evaluation and reflection on two workshops, and the findings of a literature search informed practices, with new techniques developed and trialled.

DEDICATION

To people with experiences of mental illness
and mental health service staff
who hold a vision of services
where respect, partnership and participation
are a reality.

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GLOSSARY

Aroha	–	love, affection
Awhi	–	cherish, embrace
Karakia	–	prayer
Kaumatua	–	elder
Kaupapa	–	plan, theme
Mamae	–	pained, distressed
Mana	–	influence, authority
Manaaki	–	to show respect, kindness
Mihi	–	greeting
Mokemoke	–	lonely
Pakeha	–	a person of predominantly European descent living in Aotearoa/New Zealand
Porangi	–	beside oneself, out of one's mind, mad
Rangimarie	–	quiet, peaceful
Tauīwi	–	different tribe, those who came later (Pakeha, Samoan, Chinese etc., all non-Maori in Aotearoa/New Zealand)
Tipuna	–	ancestor
Tumeke	–	'too much' – slang term meaning something is really good
Turoro	–	sick person
Waiata	–	song

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CHAPTER ONE: THE CONTEXT OF DISCRIMINATION

INTRODUCTION

This chapter backgrounds my interest in this research and examines the context in which discrimination occurs in mental health services.

The focus on these workshops stems from my role in the mainstream Like Minds, Like Mine, project against stigma and discrimination associated with mental illness. The Ministry of Health (formerly Health Funding Authority) contract for the project in the Bay of Plenty is held by the Serious Fun 'N Mind Trust, my employer.

With a Jewish background I have had a long-standing interest in education to counter discrimination. Since the mid 1980s I have facilitated anti-racism workshops (in latter years called Cultural Safety, Te Tiriti O Waitangi etc) and, from 1990, disability studies courses in which issues of discrimination associated with physical and intellectual disability have been a major component.

I have worked collaboratively in anti-racism work with other Tauwiwi and with Maori facilitators. Throughout those years we continually refined and improved our courses, and developed new resources and teaching techniques. However I have had frustratingly little time to research relevant theories and best practices in often challenging work. This study has given me time to do this, informing my practice in all areas of adult education to counter discrimination.

I came to work in the campaign against stigma and discrimination associated with mental illness in 1999 with no background in mental health and no real understanding of either the sites or depth of discrimination associated with mental illness. On talking to people with experience of mental illness over the first few months I became aware that one of the key sites of discrimination that impacted negatively on their lives was within mental health services themselves. People with experience of mental

illness reported unnecessary levels of coercion, coupled with paternalism, disrespect and lack of voice. A workshop for mental health services was developed to reduce this discrimination.

My role in this research has been to develop resources, arrange training for facilitators, organise workshops for mental health service staff and students, evaluate them and, through this research further refine them.

STIGMA AND DISCRIMINATION AND MENTAL ILLNESS

Discrimination in the field of mental illness is linked to other forms of group oppression, such as racism, sexism, and heterosexism in Western societies. Hodge, Struckman & Trost (1975) saw these as rooted in Dualism, a term they used with a capital 'D' to refer to the notion of the opposition of objective forces of good and evil and the notion of the will. These two concepts underpinned traditional western thought and cultural life, with good seeking mastery over evil. People and their actions could be ranked in order of their proportions of good and evil; and good should control evil. These views justified the concepts of hierarchy and authoritarian rule underlying Western racism (white people were more 'good'), sexism (men were more 'good' and should have authority over women) and colonialism. These concepts are also central in the modernist medical model of mental health services prevalent in Aotearoa/New Zealand.

Although cultural concepts and justifications link discrimination in the field of mental illness with other oppressions, discrimination associated with mental illness is especially strong and hard to dislodge. In western discourse people with experience of mental illness are non-people, for they cannot 'think straight' and have 'lost their mind'. Not only are their thoughts and ideas of no worth, but they are inherently and irredeemably dangerous or 'evil'. There is no positive value in mental illness. Community structures and social conditions, such as poverty and exclusion, are not viewed as having a role in provoking or maintaining mental illness, as mental illness

is located in individuals. The strength of this discourse and justifications of discrimination may be a reason for the relatively recent growth of this movement for social change.

In the National Project to Counter Stigma and Discrimination Associated with Mental Illness, stigma and discrimination were defined in the following way:

stigma is like the 'stamp of disapproval' carried by an individual: a mark of shame or social disgrace. It is something attached to a person that can mark them as unacceptable. Discrimination, on the other hand, is an act or belief that results in the systematic unfair treatment of a person or group because they are different (Like Minds, Like Mine pamphlet: Mental Illness: Changing Our Attitudes, 2000).

Stigma is a mark seen as attached to the individual, whereas discrimination occurs as a result of behaviour. Discriminatory behaviour denies people a voice and access to employment, accommodation and good services. It has a profound effect on the quality of people's relationships and lives.

The stigma and discrimination associated with mental illness is deeply entrenched in western society's commonsense notions of 'reality' and informs the practical ways in which mental illness is perceived, problematised and 'treated'. Jenny Morris (1991) wrote about the effect of having a physical disability, but her story was similar to many told by people with experience of mental illness:

I didn't fully realise it then, but by stepping over that wall I became someone whose physical condition others feared... They therefore used a variety of defense mechanisms to prevent themselves having to identify with my reality. These defense mechanisms all took the form of people separating off from me... In subtle and not so subtle ways a number of people conveyed to me that they felt my life was no longer worth living. (p.2)

Yet there are also differences between the discrimination experienced by people with physical disability and people with experience of mental illness. The nature of the illnesses is fundamentally different. A diagnosis of mental illness is a judgment

primarily based on a person's behaviour, so there is an implied criticism that can be seen by the person or by others as an attack on their identity and self-esteem (Rogers, Pilgram & Lacey, 1993). The consequences of the label of mental illness are much greater than those of physical illness. In her seminal work on stigma and discrimination associated with mental illness, Sayce (2000) wrote that it was common for people to tell their employers that they were sick, implying they were physically ill when they were in fact distressed. People preferred to keep distress private was because it was a stigmatised state. Charlton (1998) noted that, in his international work in the disability rights movement, he received "almost universal confirmation that people with mental illness are the most discriminated against and the most isolated in their respective countries". (p.6/7)

Unlike the stigma of physical disability, which often arouses the emotion of pity, the stigma of mental illness arouses fear. When I discussed the need to avoid the 'charity and pity' approaches, with a member of the Trust's advisory group, he said, "Pity would be a good start" (Geoff Harman, personal communication, 1999). Fear is a more primal emotion, harder to dislodge, and more distancing than pity. Films and media reinforce the idea that people who have lost their mind are capable of unpredictable atrocities. Public debates are held in the media on whether to extend professional power to restrain or remove people or force them to take medication. Chomsky and Herman (1988) saw the media playing the greatest role in 'manufacturing consent' through the use of filters that selected and shaped information.

Because of this view that people with a mental illness are to be feared, discrimination in the field of mental illness may be more difficult to counter than the discrimination surrounding other disabilities. In England it has also been shown to be more pervasive. Sayce (2000), quotes an English Harris public opinion survey that found

19% of those surveyed said they would feel comfortable with someone with a mental illness, compared to 59% with someone using a wheelchair. (p.67)

Stigma and discrimination are widely regarded as barriers to people becoming well after an episode of mental illness. Seeking help from mental health services brings both advantages and disadvantages: help and support, but also a psychiatric diagnosis and label, which may affect self-concept, future employment and relationships. Difficulties experienced obtaining work and housing; retaining good relationships with families and friends contribute to social isolation, poverty and stress. The Mental Health Commission (1998b) noted that

One of the most painful, widely felt, and insidious problems for people who experience mental illness, is social exclusion. The direct effects of mental illness may contribute to social exclusion in some cases and at some times, but the major contributor is discrimination.

People with mental illness may be the subject of ridicule, harassment and abuse. Or they may simply be forgotten or ignored, denied access to opportunities most people take for granted. (p.2)

Becoming internalised, stigma and discrimination work insidiously, denying hope and the possibility of recovery. Many people with experience of mental illness develop shame, coming to believe that they are less able than others. The feelings of inferiority make it difficult for many people with experience of mental illness to confront and contest their own powerlessness.

The Blueprint for Mental Health Services in New Zealand (1998a) echoed this

One of the biggest barriers to recovery is discrimination. That is why stopping discrimination and championing respect, rights and equality for people with mental illness is so important. It is as important as providing the best treatments or therapies. (p. 18)

But it is not only service users who are hurt, for the discrimination also acts as a barrier to people accessing services. Sayce, (2000), wrote that discrimination on mental health grounds affected millions because "so many people fear being 'on the wrong side of the line' and go to such pains to make it clear, not least to themselves, that even when distressed they are not 'mad'". (p.9)

Sustained discrimination brings oppression. This occurs when groups are placed in positions of inferiority, controlled by powerful others. Power is diffuse and complicated; working not only through overt tactics such as force and coercion but through legitimation and consent. Prevailing ideologies impress on people the normality of the power and privilege held by certain groups such as professionals.

Foucault (1980) explored how power shaped relationships, established and implemented through discourse. The 'commonsense of exclusion' for example, was seen in the words 'mad' and 'insane' used to refer to anyone who was outcast or not worth consideration.

Historically humans were thought in Western Europe to be partly driven by primitive animal instincts that were evil making them potentially greedy, selfish and hostile. From the middle ages people with experience of mental illness were seen as having a predominance of animal within them (Foucault, 1963) and lacking the capacity for reason.

Reason was the mechanism through which people controlled their passions, enabling them to be moral, and autonomous. Such people, fulfilling their duties as citizens could access the rights of full inclusion in society. In contrast, 'mad' people became frustrated as they were unable to use reason to satisfy their needs and this upset their nervous systems. They were not worthy of respect or citizenship. In need of protection from themselves, it was in their best interests that others made decisions for them. According to Sayce (2000), this 'commonsense of exclusion' said people with mental health problems should be placed at a distance.

THE HISTORY OF STIGMA AND DISCRIMINATION IN MENTAL HEALTH SERVICES IN AOTEAROA/NEW ZEALAND

The history of mental health services in this country is almost entirely dominated by Western practices and concepts of mental illness. Only in the last decade has there been recognition of indigenous beliefs and ways of supporting people with experience of mental illness.

Maori people with experience of mental illness face discrimination on two counts: both discrimination because of their experience of mental illness and through their inability to access culturally appropriate and safe support within most mental health services. Women also report difficulties accessing appropriate and safe services, as women-only services are rare.

INSTITUTIONALISATION

For over a century discrimination was practised through the physical segregation of people with experience of mental illness into institutions. New Zealand followed English practices with the first institution, the Karori Lunatic Asylum, opening in 1854, as a "place of refuge for troubled minds" (Williams, 1987 p.3). The earlier harsh treatments in British institutions using strait jackets and irons and fetters were no longer in vogue, and treatment was by 'moral management'. Quiet routines, ordered programmes of church services, recreation and manual work in the gardens would restore patients to health. These first asylums were close to towns to enable family contact.

Patience, gentle treatment, nourishing diet, cleanliness with light employment or exercise goes far to recover the lunatic, and in chronic cases serves to make them comfortable and even happy. Amusements for the insane are indispensable... Good example in the

attendants is the greatest guide and gives confidence to the patients (Dunedin Asylum Keeper's Journal, 20 April 1884, cited in Brunton 1985 p.46).

New Zealand asylums were under the control of lay people until doctors successfully campaigned in the early 1870s to put medical men in charge (Williams 1987 p. 21).

In the mid 1870s the clientele of the asylums began to change from people seen as acute and curable to a predominance of people whose illness was viewed as chronic. Williams (1987) documented the reasons for these changes:

The country was entering a depression and there was an aging bachelor population, no social welfare and workers suffering from syphilis and drink had no relatives to care for them. (p.28)

With stretched resources and overcrowding, custodial care, seclusion and mechanical restraint became common. From the early 1870s the asylums became to be identified with incurability and stigma associated with mental illness was clearly on the increase.

A sojourn in an asylum leaves behind it a ban and a disqualification which the relatives of the insane are unwilling to incur... A belief is cherished that restoration to reason may be obtained by home treatment and hence the insane are not sent to asylums until hope and patience are exhausted (Wellington Independent 12 October 1871 cited in Brunton, 1985, p.49).

The heightened stigma has been blamed (Williams, 1987; Brunton, 1985) on the tendency for the new penny daily newspapers of the 1870s, to publish sensational stories of horror and violence in asylums overseas. They followed these stories with a hunt for similar incidents in this country. Williams (1987) wrote that this caused a

public reaction of fear and withdrawal and a demand for tighter security at the local asylums. The public mood changed from sympathy to one of suspicion, self-protection and indifference. (p. 28)

Fearing exposure of the deteriorating conditions in the asylums, public access was limited. Security was tightened, walls became higher, and new asylums, Seacliff,

Porirua and Tokanui, built from 1878 to 1912, were further from cities. This led to more ignorance about mental illness and increased antagonism in the community.

Depersonalised, overcrowded, remote institutions, starved of funds gradually became the norm during the next 80 years as policies and procedures became a compromise between the desirable and the politically possible.

DEINSTITUTIONALISATION

Small improvements occurred after both world wars, as returned servicemen suffering from shell-shock were seen as worthy of better treatment. There was a renewed emphasis on rehabilitation and therapy. Acute wards within hospitals were developed in order to treat people without sending them to the institutions. But most changes occurred from the mid 1950s as the use of new medications resulted in shorter admissions and more people were discharged (Abbott, 1986, p. v and Brunton, 1985, p. 57). Community care was viewed as feasible and community residential services began with the first hostel for former long-term patients opening in Wellington in 1961.

Deinstitutionalisation accelerated in the 1960s, partly fuelled by public concern and critiques (Goffman, 1961) of institutions, on the grounds of the loss of identity and competence resulting from living in rigid organisations. The move out of institutional care was also influenced in the 1970s and 1980s by the availability of improved medication and a new emphasis on human rights.

PARADIGMS IN HEALTH CARE

Seedhouse (1988) saw signs of a shift in the medical paradigm on which health care has been based. Common assumptions in this paradigm, or medical model, steeped in positivism and modernism, were that health was the absence of disease; disease would be cured through medical science, medical training centred on facts and

technical skills, and there was a strict hierarchy among professionals who made decisions without involving patients.

Paradigms are created and reinforced through discourse. Language plays a central role in the formation of ideas, constructing commonsense reality and giving a basis for identity. The creation of these discourses, influenced by people in power, defines how life is experienced, seen and interpreted.

THE MEDICAL MODEL

Large institutions no longer exist but the discourse and practices of the medical model still hold sway and have a major influence in the discrimination and marginalisation of people with a disability or experience of mental illness. In the field of mental health, medical power is especially strong with the Mental Health (Compulsory Assessment and Treatment) Act, 1992 (and amendments) enabling medical authorities to take away a person's right to refuse or to choose treatment.

Seedhouse (1988) noted this paradigm as one where the medical profession

...defines its own rationale and influence without consulting those it seeks to serve, where the health service is organised in strict hierarchical lines, where curing disease through science is the primary motive... (p. 9)

Foucault (1980) showed how power relations function at the level of knowledge, of creation of ideas. Power was not merely a negative force, used to oppress, but was linked to the production of the social world through the legitimisation of social discourses. The discourse of applied science enabled the medical profession to control individuals. Individuals were observed, categorised and contained, becoming 'cases' or 'patients', their behaviours meticulously documented in ways used to justify continuing control.

In an influential critique of professional power, Illich (1976) wrote that a patient's sickness

... is taken from him and turned into the raw material for an institutional enterprise. His condition is interpreted according to a set of abstract rules in a language he cannot understand....the sick person is deprived of meaningful words for his anguish.... (p. 175)

Professionals gave ordinary processes strange and powerful names to gain control and mystify lay people, both patients, families and communities. Technical language was an integral part of the professional façade (Brandon, 1991; Illich, 1976). The illusion of control was based on the assumption that the medical profession was able, using scientific methods, to accurately control and treat people. When media reports increased community fears of people with mental illness (both in 1870s and currently) there were frequent calls for the medical profession to be given even greater powers to control and incarcerate people who were unwell.

Once labelled with a mental illness people become enmeshed in the medical model and may find it difficult to get out. In 1973 Rosehan (1989), along with seven others gained admission to 12 different hospitals in the United States by talking about 'hearing voices'. Even though they reported their voices stopped on admission, it took some of these researchers many weeks to convince medical authorities they were well enough to be discharged. Most of their behaviours were interpreted in the light of their illness, and used to confirm the original diagnosis.

Clearly within the classic medical model there is no place for the voice of people with experience of mental illness. Their history is written by others, the validity of their perspectives denied by the label they receive.

Cath Roper of Australia, who has experience of mental illness, wrote

I have no space to speak until I cast off the labels I have been given, until I discard the medical model - become the 'insightless creature'. Because how do you speak when you are only asked certain questions which have certain answers?

How do you speak when you hear the gavel of dismissal: the rules are all pre-determined, the court is in session, the way you demonstrate insight is to say you know you have no insight? ...I cannot live in that place, that has been marked out for me - that

narrow, arid, sterile place, that hopeless place, where dreams are only disease.

I have been filed, taken, classified, named, categorised, abused, labelled by your institutions (Roper and Pearson, 1999).

Within the overarching medical paradigm there are different understandings of the causes and treatment of mental illness that have informed service development in the past century, both biological and psycho-social models. Common to both is professional power. The relationship between professionals and people with experience of mental illness is one where those seen as 'knowledgeable' and 'skilled' act on those labelled 'unwell'.

THE BRAIN DISEASE (BIOLOGICAL) MODEL

In this approach, the hope of the future rests with science (Sayce, 2000). As the genetic and biochemical roots of problems such as schizophrenia and depression are gradually uncovered, we will see that a disease of the brain is no different from a disease of some other bodily organ. Beliefs in biological and genetic causes of mental illness have gained favour in recent decades, both within the profession and in public education, especially in the United States. Studies have shown a correlation between these beliefs and negative attitudes towards people with a mental illness (Read & Harre 2001), finding they reinforced the view that people could not control themselves and were likely to be unpredictable. Exaggerating the difference between those that have, and those that have not yet had a mental illness encouraged distancing, fear and scapegoating. It also produced patronising attitudes. 'They' were not only different from 'us', but also child-like.

People used to be called crazy and lunatic. A lot of hatred was directed at them. NAMI¹ stepped in and said, no, don't hate them, they're sick. Pity them. Now we're stuck with a lot of pity. I wish someone had had more foresight and substituted something different for the hatred (woman user/survivor, Massachusetts, 1995, quoted in Sayce, 2000, p. 94).

¹ The National Association for Mental Illness

One study showed that within mental health services, professionals with a biological perspective were less inclined to involve patients in the provision or management of mental health services than were professionals with a psychosocial perspective (Kent & Read, 1998, cited in Read & Harre 2001 p. 225).

The brain disease model had the advantage of being a 'no fault' one, with any inability to function seen as caused by the individual's illness. Such beliefs, locating the cause of mental health problems outside an individual's personality, did not blame the person and had been shown to be associated with better health outcomes than beliefs that are blaming (Barnes 1999).

Yet the brain disease model also left no room to acknowledge, or act on, disempowerment caused by the person's social or physical environment, nor understanding that mental illness may be exacerbated by stigma and discrimination within both services and community.

THE INDIVIDUAL GROWTH OR PSYCHOSOCIAL MODEL

This model sees wellness and unwellness as a continuum and both the social and physical environment as causing distress. Therapy is the primary method of rehabilitation. Ultimately everyone could benefit from counselling which helped us become emotionally literate. Psychotherapy from the early 20th century and the New Age and self-help movement in the late 20th century have permeated our culture. Subconscious feelings and defense mechanisms have become part of everyday language (Sayce, 2000).

The advantage of this model to service users is that professionals working within it are often less judgmental. Read and Law (1999, p. 219) cite studies showing that medical model professionals perceived a videotape of a 'patient' as more disturbed than did professionals with a social learning perspective. However therapists still strictly maintained their professional distance.

This psychosocial model has widened the scope of professional power through bringing more life events into the domain of therapists and psychologists. McKnight (1995) gave an example of the growth of grief counselling replacing and undermining friends, family and natural community support at a time of bereavement. He saw the rise in services as disempowering communities and pathologising everyday stressors.

A subset of the psychosocial model is the one seen as perhaps the least discriminatory – the social deprivation model. This approach sees marginalisation as a causal factor in the prevalence of mental illness among ethnic minorities (for example, statistics show up to 60% of patients in psychiatric institutions are Maori: Johnstone & Read 1999) and people living in poverty. Brandon (1991 p.5) noted that the ‘most important and relevant symptoms of mental illness are frequently poverty and powerlessness’.

The medical model is now being challenged on many fronts, both from people with experience of mental illness and from within the professions. A Harvard psychiatrist, Mack, (cited in Spaniol & Cattaneo, 1997) saw many of the disorders professionals encounter in people with psychiatric disabilities resulting from the sense of powerlessness and helplessness engendered by their treatment.

Walsh (1994) quoted evidence by a psychiatrist to an Australian enquiry that viewing patients within the medical model, increased dependency, lowered self-esteem and empowerment. He advocated empathic relationships between staff and patients, noting that nurses used the excuse of ‘professionalism’ to objectify patients. He gave as examples

...the standard patient greeting, ‘how are you today?’ which gives the impression you neither care nor are really expecting a reply. Or staff handover where patients are spoken of as a constellation of behavioural problems. Or when patient distress is first met with medication rather than empathy. (p.117)

Few people hold solely to one or other of the models. Most see mental illness as a result of various factors, genetic, individual, social, but vary in their views of the importance of these factors.

THE CULTURE OF MENTAL HEALTH SERVICES

Both the biological and psychosocial models remain firmly within the overarching medical paradigm, which informs the culture of mental health services.

In the psychosocial model some therapists advocated a democratic model of therapy with a partnership approach, yet power was given with strings attached and could be taken back if progress (measured by the therapists) was not made. Brandon (1991) saw phrases such as 'therapeutic reality' as concealing authoritarianism, and modern 'democratic' therapists as heirs of the moral management tradition of the early 19th century, "concerned with the good of the people rather than the transfer of power". (p.146)

He noted that even with changes in beliefs about the causes of mental illness and treatments offered, little changed for the patients. It was still the individual that needed to be changed and just a different group in charge of the changes.

Professionals view themselves as the ones bringing knowledge, skill, 'reason' and control into their relationship with people with experience of mental illness. This view lies behind the culture of mental health services with its staff-user relationships of 'high distance'. Most staff interact only in a task oriented way with service users. Interventions, such as behaviour therapy, are aimed at diagnosing problems and changing people, rather than accepting and responding to their perceptions and expressed needs. When a relationship of manipulation became the sole relationship the person was treated as an object instead of as a human 'subject' (Seedhouse, 1995, cited in Barnes, 1999).

Some service users have seen manipulation as the motive for professionals' interest in users' views. Roger, Pilgrim and Lacey (1993) noted

The goal of compliance with treatments prescribed by medical practitioners, accompanied by an uncritical acceptance of the inherent desirability of professional practices, often seem to lurk behind a concern to find out the 'patient's views'. (p.2)

Within tertiary mental health services the distance between staff and people with experience of mental illness is maintained through mechanisms underlining the difference in status between the two groups. Language, uniforms, secrecy (a reluctance to share information) use of physical space (separate staff rooms, toilets) all signal who is assumed 'well' and who is viewed as 'unwell'. Much discourse clearly delineates those who have power from those who don't, through the use of such words such as 'parole', 'allowed' and 'compliant'.

Discrimination resided in the way staff made every day decisions and developed and controlled their relationships with people with experience of mental illness (Dominelli 1997). An example, cited by Patricia Deegan (1997) was the rage she felt when, as a teenager, she was given a diagnosis, with little hope for a quality life. She wrote that "one must recover not only from the mental illness, but also from the internalised stigma, low expectations and dehumanising clinical practices" (p.16).

Often staff stay within their offices or workstations, acting as observers, reducing their opportunities to interact with patients. Staff roles emphasise monitoring distress rather than responding to it. Brewin commented that

...psychologists traditionally work with either the ability to remember or forget distressing experiences, rather than actually hearing these memories (quoted in Barnes, 1999, p. 404).

Users experienced such social relations within services as abuse (Barnes, 1999). Barnes echoed the ideas of Mack (cited in Spaniol & Cattaneo, 1997), noting that lack of respect within services led to further trauma, added to distress and exacerbated illness. As a condition of treatment, within the culture of mental health services, service users had to discard their own self-concept and take on the staff's version of themselves.

People with experience of mental illness viewed the medical paradigm as abusive and oppressive (Brandon, 1991; Roper, 1999; Deegan, 1997). Deegan noted "...any act

which reduces the human subject to an object to be acted on is an oppressive act”

(p.14). Consumer-led research into acute, hospital based care noted

The loss of self-esteem and loss of our dignity ... the effects of being treated like children, directed, controlled and spoken to with less than adult respect; powerlessness and the frustration of not being able to make ourselves heard over the clamour of ‘science’; the awful effects of profound shame and sometimes self-disgust; anger and frustration when we are locked up against our wishes and don’t understand or when drugs don’t work or have side effects which cripple us [and] for some of us sheer relief that our pain is being taken seriously at last (Wadsworth & Epstein, 1996, p. 65).

People with experience of mental illness acknowledge many individual examples of good practice by staff, yet with the medical model underpinning service culture, it remains authoritarian, paternalistic, monocultural and damaging.

MAORI EXPERIENCES OF MENTAL HEALTH SERVICES

Colonisation led to the imposition of Western medical practices on Maori. These were based on individualism and independence and economic rather than social or spiritual values. One Maori who had experienced mental illness said

I’d wake up in hospital and they’d say ‘We’re going to help you’. And I believed them. They didn’t ask me anything about who I was, where I came from, that kind of stuff. Just that they were going to help me.....I felt intimidated, suspicious and very much alone. But I also met people in hospital who I identified with and they always happened to be Pakeha. I had given up on being Maori, The shame thing. I didn’t want to be Maori. I don’t think there was even a Maori on the staff on my ward. That was a major hindrance to my cultural well-being.’ Fenton & Te Koutua (2000, p. 20-21).

Such experiences have been noted in government reports where policy changes have been signalled. The Mental Health Commission’s Blueprint for Mental Health Services in New Zealand (1998) noted that

The high Maori re-admission rates into hospitals attest to the fact that Maori needs are not being met and something dramatically different needs to happen. Accepting Maori concepts of healing and ensuring that service contracts are supportive of this are essential if

significant improvements in Maori mental health status are to be achieved. (p.58)

In the past decade some residential and community supports have been provided by and for Maori. In some inpatient wards, Maori staff now support Maori service users. Yet, of practising psychiatrists surveyed in 1999, more than half said their training did not prepare them to work effectively with Maori (Johnstone & Read, 2000).

NEW PARADIGM: MOVING TO A RECOVERY MODEL

Given that the pervasive medical paradigm underpinning the culture of mental health services is recognised as damaging, what is the vision for change?

Seedhouse (1988) believed a new paradigm in general health services was beginning to take effect, based on a belief that health is more than the absence of disease. In this paradigm, curing disease was important, but

not as important as creating and increasing the autonomy of people who request or need health care... and as respecting people's choices even if they conflict with given advice. (p. 9)

This was a vast shift in the understanding of the nature of health and removed it from the exclusive realm of applied scientists. If autonomy and choice were to be central to health services significant changes in relationships and practices were necessary.

Moves towards autonomy and recognition of the validity and importance of the patients' views are more problematic in the field of mental health. Because of what is seen as 'impaired mental status' service professionals working within the medical model may see users as lacking the ability to assess their own treatment adequately. In Aotearoa/New Zealand there is a growing consumer movement but so far it has been less visible than in the other disability and health areas. There have been notably fewer complaints about mental health than physical health services since the inception of the Health and Disability Services Consumer Rights Act (1994) (website: www.knowledge-basket.co.nz/hdc).

Marsh et al (1999) saw mental health services as needing to be committed to a recovery model. This would develop "a person-driven system that can meet the essential needs of people with mental illness – as they perceive them – in their communities" (p. 358). They envisaged a paradigm shift in professional practice from a disease based model to a health based development model; from a view of a person as mentally ill to one of a person with a disability, from the goal of intervention being treatment to a goal of recovery; from professionals as practitioners to professionals as consultants; from an authoritarian service to an educational service. Such practices are sometimes termed 'strengths' or 'resiliency' models, but are more commonly linked with a recovery model, based on the concepts of partnership and participation.

There are signs that a paradigm shift towards such models is occurring, signalled by government legislation such as the Health and Disability Commissioner Act (1994), which limited professional power and supported the rights of health consumers to full information and decision making. Within the mental health field this power is still limited by the right of professionals to insist on treatment where there is (in the eyes of the professionals) significant danger to the person who is unwell or to others.

In allied fields, there are some models of how this new paradigm may be applied. Within social work the 'anti-oppressive practice' approach focused on creating a relationship that maximised the autonomy of service users. Empathy and power sharing were central (Dominelli, 1998). Practitioners needed to understand how power operated within social relations, and apply the principles of egalitarianism in the relationships with their 'clients'. In counselling, narrative therapy (Parton & O'Bryne, 2000) builds on people's stories in an empowering and respectful way to help them re-author their lives to bring about change.

Yet pure egalitarian relations are acknowledged as unreachable in relationships between professionals and clients. Dominelli (1998) noted "the best that can be achieved is a lowering of the power imbalance through a continual process of identifying the sources of power differentials and eliminating as many of these as possible". (p. 9)

Approaches that increased autonomy and reduced the distance put by the medical model between staff and people with experience of mental illness were endorsed by Deegan (1997), a service user and professional. She wrote

...the hard part is daring to be bold and brave enough to step out from behind our professional façade and to allow our hearts and minds to be touched, broken open and moved to compassion by the strength, courage and fiercely tenacious spirits of people with psychiatric disabilities as well as the suffering, poverty and injustice that people labelled with mental illness experience. (p. 13)

She advocated putting the 'human' back into human services, noting that power was not finite but could be created when staff allowed themselves to be vulnerable and moved by the suffering of those they supported. Wadsworth & Epstein (1996) noted that a 'culture of busyness' made real communication rare. "You tell your story and somebody makes a decision about you and you're shunted off" (p.67).

Research supported this approach as good for recovery. Barnes (1999) wrote that in settings as diverse as inpatient services and community care, staff-user relationships characterised by low distance (with staff joining service users in activities) resulted in "good mental health outcomes and increased user involvement". (p. 410)

These approaches all centre on enabling the perspectives of service users to be acknowledged and validated. The historical silence imposed by the medical paradigm gives way to an acknowledgement that the voice of service users must be heard, both in the individual relationships between people and their health professionals and in management and policy decisions.

In this new paradigm premised on western individualism, personal autonomy is central to health care. This does not fit easily with Maori views of the importance of whanau. Criticism has been made of the privacy legislation on these grounds (Selby, 1995). O'Hagan (2001) pointed to the need to acknowledge the potential influence

and importance of whanau and communities to support recovery in Aotearoa/New Zealand.

Discrimination against people with experience of mental illness is now the focus of a major public health campaign in Aotearoa/New Zealand. The five year Project to Counter Stigma and Discrimination associated with Mental Illness, (known as Like Minds, Like Mine, Like Mine), was initiated in 1996, by the then Health Funding Authority with an initial allocation of \$10.4 million. The project, now jointly managed by Public Health and Mental Health for the Ministry of Health has been extended to 2003. Its vision was to 'work towards creating a nation that values and includes people with mental illness' (Like Minds, Like Mine, National Plan, May 1999).

National strategies link with community based projects, such as those of my employer, the Serious Fun 'N Mind Trust, which aims to achieve sustained respect for people with experience of mental illness.

The origin of this campaign goes back to the 1996 report of the government inquiry into mental health services (Mason, Johnston, & Crowe). A chapter was devoted to the difficulties caused by sensationalist media coverage and the need for a public education campaign to counter discrimination in the community. This was followed in 1998 by the Mental Health Commission's Blueprint for Mental Health Services, which delineated the problem of discrimination within services based on the medical paradigm.

It is widely acknowledged that discrimination generated by the mental health sector against people using services is a major issue.... At all levels, discrimination leads to decision-making by the workforce without the involvement of service users. At the individual level, service users often complain that mental health workers fail to give them respect, protection of rights and equality.

It is almost inevitable that when people experience discrimination from others, they will internalise the messages they are given, The mental health workforce must recognise this, and develop a recovery

approach that gives service users hope, a sense of self-worth, and a sense of belonging. (p.19)

The driving force behind changes in this country has been the Mental Health Commission, set up in response to the recommendations of the government's 1996 "Inquiry Under Section 47 of the Health and Disability Services Act 1993 in Respect of Certain Mental Health Services" (commonly known as the Mason Report). Established as a Crown entity in 1998 the Commission's role was to ensure the implementation of the National Mental Health Strategy by monitoring and reporting on the performance of key agencies.

In 1998 the Mental Health Commission published a "Travel guide for people on the journeys towards equality, respect and rights for people who experience mental illness". One section was devoted to ways to move towards a health sector that "values people with mental illness and treats them fairly". Some actions advocated were to:

- Raise awareness of the harmful effects of some standard health practices and systems on mental health.
- Dissolving the 'them and us' attitude.
- Train workers in the kaupapa of zero tolerance of discrimination.
- Ensure that the relationship between service users/people with experience of mental illness and workers in mental health services is one of equality, respect and power.
- Have people with mental illness involved in mental health workforce recruitment, selection, performance appraisal, education and training. (p. 16/17)

Towards the end of this research the Commission also published (2001) a set of Recovery Competencies for staff of mental health services, compiled by Mary O'Hagan. Recovery is defined in the Blueprint as the ability to live well in the presence or absence of one's mental illness. Mary O'Hagan wrote that the recovery approach for people with major mental illness came from the United States and has three main sources: the generic recovery or self-help movement; the mental health

service user movement, and psychiatric rehabilitation focussing on community integration. She added that

This vision comes out of the United States and is more individualistic and monocultural than many New Zealanders feel comfortable with....the competencies in this paper are...an attempt to redefine recovery for the contemporary New Zealand context. (p.2)

The competencies for mental health staff included demonstrating:

...an understanding of discrimination by the health workforce.
including

...an understanding of discrimination in the management of services
eg. weak consumer participation, lack of a complaints procedure.

and

...an understanding of one-to-one discrimination eg. derogatory or incomprehensible language, controlling behaviour, paternalistic attitudes, neglect, abuse. (p. 55)

The leadership of the Commission reinforced the Ministry of Health policies and protocols such as the National Mental Health Standards (1997) and Guidelines for Consumer Participation (1995).

Another visible sign of change has been in language. In many movements against oppression the right to name ones own group has been a symbol of growing assertion. As de Bono (1985) wrote

Words come to be laden with emotional values and once so laden can never be cleansed. Words are a living accumulation of our history and through them we become trapped in idioms which are long past their usefulness. (p.69)

'Niggers' became 'blacks' and 'African Americans'; 'girls' became 'women', 'handicapped' became 'disabled'. In the field of mental illness, the changes have been from 'patients' to 'clients' to 'consumers', with most changes spearheaded by professionals or managers. In Britain the term 'service user' or 'user' is common.

In Aotearoa/New Zealand, people with experience of mental illness in the 1990s used the term 'psychiatric survivors'. More recently concerns have been voiced about the use of the term 'consumer', which implies a passive role and choice of service - a privilege almost unknown, except by those who can afford private care. A term that gained increasing usage during the course of this study was 'tangata whai ora'. Suggested by Professor Mason Durie, it can be translated as 'people seeking wellness', emphasising the active role people play in their own recovery.

Yet some service users (Deegan, 1997) and other researchers (Shera & Delva-Tauiliili, 1996) have pointed out that changes in the names we call one another, from doctors and patients, to staff and clients, to providers and consumers, have yet to change the fundamental relationship between those labelled with mental illness and those who are not. This relationship "...has remained essentially unchanged for centuries" (Deegan, p.13).

In the United States, Deegan (1997) saw only surface changes over the past decades, writing that changing systems, language, reallocating funds and moving to community based models was the 'easy part'. She noted that real change was quite uncomfortable and we may content ourselves with superficial change. In Aotearoa/New Zealand Mental Health Commissioner, Julie Leibrich (1998), echoed her concerns, seeing discriminatory behaviour in the semantic games,

playing with words so you avoid dealing with something. It is about renaming and renaming something rather than confronting the underlying problem. (p. 6)

Sayce (2000) echoed the need for change to affect relationships, not just the language, method and site of services.

...we are quick to spot recent changes in mental health policy and practice, such as hospital closure programmes. It is harder to notice the deep continuities of belief, and treatment of users - although it is often apparent to users. ...In 20 years' time, the continuities will be more apparent. It will be clear that by 2000, we had changed the place and organisation of services and opened up some new

opportunities, but not effectively challenged the whole notion that people with mental health problems are inferior. (pp. 77-78)

THE ROLE OF TRAINING

Even when supported by government policy, changes to the culture of mental health services so that they support recovery will require sustained effort on a number of fronts. Braye and Preston-Shoot (1995) called for management styles which were democratic rather than autocratic, user involvement in planning, and a culture in which power was recognised and feedback on how it was used was permitted and encouraged. Part of the change would come through training of staff and students, but to be effective training must be accompanied by structural and cultural changes to cement in desired behaviours.

Training should be broader than a focus on skill development, to include a staff and organizational development approach, where agency policies and strategies are connected directly to individual and group learning needs. Equally knowledge and skills from training will wither if not linked to an empowering agency culture containing, inter alia, supervision, teamwork and appraisal. (p. 172)

The 2001-3 Like Minds, Like Mine, Like Mine national plan advocated a rights-based approach to change involving the enforcement of sanctions against discriminatory behaviour, accompanied by workplace training to help people understand why legal provisions are in force.

This was in keeping with the findings of positivist attitude change research that pointed to the importance of context. After years of controversy over the attitude-behaviour relationship most researchers now agreed that behaviours did not always reflect attitudes and the social context surrounding the behaviour was important (Allport, 1954). Someone may act positively towards people with experience of mental illness in one setting, but act differently when among peers who shun people with experience of mental illness.

Changes in policies and procedures necessary for cultural change within organisations was clearly beyond the scope of this research, which focussed only on the effectiveness of a five hour workshop, a small part of the whole picture. This thesis aimed to discover how to make staff education as effective as possible, so their practices are consistent with a recovery model.

Barnes (1999) recommended that education developed students' understandings of the meanings of discriminatory social relations for mental distress. Like Deegan (1997), she suggested it was important for students to have the opportunity to dialogue with service users to open the door for students to be moved, motivating real commitment to work for the service user.

The acknowledgement of the voice of people with experience of mental illness as not just valid but essential to good health care is beginning. Recent government policies have encouraged the employment of consumer advisers within tertiary mental health services with the aim of influencing management and policy decisions. However the voice of people with experience of mental illness is rarely heard in the training of mental health support workers and clinicians. Only occasionally is someone with an experience of mental illness invited to speak to staff or students. This often remains a token input (perhaps a couple of hours for every 10 weeks of training), without payment.

The level of stigma and discrimination within the mental health field and community in general has been so high that few people with experience of mental illness, on becoming well enough to work, wish to remain in the mental health field. Many learn to cope with their illness, renew their former lives, careers and parenting commitments and rarely acknowledge their mental illness to themselves or others. Others build on their experience and work in mental health services but do not divulge their own history of illness.

With the media advertisements in 2000 raising the visibility of the Like Minds, Like Mine movement, more people are beginning to acknowledge their tangata whai ora

status, whether publishing articles and books about their experiences, attending courses in public speaking or offering to facilitate courses for other people with experience of mental illness and for mental health services.

A long-term goal of some people with experience of mental illness supporting the Bay of Plenty project has been to become key facilitators of training of mental health service staff, although this goal was challenged during this study (see Chapter Four). This goal appears achievable.

A first step to the goal was to develop a five-hour workshop facilitated by people with experience of mental illness. This would enable their voice to be heard and demonstrate their ability to play an important role in staff development. The one-day workshop central to this research represented this first step, and its development is the subject of following chapters.

Chapter Two summarises the main learning from the initial literature search on learning, attitude change and initiatives in anti-discrimination education that informed the first workshop of this study. Chapter Three delineates the research techniques used. Chapter Four details the learning that resulted from the observation and reflection on the workshops and their subsequent redesign, and the results of further literature searches that were carried out. Chapter Five reflects on the second workshop and plans for the future, as well as the wider implications of ideas and reflections that have come about during this process.

CHAPTER TWO: LEARNING AND SOCIAL CHANGE

INTRODUCTION

There are a number of social and psychological studies that can inform the design of workshops to reduce discrimination. Some which informed the development of the early workshops, trialled before this study began in 2000, were:

- Theories of adult learning, particularly those of experiential learning and critical reflection for adult students and professionals.
- The role of workshops and learning in movements for social change.
- Theories of attitude formation and change and the relationship of attitudes to behaviours.
- Experiences of anti-racism workshops aimed to reduce discrimination.
- Reflections on the centrality of discourse in establishing and sustaining discrimination.
- Reflections on the effect of facilitator identity on workshop effectiveness.

This chapter will examine each of these in turn. Literature searches were also carried out before the first workshop included in this study and after each workshop was evaluated. These informed analysis and raised new questions. These findings are integrated into Chapter 4.

ADULT LEARNING

A central debate in western education circles has been the role of the teacher or facilitator in learning. In traditional societies learning focussed on acquiring the outlook, knowledge and skills necessary to perform well-established roles and customs. Learning was confined to preserving ways of knowing, and the continuation of culture. As western academic education evolved, indirect knowledge was transmitted by teachers. Within formal education settings student participation was often confined to following lectures and answering questions. These forms of learning

have been challenged by experiential learning theorists who advocate techniques closer to the meaning of the Latin origins of the word 'education': 'educare'. This is literally translated as 'to bring out of' or 'to lead forth'.

Andragogy was a term proposed for the study of adult education back in the 1960s (Merriam 2001, p.5) with five assumptions about adult learners underlying it:

1. They had independent self-concepts and could direct their own learning
2. They had accumulated a reservoir of life experiences that were a rich resource for learning
3. Their learning needs were closely related to their changing social roles
4. They were problem centred and interested in immediate application of knowledge and
5. They were motivated to learn by internal rather than external factors.

The first four seemed to have held true for most of the participants on our workshops although the fifth was less clear, and by the second workshop, which was compulsory for some participants, clearly not all participants were self- motivated.

A major stream of adult education research has been that of experiential education which was based on the understanding that learning was by nature autonomous. No one can learn for someone else. To learn was "to come to understand something or to acquire a skill, either of which is retained by practice or rehearsal" (Heron, 1993, p.14). All learning was re-learning, for no one came to education as a blank slate, but with a wealth of experience, (Kolb, 1984). Learning occurred and knowledge was created when, through new experiences or information, previous knowledge was reassessed and changed.

This did not deny the legitimacy of educational authority, for knowledge and skills could be passed on. Facilitators could offer alternative perspectives, different concepts and frames with which to view the world, help people name realities not visible within the dominant discourse, and contribute stories of how others have operated within power constraints. Carefully crafted questions could support the search for meaning of experiences. The challenge for teachers was to bring their own

perspective and facilitate learning without dominating, using their authority to promote student autonomy.

The ideas of experiential learning have spread widely through western education circles. Weil and McGill (1989) saw four areas in which experiential learning theory informed practices:

1. Assessing and accrediting learning from life and work experience.
2. For group consciousness raising, community action and social change.
3. Bringing about change in structures and techniques used in adult education.
4. For personal growth and development and group effectiveness.

The second and third areas are relevant in this study as they have been used to support professionals who bring a wealth of experience to workshops, to reflect on and change their work practices.

EDUCATION AND SOCIAL CHANGE

All learning has consequences for society as well as for individuals, whether acquired in education institutions or through daily life. People live in social networks, their learning and behaviour affecting their interactions with others. Several commentators have seen education as a system of social control in societies characterised by relations of power and domination (Freire, 1972 & Illich, 1977). The traditional 'banking' approach to education reinforced this control with learners viewed as empty vessels, there to absorb knowledge that would fit them for their roles in society.

Freire worked to support people from oppressed and marginalised groups to understand their oppression and take action to transform their world. (Freire, 1972). This he termed liberating education, education that emphasised participation and dialogue. Freire used the term *praxis* for the process whereby learners were distanced from their world in order to view it in a new and more critical light.

Knowledge was not an independent entity that could be given to someone. Instead it was continually created and recreated by each learner. In problem posing experiential education, teachers gave up some of the power of their position to become facilitators or 'animators', raising questions for participants who actively described their situations, analysed them and planned action.

Through such processes people became disenchanted with the old ways and more willing to change. Alinsky (1971), in his manual for social change, saw revolution as needing to be preceded by reformation. People would be motivated to change by becoming aware of the problems in the prevailing system.

Freire's early work (1970) was based on non-formal education of the oppressed in South America, but his later work (1987) was applied in new social movements in western societies. Throughout, his focus was on the oppressed, groups that had been marginalised. This study however, focuses on people who work for and represent 'oppressors', for mental health services are seen as a site of discrimination. In spite of this different focus, Freire's educational approach, which supported people to reflect on and analyse their own situation and role, is useful for both the group holding power and those seeking to increase their power in a movement for social change, as it supports individuals to reflect on their role in resisting or promoting social and organisational change.

Yet some difference in approach may be necessary to ensure effectiveness when working with the group that holds the greater power. Rather than supporting people to understand their own oppression, the aim is to make visible how people's actions may oppress others, to help them empathise with the group that is oppressed. Whereas an oppressed group can see direct personal benefit in changing their behaviours in order to liberate themselves from oppression, behaviour changes by people in power may not bring direct personal benefit. This may be especially true where management does not support changes. Only where managers support the new paradigm will new behaviours of participants be welcomed and rewarded in their workplaces.

A useful overview of forces that work for social change was put forward by Gladwell (2000). His central thesis was that ideas, products, messages and behaviours spread like viruses. He studied both social change and epidemics of disease and found three 'agents of change' in common which he named as follows:

1. The Law of the Few. Social 'epidemics' were driven by a handful of exceptional people who were energetic, influential and willing to take risks. Some were connectors, bringing people together; others acted as 'mavens': gathering and spreading information. Yet a third kind were salesmen with energy, enthusiasm, charm, and optimism.
2. The Stickiness Factor. People promoting new ideas often looked for ways to reach people with messages but it was even more important that messages stuck in people's minds. Advertisers used catchy tunes or coupons that people had to fill out; public health educators needed to give instructions and aids to make new behaviours easier to perform.
3. The Power of Context. Epidemics were very sensitive to conditions and circumstances. Specific situations were so powerful they overwhelmed people's inherent predispositions, values, and upbringing. Even fundamental characteristics such as honesty varied according to circumstances. For example, people studying religion more often ignored someone in need when they were in a hurry. Although people's individual characters, habits, interests, were important they were hugely influenced by context (p.160). Small environmental changes could make a big difference to behaviours.

There are some useful messages here for anti-discrimination work in organisations:

- Cultural change may be hastened with the 'buy-in' of a few key people (not necessarily those in power but those who are respected or central to networks).
- Key messages of workshops must be 'sticky' in order to be retained.
- The context of work practices (policies and procedures, performance appraisals and the like) needed to be changed in line with new learning.

EXPERIENTIAL LEARNING

Most workshops aimed at social and cultural change used experiential learning techniques involving active participation by learners. Kolb's early work (1984) on experiential learning and further work by Heron (1993) pointed to the importance of reflection also being central in workshops. In its broadest sense, experiential learning arose from first hand direct experience. Participants personally encountered people or places or things that were relevant. Within workshops this may happen either literally or symbolically, through structured classroom based experiences. Encounters could be immediate, or recalled from past personal experience. Reflection on experiences turned them into learning.

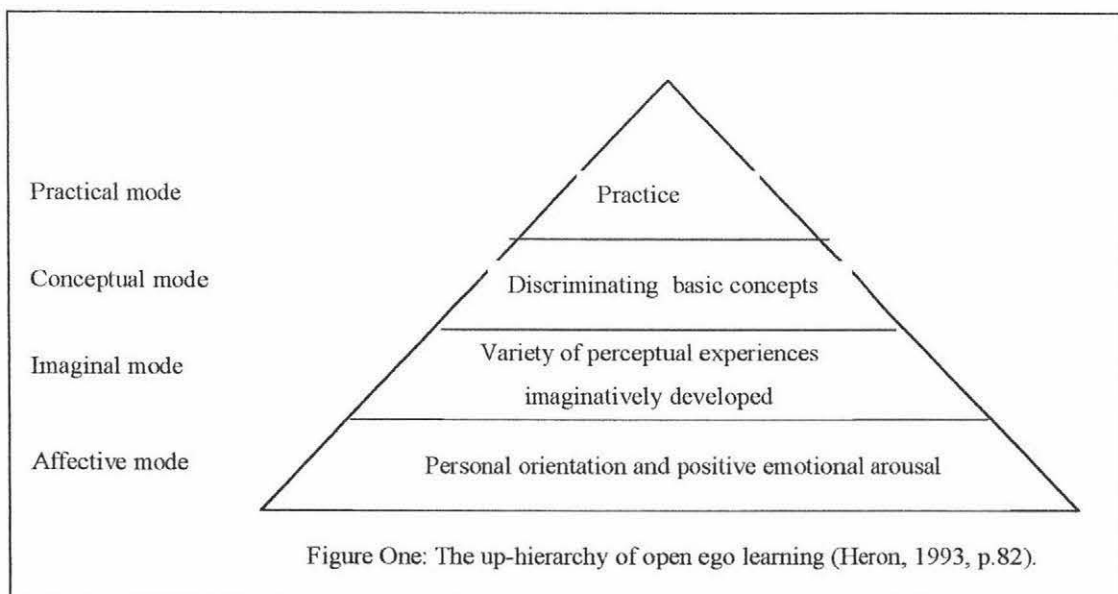
Kolb (1984) developed early experiential learning theory. He recorded that he was influenced by the work of Dewey, Lewin and Piaget, who all challenged the traditional way knowledge was thought to be transmitted. Dewey showed how education, work and personal development could be integrated, and stressed the value of experience as a source of knowledge. Through humanist psychologists such as Jung, subjective experience came to be valued and Lewin worked with these ideas in early action research; and Piaget's work on cognitive development pointed to the value of experience. Erikson extended Piaget's approach to children's learning and showed the influence of environment on adults. Learning came to be understood as a life-long process.

Building on the work of these theorists, Kolb (1984) developed education techniques based on the way people learn from experience. He advocated a four stage learning cycle as the basic educational structure. Concrete experiences were followed by reflective observation, leading to abstract conceptualization and then active experimentation with new modes of experience. Each stage promoted different abilities – behavioural, affective, symbolic and perceptual. Learning took place as knowledge was actively transformed within this cycle with the reflective stage seen as critical (Schon, 1987, Boud, 1985, & Freire, 1970).

Taking time to reflect on one's practice is increasingly important for professionals. Once seen as unquestioned authorities in their field, professionals now often face criticism and blame for mistakes, ineffectiveness and impropriety. Much professional education and practice used to be grounded solely in systematic scientific knowledge. In contrast, an experiential learning theorist, Schon (1987), saw effective professionals, whether engineers or clinicians, needing skills to make decisions in situations of uncertainty and in the face of conflicting demands. Schon promoted 'reflection in action' for all professionals: a process he saw as artistry rather than a scientific process.

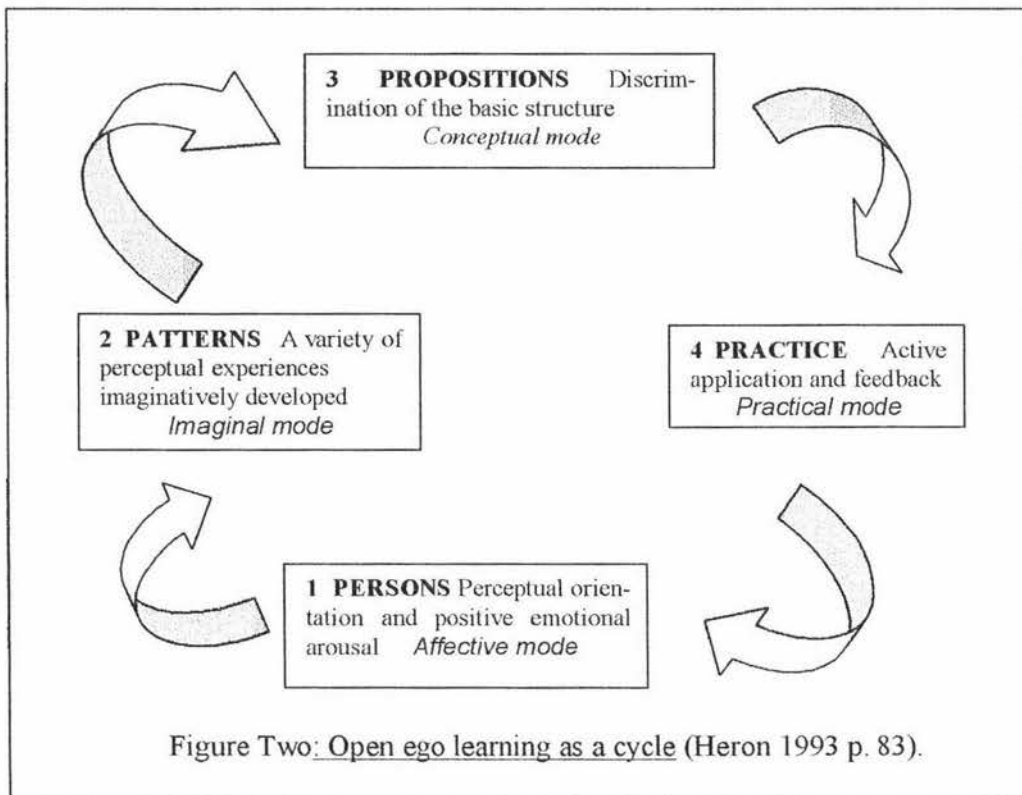
However the skill of reflection is not yet central in the education of health professionals. Boyle (1994) noted nursing students on practice experienced discomfort as they knowingly participated in "care which can best be described as routinised, desensitized, habitualised" (p. 154). Due to a lack of emphasis on reflection and autonomy in their education, they were not prepared to effectively deal with such situations.

A particularly useful model of experiential learning is that developed by Heron (below). In a four-stage 'up-hierarchy' model of experiential learning, that he termed 'open ego learning', the more deeply each stage was entered into, the more it enriched and empowered subsequent ones. Our psyches were grounded in feeling



and from them emerged our imagination, memory and perception. Based on these were the domains of thought and language (conceptual mode) and then the practical modes of intention and action.

Open ego learning was a first step toward full blown holistic learning, which involved intuition and reflection and deeper levels of the psyche. Developing the up-hierarchy into a learning cycle, Heron showed how it could be used to incorporate the stages into workshops.



1 **Persons** referred to the “grounding importance of conscious feeling” (Heron, 1993, p.87), about acquaintance, empathy and attunement, a pre-condition of all experience. Heron saw this as a spiritual stage as the person opens up, acknowledging the transcendental self. Learning occurred when, “emotionally engaged I can notice that what I perceive is discrepant from my conceptual models so I modify my actions” (Heron, 1993, p.87). In workshops this encompassed orientation and physical and

mental relaxation exercises that helped participants attain a positive emotional attitude to learning and resolved the negative emotions that obstructed learning

2 **Patterns** inter-wove and combined perception, memory and imagination. Heron (1993) noted that too often in Western culture facilitators went straight for conceptual content and left out the essential creative imagination. In a workshop setting this might involve a wide range of images, stories, songs that illustrate ideas using techniques such as role play, stories, analogy, sound, graphics etc.

3 **Propositions** refers to the more commonly used experiential technique of reflection. In workshops this might involve using questions and discussion to raise issues and tease out problems.

4 **Practice** was the action part of the cycle. In a workshop this might involve looking at the practical implications of learning and making action plans. Within this part of the workshop there was often a secondary cycle, as what was being experienced affected the learner, was taken in and processed.

Heron also recommended using multi-perceptual techniques. What had been termed 'superlearning', emphasised techniques appealing to sight, hearing and kinaesthetic senses, encouraged relaxation and increased indirect learning.

After researching these techniques and processes of experiential learning underpinning the design of the Trust's workshops, my attention turned to literature on attitude and behaviour change.

ATTITUDE CHANGE

A large body of positivist research in social psychology also proved useful in the design of workshops. There remain heated debates in this field (Olson & Zanna, 1993) but some common ground and useful insights are to be found. Early research on university students concentrated on quantitative studies of attitudes. An attitude was an 'evaluative state of mind towards some object' (Fishbein & Azjen, 1975) and was a product of people's thinking (cognition), emotion (affect) and action (behaviours). It

was hoped that through influencing people's attitudes, behavioural changes would result. Various strands of attitude research evolved that have relevance to this study:

1. Personality research (Adorno, Frenkel-Brunswick, Levinson, & Sanford, 1950) examined the personalities and childhood experiences of people whose attitudes were measured as prejudiced, aiming to discover why some people were attracted to democracy and others to fascism. They found that people with authoritarian personalities were more likely to be fascist. This allowed for variability of individuals but made prejudice pathological. Yet racism and stigma and discrimination associated with mental illness are based on widely accepted beliefs. This approach did not account for prejudices held by people who may not be authoritarian, prejudices that may manifest as 'benevolent' paternalism.
2. Cognitive dissonance research looked at how people gained information and developed ideas or beliefs about the attitude object. Festinger, (1957, cited in Eagly & Chaiken 1992, p. 505) researched the idea that people tended to approach and attend to information that upheld their attitudes and beliefs but avoided or paid little attention to conflicting information. Cognitive dissonance theory showed people reluctant to advocate a view that violated their own attitudes unless they were motivated by a strong inducement.
3. Attitude change. Research by Brehm & Cohen (1962, cited in Eagly & Chaiken, 1992, p. 582) showed that strong attitudes were resistant to change; and attitudes became stronger and more resistant to change to the extent that people engaged in behaviour that linked them to their existing attitudinal position (Keisler, 1971, cited in Eagly & Chaiken, 1992, p.582). Other researchers (Cooper & Fazio 1984, cited in Eagly & Chaiken, 1992, p.677), have shown attitude change following dissonance more strongly in situations where subjects took responsibility for bringing about an unwanted consequence. They hypothesised that the 'good person-bad deed' inconsistency made people uncomfortable and induced them to change their attitude.

4. The complexity of motivations. Early research looking at how attitudes affect behaviour was challenged by Fishbein & Azjen (1975), who showed that attitudes were not the only precursors or predictors of behaviour. More complex cognitive representations and processes, including beliefs, intentions and goals, interacted with attitudes in the planning and execution of actions. For example, researchers in the 1980s (Dovidio et al., 1989, cited in Olson & Zanna, 1993) demonstrated that beliefs in fairness and equality may restrain people who espouse racist attitudes from overtly racist behaviours. Only when they could be rationalised, did negative behaviours emerge. An example can be seen in the paternalism rife in the field of mental illness, justified by the belief that an experience of mental illness leaves people unable to make good decisions.
5. Behaviour change preceded attitude change. Eagly & Chaiken (1992) acknowledged the relationship between attitudes and behaviour was more complex than had previously been recognised, identifying habits, self-identity and norms as also influencing behaviours. They also reported on studies showing that behavioural change often preceded attitude change. Although a person may feel negative towards someone, their behaviour might be positive because of other factors (perhaps the person is their employer, or legislation and policies prohibiting discrimination may be enforced). Over time attitudes changed to conform to their behaviours. This was in accord with Gladwell's (2000) 'Law of Context' and also underpinned the rights based approach in the Like Minds, Like Mine movement, which promoted policies, procedures and laws to enforce non-discriminatory behaviours. Current recommendations are that these approaches still need to be supplemented by education to help people understand why policies have been put in place (Like Minds, Like Mine, Like Mine national plan 2001 p.6).
6. Role playing and attitude change. Arising from the idea that behaviour change could precede attitude change came studies that measured the attitudes of subjects after they either advocated for a position themselves or listened to someone else advocating for a position. Results showed that communicating a position oneself, rather than listening to someone else do so, was the more

effective way to change attitudes (Janis & King, 1954, cited in Eagly & Chaiken, 1992, p.501).

As well as pointing to a need for organisations holding workshops to be concurrently reviewing their policies and procedures, the understanding that behaviour change often comes prior to attitude change also has implications for workshop design. It would be helpful for participants to have opportunities to behave in ways congruent with the new paradigm during the workshop, through techniques such as role-play or group discussions where they can advocate new ideas. This pointed to the need to use experiential learning techniques that involved not only reflection on previous experience but also practical demonstration of new values, discourse and behaviours. This approach was also confirmed by my personal experiences and literature in anti-racism education.

LESSONS FROM ANTI-RACISM EDUCATION

A study by the International Labour Organisation (1999) examined the effectiveness of one day workshops aimed at achieving equality for migrant and ethnic minority workers in Europe. It looked at workshops solely providing information; ones aimed at attitude change; and ones focussed on behaviour change through compliance with policies and regulations. It was found that workshops concentrating on giving information on different cultural characteristics appeared to act to confirm stereotypes. The International Labour Organisation report (1999) suggested cultural information also needed to emphasise characteristics different cultural groups have in common. The findings were supported by Dominelli (1997) who noted that such approaches focussed attention on ethnic minorities and their communities rather than on white people and their power structures.

Notably participants attending workshops centred on attitude change left feeling frustrated and powerless to change the phenomenon of discrimination in their daily work. While they recognised that discrimination was a problem they had not been provided with the tools to resolve it. This finding echoed the earlier critique of

Katz's Racism Awareness Training (1978) by Dominelli (1997, p.18), as having failed to root racism within a patriarchal capitalist society; and having created an end product of paralysing guilt rather than a spur to action. Maximum effectiveness, according to the ILO study, resulted when this spur to action was provided, in workshops that aimed at behavioural change and offered concrete and practical guidelines.

THE CENTRALITY OF DISCOURSE

Experience may be the basis of learning but the language describing experiences frames them. Language closely mirrors power relations so people can become trapped within the dominant paradigm and see no other ways of being. Discourse creates stigma through 'commonsense' understandings: widespread beliefs and attributions. In the area of stigma and discrimination associated with mental illness beliefs and attributions such as the linking of violence and mental illness are used to justify the marginalisation of people with experience of mental illness. Assumptions that are so widespread in a community that they become 'commonsense', work invisibly to lead people to interpret the world in certain ways, blinding them to the reality of how power works. For example, the term, 'mental illness' and linked beliefs (such as unpredictability) that accompany the label lead to assumptions that someone shouting angrily is doing so as a result of their illness rather than as a natural response to disempowerment.

The concept of discourse embodies the notion that language is not only a means of communication of facts and feelings, but also of ideology: the choice of particular words and phrases structures expectations and aspirations, and frames what is legitimate to think and to do (Boud & Miller 1996, p 19).

For example, many people believe democracy enables all citizens to have an equal voice. This belief may lead them to deny forces acting to silence oppressed groups in democratic societies. In such ways discourse may establish, sustain and reinforce oppressive relationships.

Another theorist, Fairclough (1989), noted that

Ideology works when its workings are least visible. If one becomes aware that a particular aspect of common sense is sustaining power inequalities at one's expense, it ceases to be commonsense and may cease to have its capacity to sustain power inequalities, that is, to function ideologically. (p.85)

Power as evident in discourse is fragmented and dispersed, seen in acts of resistance as well as in rituals of the powerful. In psychiatry (Foucault, 1973) the rituals of power were used to regulate and categorise, assess and observe people, defining what was 'normal' behaviour. Ideas expressed in discourse also worked on the minds of the oppressed, persuading people that their interests coincided with the powerful, encouraging subservience (Illich, 1976, & Breggin, 1991).

DISCOURSE AND RACISM

Wetherell and Potter (1992) examined the way discourse was used in discrimination in Aotearoa/New Zealand, interviewing Pakeha on issues of race. They tracked the twists and turns of argument and showed the construct of 'attitude' may itself be an illusion, with variations in the 'attitudes' espoused by people, even within the space of one conversation. They noted how discourse had a number of functions such as disclaiming, justifying or blaming. Words used varied in meaning and implication (e.g. 'immigrant'), as did the context in which people used language.

Their research affirmed the subtlety and ambiguity of racism as people used arguments to justify sometimes contradictory stances. Anti-racist arguments can be meshed together with support for racist policies; an argument mobilized in one direction only to veer back on itself.

Unlike the positivist psychologists' view of discourse as a symptom of prejudice located in individuals, and prejudice as an error of judgment, postmodernist discourse

structure within which struggles arose, through analysing the effects of the discourse that legitimated it and basing anti-discrimination practice on small struggles related to specific issues.

This literature was useful in pointing to the centrality of discourse and need for workshops to examine the language we use daily, how it reflects the use of power in mental health services and its implications for practices, language and behaviour.

WHO SPEAKS FOR WHOM

What you do speaks to me so loudly that I cannot hear what you are saying

- Quaker saying

Not only what is spoken but also who may speak is an issue of power. There has been a growing service user movement among people with experience of mental illness that began with self-advocacy and self-help groups. Now there is also service user involvement in the Like Minds, Like Mine project to counter stigma and discrimination, with a national advisory group to the project and individuals involved in actions throughout the country. There are also consumer advisers in many secondary mental health services and a few individual consultants working as trainers, evaluators, and advisers to services.

The often-used slogan 'nothing about us without us' was the title of a book by James Charlton (1998). He saw this slogan as encapsulating the source of oppression in emphasising issues of control and voice. He quoted Ed Roberts, a leading figure of the disability rights movement, saying "when others speak for you, you lose" (p. 4).

People with experience of mental illness who were advisers to the Trust, and who formed the reference group for this study, wished to facilitate workshops for mental health service staff themselves. This would give them a platform to be heard and model the changes they were advocating: that staff in mental health services should

listen to the voice of those they support. It would turn the common power dynamic of 'patient' and staff on its head.

This pattern of people who have been hurt by discrimination expressing this in workshops for the group that have perpetrated the discrimination is usual in the disability rights movement, where there is an intrinsically and inextricably close relationship between service user and the service provider. It differs from some practices in anti-discrimination workshops in the area of racism, where some practitioners prefer members of the group that perpetrates discrimination to facilitate workshops for other members of their own group. There are a variety of practices in the field of anti-racism and these are examined in Chapter Four, as part of a detailed inquiry that arose after the facilitation of workshops by people with experience of mental illness was challenged.

Research suggested that the voice of people with experience of mental illness was effective in promoting change. Studies on ways to reduce prejudice have often focussed on contact with members of a stigmatised group. This did not always produce positive attitude change. However evidence showed contact was beneficial where both groups cooperated and had equal status (Olson & Zanna, 1993) and had the opportunity to get to know one another (Desforges, Lord, Ramsey, Mason, Van Leeuwen, & West, 1991).

Shera & Delva-Tauiiili (1996) confirmed this finding with studies of social work students' attitudes before and after sessions of structured contact with someone described as mentally ill.

Many researchers now feel that structured contact with 'mentally ill persons', which emphasizes their strengths and allows them to educate the non-mentally ill person, is critical to long-term generalisable attitude change towards the severely mentally ill. (p. 161)

Interaction with a 'former mental patient', studied by Dansereau (1988, cited in Olson & Zanna, p.145), showed an increase in favourable attitudes among initially prejudiced subjects. This research however may not be generalisable to this study as it

was based on contact between people new to the field of mental illness who mostly had little prior contact with people with experience of mental illness. Here the focus is on mental health service staff who all have frequent and on-going contact with people with experience of mental illness, some for many years.

Frequent contact is central in the relationship between people with experience of mental illness and mental health service staff when they are unwell, although distance is maintained through professional boundaries. However staff interaction with people who have experienced mental illness but are currently in a state of wellness is less common and may help to reduce stigma and discrimination. Many staff in mental health services see people only when they are unwell, adding to the strength of stereotypes.

To conclude, this initial literature review informed workshop plans in the following ways:

Table One: Issues arising from the initial literature review		
	Issue	Considerations
1	Adult learning theory	Ensure there is application to practice
2	Experiential learning cycle and importance of reflection	Allow for stages of the cycle. Plan plenty of time for reflection.
3	Attitude formation: behaviour change can precede attitude change	Include opportunities for positive behaviours to manifest during workshop
4	Centrality of discourse	Make explicit the links between language and discrimination
5	The role of people with experience of mental illness in the workshops	People with experience of mental illness to facilitate, but check the safety and effectiveness of this decision

CHAPTER THREE: METHODOLOGY

INTRODUCTION

Looking to improve practices in education aimed at reducing discrimination, the action research paradigm immediately appealed to me as it offered a pragmatic approach inherently linked to action. Reinharz (1992) defined action research as research where action and evaluation proceeded simultaneously, and emphasised the potential of such research to change the researcher. A widely used definition (Henry & McTaggart, 1996), was

Action research is a form of collective self-reflective enquiry undertaken by participants in a social situation in order to improve the rationality, coherence, satisfactoriness and justice of their own social (or educational) practices as well as their understanding of these practices and the situations and society in which these practices are carried out. Groups typically have a variety of participants brought together by a shared concern. The approach is only action research when it is collaborative, though it is important to realise that the action research of the group is achieved through the critically examined action of individual group members. (p.7)

In contrast to much positivist research, action research does not attempt to identify one particular concern and study it in isolation, removed from its context and from the social and political constraints that surround it. It is flexible and holistic.

Action research is also situational. Knowledge gained through the collaboration of researchers, practitioners and significant others is applied to practical problem solving. Burns (1990) wrote

It aims to improve practical judgment in concrete situations, and the validity of the 'theories' it generates depends not so much on 'scientific' tests of truth, as on their usefulness in helping people to function more intelligently and skilfully. In action-research 'theories' are not validated independently and then applied to practice. They are validated through practice. Action-research is a total process in which a problem situation is diagnosed, remedial action planned and implemented, and its effects monitored, if improvements are to get underway. It is both an approach to problem solving and a problem solving process. (p. 293)

Action research can accommodate complexity and confusion. Schon (1983) noted that it could cope with the “swampy lowlands where situations are confused messes incapable of technical solutions” (p. 42). Bob Dick (1992/3) saw action research as typically beginning with fuzzy edges, with no one precise question to be answered but rather a vague aim in mind. He believed that for a researcher to be adequately responsive to a situation it was important not to begin with a precise question, and reassured intending action researchers that this would not hinder progress provided each cycle added to clarity.

Action research also brings a multitude of perspectives to bear on one complex topic, and is usually multi-disciplinary. In this study sociology and psychology, educational and learning theories and other bodies of knowledge provided useful insights.

ACTION RESEARCH IN THE FIELD OF EDUCATION

There are various action research models and ways to represent cycles of the action research process. Lewin pioneered the process in 1946 (Burns, 1990). His cycle began with reconnaissance, followed by observation and reflection (with these two phases overlapping), then planning and finally (for the first cycle) action. Then the next cycle began with observation and reflection on that action leading to revised plans, and further action.

Kemmis (cited in McNiff, 1988) developed action research in the education field to encourage professional development. Like Lewin he began with reconnaissance or analysis: discussing, negotiating, exploring opportunities, assessing possibilities and examining constraints. This helped identify the main focus of the study. Then the spiral began, with observation and action going hand in hand, followed by reflection and planning.

This process was used in this study, which began only after the initial workshops had been developed and trialled in other contexts. Analysis was already beginning, with

some questions raised, and a literature search and discussion (reconnaissance, exploring) preceding the planning of the first workshop (Workshop One) to be more systematically examined.

Jean McNiff (1988) saw Kemmis as moving away from Lewin's original concept of explanatory studies to more prescriptive study, not encouraging the search for explanations, nor reflecting the messiness of real life research and practice.

She developed a more fluid scheme, allowing for the simultaneous exploration of different ideas. In her scheme spirals broke off from other spirals. One topic might generate another focus seen as equally important to achieve improved practice. Work on two or more related investigations of different aspects of a central issue could proceed simultaneously without losing sight of the main issue.

This occurred when the reference group was challenged over their plans for people who identify as having experienced mental illness to facilitate the workshops. This practice developed because the group felt it was important that their voice was kept central, but it had not been carefully examined to see whether it was both effective and safe. The challenge put this practice under the spotlight. In a spin off to the main topic (Figure Three), I researched the many issues that arose. Information was gathered by written responses to the paper I wrote examining the issues, and from discussion at reference group meetings. In Figure Three the dotted line represents information also gained from interviews following each workshop and subsequent discussions by the reference group. The raising of this issue gave the reference group a chance to consider it carefully and answer concerns raised by others involved more peripherally in the project work. This proved the value of using a dynamic and flexible research process. By the end of the study the effectiveness of the practice was confirmed and the diagram shows these spin-off cycles completed with results feeding back into the information used in future workshops.

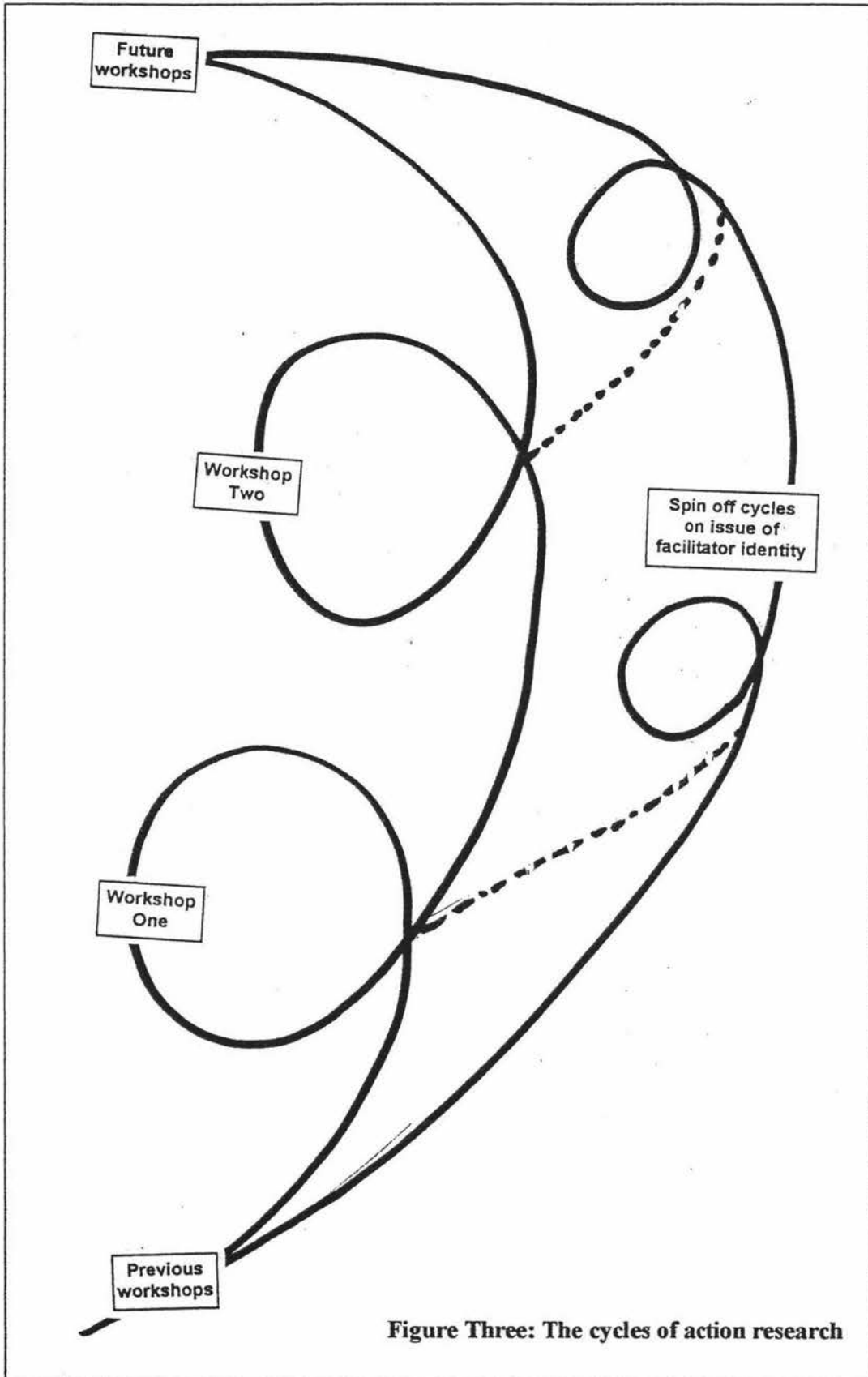


Figure Three: The cycles of action research

McNiff saw the action research process as a series of short hops (1988). Once a section was complete its impact disappeared. Seen in retrospect it would appear different than it was at the time, as people interpreted the past against their experience of the present. Notes taken close to the time of events helped avoid skewing of the data to give a more accurate picture of why decisions were made.

McNiff's elegant and flexible design has a pitfall: the process could become never-ending. Due to the timeframe of this thesis, this was not a problem. However, the practices of reflecting on workshops to ensure continual improvement in effectiveness will continue beyond this research, although with less rigour and detailed information than was obtained during this study.

PROCESSES

GROUP PROCESS

A group process is at the core of action research, and I welcomed this for its ability to widen my vision by examining learning from a variety of viewpoints. This was particularly important in this enquiry for there was little directly relevant literature on this topic, although there were lessons from other educational and social change movements.

Both Grundy (1982) and Carr and Kemmis (1986) extensively promoted the use of action research in education. Grundy (1982) described three modes of action-research, classifying them according to different degrees of group involvement and control.

1 Practical action research was process oriented, focussed on *praxis*. Practitioners used their own knowledge and intuition to reflect on the situation, with

PARTICIPANTS

Members of the reference group were people with experience of mental illness who formed the advisory group to the Serious Fun 'N Mind Trust during this time. They were Chris Hansen and Jennie Hawira, Jane Barron, Catherine Dickinson, Wendy Rahiri and Mahora Dewes. Heather Davis resigned towards the end of the study and Barbara Hart, joined for Workshop Two. Participant feedback and new plans were discussed with this group, and most attended facilitation training to learn and trial new ideas for this workshop and other Trust workshops. Jennie Hawira and Chris Hansen were key team members, facilitating Workshop One and Two, assisted by Barbara Hart in the latter.

CULTURAL ISSUES

The workshops were part of the mainstream project and not part of the separate Maori for Maori contract, or marae based work. However many Maori work within the mainstream, and some participants on the first workshop were from kaupapa Maori mental health service providers.

The trust kaumatua and Maori trustees were involved in approving the study but the kaumatua passed away before the first workshop was held and it was some months before a new kaumatua was appointed. Advice was also sought from a Maori facilitator working closely with me in another field of work. Maori were involved within the reference group and as workshop facilitators and participants. Their advice informed the changes made to the Cape Drama and the way in which the emotional and spiritual needs of participants were considered.

DATA COLLECTION

The need to gain an intimate understanding of other people's perspectives pointed to the need for qualitative data gained from interviews with open-ended questions. Also, within a short (five hour) workshop it was important not to allow data collection to intrude excessively on the already limited time available to achieve the objectives.

For these reasons only brief questionnaires and evaluation forms were used within the workshop itself. Miles (1983) noted that such qualitative data

...lend themselves to the production of serendipitous findings and ...
reduce a researcher's trained incapacity, bias, narrowness, and
arrogance; and their results ...have a quality of undeniability that
lends punch to research reports. (p. 117)

Qualitative data was gathered from participants through evaluation forms filled out immediately the workshops were completed. Course evaluation forms had a mix of multiple choice questions and open-ended questions. Space was allowed for additional comments to encourage spontaneous thought and allow for more variability in accounts. The examination of data gathered and refinement of forms used to evaluate courses has on-going useful implications for quality processes.

Evaluation of longer-term effects and reported behaviour change came through interviews with course participants 8 – 12 weeks after the workshops were completed. Interviews were semi-structured, with an interview guide of questions used, but additional questions and comments added as interviews proceeded. I used an informal conversational approach to encourage rapport.

The limitations of the data come from the recognition that there is a difference between what people say they do and what they actually do. The questions about changes in work practices since the workshop was left till the end of interviews, once a level of rapport was attained. This is because acknowledging a change in practices can be viewed as an admission of previous practices less supportive of the recovery model or showing less respect for people with experience of mental illness.

QUANTITATIVE DATA

An attempt was made to triangulate results through the use of quantitative data with pre and post-workshop questionnaires. However limited numbers made the usefulness of quantitative data problematic. The first workshop had only 13

participants, and only 11 filled out the brief pre- and post-test questionnaires (see Appendix Two). These identical questionnaires used continua to allow maximum flexibility in answers, and one open-ended question asked what role participants might play in the movement to reduce stigma and discrimination. These were filled out immediately before and after the workshop.

An analysis of the quantitative data gained from these questionnaires used in Workshop One showed no significant change in participants' understanding of the extent of stigma and discrimination in services and the community. This may have partly resulted from the fact that participants self-selected and may have had a higher level of awareness of discrimination than other mental health service workers. However comments on evaluation sheets and the interview data did show greater awareness of the extent of discrimination, and proved of much greater benefit in the subsequent cycle of reflection and planning.

I believe this discrepancy occurred because of the limitations of quantitative data in this form of study. The numbers taking part were too small to enable any degree of rigour in analysing findings; and the complexity of the questions (necessary because of the topic) was such that it could not be reduced to simple continua and short answer formats. By attempting to simplify the topic it became meaningless. In addition only a very short time could be allocated to this form of data collection in a 5 hour workshop without significantly reducing the learning time and impact of the workshop itself. The lack of time allocated meant the participants who filled questionnaires out could not do so thoughtfully. After discussion in the reference group we decided it was not possible to gather useful and accurate results from small amounts of quantitative data using brief questionnaires, and did not continue their use during Workshop Two.

ETHICAL ISSUES

The original ethics application to the Massey University Ethics Committee led to some questions and considerations resulting in minor changes in the conduct of the research and clarification of the forms used (see Appendix One).

Although the workshops were under the mainstream project, parallel to the Maori for Maori project provider, it was acknowledged that the research would involve Maori and Pakeha facilitators and participants. The section on advice to ensure cultural safety was discussed and strengthened.

Forms were clarified to make it clear that the research results were intended to improve the practices of workshops facilitated by the Trust, and practices were set to ensure anonymity and confidentiality.

WORKSHOP SELECTION

Participants were staff in mental health services in the two workshops selected for this research. Both workshops were organised by providers of the Like Minds, Like Mine, project.

In the first workshop attendance was optional. A couple of staff were from hospital based services but most from community based and small rural Maori services. The second workshop had a larger number of participants, from a variety of services, but most were staff of hospital-based services. Not all were self-selected: some hospital staff were sent by their managers as part of moves by their service towards a culture of recovery.

Two further workshops were held during the course of this study: one for social work students and one for tertiary lecturers. Informal learning from these workshops added to the learning from workshops central to this research.

PARTICIPANT SELECTION

Participants who took part in this study were self-selected, that is they agreed to fill in questionnaires, evaluations and to be interviewed. All participants in both workshops were invited to take part. Details of the study were given out and questions answered at the commencement of the workshops with information sheets and consent forms being handed out and filled in by those who volunteered to take part. Some consented to fill in questionnaires and evaluations but not to be interviewed. On Workshop One, all of the eleven who arrived on time filled out pre and post workshop questionnaires, and all thirteen completed the evaluation forms. Nine took part in the interviews. On Workshop Two, where a few participants had been 'sent' by their managers, the participation rate was lower. Of twenty-three participants, twenty filled out evaluation forms and nine agreed to be interviewed. Interviews were carried out with all participants who consented to this, apart from one who had moved from both her workplace and her home address and was unable to be contacted.

INTERVIEW FORMAT

Participants lived over a wide geographical area, from ninety minutes to six hours drive from my home. Because of logistics many interviews were held by telephone. Telephone interviews did not appear to affect the quality of data gathered with participants speaking openly about the emotional and other effects of the workshops. To ensure the accuracy of recording, transcriptions were sent to all participants, who were invited to make any amendments or additions.

The form of interview used was a focused interview (Sarantkos, 1993, p. 253). It was semi-structured, with a standard set of questions (Appendix Two) used, but further questions were added when necessary to clarify issues. Most questions were open ended to ensure participants were free to give information on different aspects of the complex issues. Questions that were easier to answer preceded others. Left to the end was the potentially most problematic question:

Is there anything you might be doing differently as a result of this workshop? Any change in your practices or use of language?

Defensiveness can result when people are asked to disclose personal behaviour changes. In this case such disclosure implied previous behaviours were less than ideal and, in this case, may have been discriminatory. Leaving this question until after rapport had been gained was effective, with all participants reporting some changes.

CONFLICT OF INTEREST

Conflict of interest was minimized as I was not in an on-going relationship with workshop participants, and the workshops were not assessed.

However I was in a position to influence the work of facilitators and this could have proved problematic. This was clearly understood at the outset of the project, when the reference group first agreed to take part. It had no noticeable effect on people's contribution to discussion, perhaps because there was a high level of trust within the group.

DATA ANALYSIS PROCEDURES

A reflective process was used to consider the qualitative data. Henry and McTaggart (1996) wrote that reflective practice

...specifies that the situation, and the use of information pertaining to it, must be investigated, interrogated, critically analysed, such that new evidence is collected and old information is checked for its possible use in altered forms, alternative formal and informal theories are assessed and tested and the quality of information used is evaluated for its accuracy. (p. 11)

This study has been based on a broad social analysis: of practice, the way language is used, organisation and power in mental health services. It has been important to seek input from people with different viewpoints: facilitators, other people with experience of mental illness and people working in the mental health sector. These people's views all helped to inform, initiate, and suggest changes and improvements, and

ensure the workshops kept focussed on changes in mental health services in line with current best practice recommendations.

Positive information and agreement helped confirm that the workshops were 'on the right track' but some key information came from disagreement. Bright (1996) wrote that

Negative or disconfirming information poses the more significant implications in terms of signaling the need for improved information collection and/or analysis and the consequent redesign of action. (p. 165)

Disagreement with the reference group's intention to have people with experience of mental illness facilitate the workshops was particularly important and led to further literature search and discussions about this aspect of the study.

The examination of qualitative data is always problematic as there is no precise way to recognise themes. I read them over several times to become familiar with them, collated data from the interviews to help identify recurrent themes, and shared and discussed them with the reference group.

VALIDITY ISSUES

Triangulation is the recognised method of overcoming problems related to validity in qualitative research. Gathering data from several sources is one way of verifying data presented in one-to-one situations and enables cross-checking for consistency.

Checks with participants are considered to be most important and have been termed 'face validity' (Lather 1986). Participants interviewed for this study were given copies of their transcripts for verification. Most returned them without changes, a few added new information triggered by their reading.

Post workshop debriefs with facilitators, mental health service staff and participant observation added to data. This was particularly important following Workshop Two where a number of participants showed some resistance to learning and opted not to take part in interviews.

To summarise the methodology is based on techniques of action research. As such its validity can be seen in recorded changes and improvements in effectiveness of the workshop. Action research is grounded in the specific situation, however there have also been findings with relevance to other workshops aimed to reduce discrimination; as well as ideas that inform other actions aimed at changing the culture of mental health services towards a recovery model.

CHAPTER FOUR: THE CYCLES OF RESEARCH

INTRODUCTION

This chapter covers the planning, observation, reflection and action cycles of learning during Workshops One and Two. It begins with the spin-off cycles examining the issue of facilitator identity that arose after the initial challenge to plans to have people with experience of mental illness facilitate the workshops.

ISSUES OF FACILITATOR IDENTITY

McNiff's fluid action-research design proved its usefulness when the decision made by people with experience of mental illness to facilitate the workshops themselves was challenged by a person influential in the project. A spin off cycle of observation, reflection, planning and action occurred which was peripheral to the original purpose of the study but simultaneously fundamental to practices. The issue had far reaching implications, with some relevance to other anti-discrimination education.

The reference group had made the original decision. The group had discussed other models such as those of some Treaty workshops where participants separate, with Maori facilitating courses for Maori, and Tauiwi facilitating courses for Tauiwi. They decided that in this field it was important that the voice of tangata whai ora, silenced for so long, was heard directly. Although they knew that they might be challenged and confronted with discriminatory remarks, such experiences were not new to them, and at least in this setting their viewpoints would be heard.

The issue of facilitator identity arose when some team members were invited, as part of their training, to observe a workshop on discrimination held for mental health service staff by a facilitator without experience of mental illness. The presence of people with experience of mental illness in this workshop was challenged, by a mental health services staff member, on the grounds that it was unsafe for mental health

service staff on workshops about discrimination to be “subjected to observation by tangata whai ora”. Six weeks later, when family/whanau wished to attend a workshop alongside mental health service staff there was a directive that “there must be no mixed groups”.

A decision made, on any grounds, that people with experience of mental illness should not facilitate nor attend workshops for staff is inherently discriminatory. It removes power and choice from them by preventing their attendance at the same workshops as ‘professionals’ and taking part in educational opportunities. Such a decision, in a project aiming to reduce the discrimination and stigma associated with mental illness, was immediately controversial. One response, from reference group member, Chris Hansen, who had herself been a manager of a mental health service, was:

If I am told I cannot attend a workshop because I am tangata whai ora I feel very insulted, banned from being in a situation where I could learn a lot. If the safety or learning of staff is so compromised by my presence I would like that explained in writing to me. We have an equal right to access knowledge.

The challenge did, however, have a positive impact, ensuring careful consideration of the issues and implications of facilitator identity.

PROCESS OF INQUIRY

Clearly identity, safety and educational effectiveness needed to be examined in the light of the aims of the workshops. I circulated a discussion paper for people involved. A Pakeha facilitator of Treaty workshops for over a decade, the issues were not new and the paper examined parallels in these workshops to reduce discrimination.

However although there are lessons to be learnt from other anti-discrimination work, it became clearer to me over the 18 months that there are also two significant differences. Firstly there is an on-going and very close relationship between mental

health service staff and people with experience of mental illness, who are highly dependent on staff during periods of unwellness. Secondly, due to their professional training and workplace experience, staff see themselves as experts on the needs of people with experience of mental illness, and see the maintenance of professional boundaries as important to their effectiveness. As I progressed I realised that the core relationship between those who discriminate and those discriminated against in this context, based on a combination of professional distancing and one-way intimacy, is substantially different from that in other movements against discrimination.

The reference group also met to consider the issue. Collated responses from both the paper and the meeting were then redistributed to all parties. After this process, the reference group endorsed facilitation by people with experience of mental illness in workshops for mental health service staff, but gave closer attention in their planning to issues of safety and ways to encourage open discussion. Subsequently, in workshop evaluations and during interviews I included questions to elicit participant perceptions of safety and the implications of facilitator identity on learning, and also examined the literature in this area.

The rest of this section examines the issue from different angles, documenting the processes of reflection, observation and analysis, and the implications of new understandings for further workshops. Excerpts from the original paper, reference group and other discussions and written responses, findings from the workshops and literature review are included.

WORKSHOP AIMS

Discrimination within mental health services is evident in behaviours that act to distance service users from staff, practices common in the culture of the 'medical model'. The workshops aimed to narrow this distance, enabling professionals and families and people with experience of mental illness to work closely as equal partners. The original (July 2000) discussion paper noted that

The desired end is to function together, acknowledging the strengths and gifts in one another.

The question was whether, to achieve this aim, workshops without the presence of people with experience of mental illness would give added safety and enable more open discussion.

IDENTITY ISSUES

What is mental illness? Who can claim to have an experience of mental illness? When groups are separated on grounds of ethnicity or experience, identity issues inevitably arise. If distinctions are made definitions need clarification. Is self-definition enough?

The reference group addressed the question of identity. Originally a loose form of self-definition was accepted. With high levels of stigma and discrimination it seemed unlikely that people who had not experienced a mental illness would wish to claim such identity. However a year later, this issue was revisited. In parts of the project, some people, having experienced a relatively minor illness treated by their general practitioner, were claiming tangata whai ora identity.

In August 2001 a meeting was held for both the reference group and other tangata whai ora who wished to join the facilitation team. The definition chosen by this group was: 'tangata whai ora are people who have received secondary mental health services'. However, the meeting also noted that identification was

more to do with the level of the effect of the illness on someone's life. People identifying as tangata whai ora when facilitating workshops should feel passionate about the kaupapa from having experienced stigma and discrimination themselves. (meeting minutes, 24/8/01)

The group noted that everyone had a part to play in the movement, and there were roles for people who have experienced a more mild mental illness. It was also felt that if by Maori for Maori workshops were developed then Maori members of the team

would decide who could identify as tangata whai ora facilitators in those situations. People who have not used secondary services, but had support within their whanau and/or Maori healing may have valuable insights to offer staff of Maori mental health services.

DUAL IDENTITY

During the late 1990s with the influence of postmodernism, there was a growing recognition of the fluidity of identity, of multiple identities – based on family, experience, ethnicity, sexuality. (Flannery and Hayes 2001). People have many roles and facets of heritage and lifestyle, some of which assume importance one day, some another, all equally valid. People choose how they identify at any one time or place.

Quite a few people with experience of mental illness are now employed as staff in mental health services. Some are in roles where they are identified as people with experience of mental illness (e.g. consumer advisers), others are employed as nurses and other clinicians. A number of people with experience of mental illness are now enrolling in training courses for mental health staff, so the incidence of dual identity is likely to increase.

ISSUES OF IDENTITY AND SEPARATION

Issues of dual identity arise in Treaty workshops when people identify with both Maori and Pakeha heritage. As a workshop participant I had personally experienced the dilemma that can result. During a workshop along with other participants, I was instructed to “cross the floor if you are Jewish”. With both Jewish and non-Jewish heritages important to my identity, I had no place to stand that did not deny part of who I am.

In Treaty courses in many tertiary institutes, separation into caucus groups was the norm during the late 1980s to mid 1990s. This was seen to be safer as Maori students would not have to face racist remarks; and educationally more effective as

participants would be more open in their questions. These issues were also seen as relevant for workshops in the field of mental illness. A former mental health service manager responded to the original discussion paper saying:

I support the separation of consumer and staff in the first instance. This view stems from many years of personal experience in both consumer-staff mental health issues fora and also and in particular dealing with training for Maori and non-Maori staff regarding the Treaty of Waitangi and the application of the document and its origins to the Health sector.

The issues that are often raised and needing to be dealt with effectively have more often been dealt with more sensitively, effectively and without compromise in facilitated settings with the respective parties in the first instance in isolation. In most if not all instances in my experience, the significant value of this positive and appropriate separation (not discrimination) is not readily apparent to those becoming involved until they have been involved in this way. Once the involvement has occurred and the benefits apparent then the integration occurs very usefully from a position of understanding and the benefits for all (which of course is the objective) can be effectively realised.

An ability to ask questions openly is conducive to good learning, and I have personally experienced a higher level of willingness by Tauwiwi to ask questions that may seem discriminatory in Treaty workshops where Maori are not present. There is a natural reluctance to bring up issues that might offend other participants. In mixed Treaty workshops however we addressed this reluctance to raise difficult questions by listing all participants' questions for discussion and unspoken ones that are often raised in other forums.

Caucusing

In Treaty education caucusing (dividing into groups based on ethnic identity), has been a controversial practice for many years. Although it became general practice in technical institute courses, including some I facilitated in the early and mid 1990s, I witnessed some strongly negative reactions from students distressed about separation, often from people with both Maori and non-Maori heritage. Negative reactions reduced when facilitators began emphasising the richness of dual heritage.

Participants were told that the choice made when caucusing was only about which cultural perspective people wish to learn about and which cultural learning style they preferred. Unlike the choice I had faced, this did not impact on their ethnic identity.

Some tertiary institutes now allow for more student choice, while retaining Maori only courses for those who wish that option. Parallel courses are less often tagged for 'Maori' and 'Tauwi' but rather 'Maori' and 'mainstream'. Mainstream courses are open to everyone. Maori students, and those with dual identity, choose which course to attend. In a course I facilitated in 2000 about 20% of students with some Maori identity attended the mainstream classes, facilitated only by Pakeha. The choice is still not easy and once courses begin some students with dual identity change their minds and move across to the other course.

In the field of mental illness courses were already being held by and for people identifying as having experienced a mental illness. The need for people, subjected to oppression and discrimination, to have separate space to come to terms with their situation and gather strength to change it, is common and no longer controversial. What was at issue was the right of people with experience of mental illness, people subjected to oppression, to facilitate and attend workshops on discrimination that directly affected them, provided for mental health staff.

HIDDEN IDENTITIES

Not only is identity fluid, but also it is often hidden. Discrimination is still so prevalent that many people with experience of mental illness do not feel safe revealing their identity. During the course of this study I met both hospital and community based mental health service staff who did not acknowledge their own experience of mental illness to their colleagues, unwilling to face the discrimination they witnessed daily in their workplaces.

One participant revealed her tangata whai ora identity half way through the first day of Workshop One. During an interview she later said:

I was feeling fragile myself but their (facilitators) courage gave me the courage to say I am tangata whai ora too.

When asked whether she would not have preferred to attend a workshop specifically for people with experience of mental illness her reply showed some of the many ramifications of open identity:

I knew there was one specifically for tangata whai ora but I chose to go to the staff one as to go to the other would have identified me as tangata whai ora to other staff. Also I felt the other tangata whai ora would have suspected my motives for being there because I am staff. I guess you could say it was a political - office politics - decision.

After the first workshop it was clear that facilitators would never know whether participants with an experience of mental illness are present. However educationally effective or safe it might be, it was not possible to plan for a workshop that does not have a 'mixed group' of participants.

Because identity is fluid and often hidden, it is not only impractical but also impossible to guarantee that staff will 'not be subject to observation by tangata whai ora' during a workshop, even when facilitators have no personal experience of mental illness. However, such observation may be covert and unacknowledged where identity is hidden. Staff with an experience of mental illness may be present in any workshop (and in any mental health service) and this needs to be taken into account in planning.

Some mental health staff believe that in staffrooms they can 'sound off' and speak negatively about people with experience of mental illness, confident that they will

not be overheard. In the interviews following the Workshop One, an in-patient staff member said

In the ward we need to let off steam, not in front of the people, but in the background. We get cynical, use some words... we can use inappropriate words ...

Clearly this belief is unfounded.

Arana Pearson, consumer adviser in the Mental Health Commission noted (personal communication, November 2001) that the crucial issue is one of identity versus role. Staff in roles of service professionals sometimes declared their identity as a people who have used services in the past. Yet in their service delivery role they were in a different role to people who receive services. He asked whether “people who over-invest their identity in their role, on either side, reduce their humanity?”

SAFETY AND EFFECTIVENESS: BALANCING RISK AND OPPORTUNITY

Issues of identity, central to self-concept, and issues of mental health and illness, touch people deeply. There is a risk of arousing negative emotions unresolved during the workshop that stay with them afterwards. Techniques are needed to safely handle emotions aroused and these are discussed in another section of this chapter. At issue here is whether the open presence of people with experience of mental illness make mental health staff feel unsafe or defensive, and if so whether this will result in a reluctance to participate. A respondent (who identifies as tangata whai ora) to the original discussion paper wrote:

...if groups are therapeutical rather than educational, there may be a need for non-mixed groups. In my own experience it can be difficult to be safe, when exploring often painful, sometimes raw feelings, when the group is mixed. Having said this the distinction between therapeutic and educational workshops often gets blurred, as you have pointed out, and not everyone will have had my experience!

In interviews following the first workshop the issue of safety was explored with the question: *Did you feel safe to speak and say what you felt?*

Only one person said that she did not feel safe to speak openly. However it was not people's identity that made her feel unsafe, but her relationship with another participant. She said,

I felt quite threatened. Not by the facilitators. By one other person on the course, who often was in the smaller groups with me. She had complained about our [service's] treatment of her client when she [the client] was in the ward.

During the second workshop a service user had been invited to attend alongside staff who supported him. An interviewee commented

...they didn't like having X there. They felt they couldn't discuss things so freely in front of him since he's not very discreet.

This confirmed a proposition put forward by a member of the reference group who thought it was 'probably important for staff not to be with their own clients'.

Following this consideration arising towards the end of the interviews, an interviewee was asked: *If local tangata whai ora were present would that make it more difficult for you to speak openly?*

She responded:

No, we should be honest with them, let them know how we feel, how we also get stressed but still need to focus on them. They're pretty honest to us and it might help them understand where we're coming from, and bring them closer, so it's not us and them.

Interestingly both concerns raised about safety in interviews were based on people's past experiences with one another rather than issues of identity.

FACILITATOR SAFETY

The issue of the stress on facilitators themselves was raised during the study. The group decided that this was best dealt with in two ways: there should always be two people facilitating a workshop so they could support one another, and a third facilitator should be contracted to be on 'standby'. No one should feel that they must

facilitate when they were unwell, physically or mentally, or when needed by their family. The third facilitator on standby meant that workshops would not place undue stress on any one person.

POSITIVE SIDE EFFECTS

One of the strongest threads that ran through the interviews was the impact of having a workshop facilitated by people who openly discuss their own identity and experiences of mental illness. In the interviews following Workshop One a respondent said

The strongest thing for me was not buying into the secrecy of unwellness. It seems small, but it is powerful... people remaining silent about their own perspective feeds into discrimination... they're shoring up the fact that there is something to hide.

Three positive side effects of having facilitators with an experience of mental illness were noted:

1 Modelling behaviour change

A central tenet of the recovery model is that the voice of people with experience of mental illness should be central in services. Participants who were at least a little open to new learning modelled the key behaviour being promoted: that is listening to the perspective of people with experience of mental illness.

2 Credibility

An authority of the 'art of persuasion', Mills notes that:

One can stand as the greatest orator the world has known, possess the quickest mind, employ the cleverest psychology, and have mastered all the technical devices of argument, but if one is not credible one might just as well preach to the pelicans (Gerry Spence, cited in Mills 1999, p. 14).

Under the medical model expertise is seen to lie with professionals so it might be that for people who come from that paradigm, facilitators identifying as people with experience of mental illness would not necessarily add to the credibility of the

message. Yet interviews showed that at least among participants open to change who took part in this study, the messages gained extra credibility.

Comments included:

It was more meaningful than having it run by professionals from their point of view, it was really good to have the client perspective. It made me think about how I related to tangata whai ora and reflect on how possibly I had been judgmental.

This made the reference group aware that staff, working with people who are unwell, rarely meet people with experience of mental illness in recovery. Once well, people leave the services and get on with their lives. Other people with a personal experience of mental illness, when amongst work colleagues or friends, may choose to not disclose their mental illness for fear of discrimination.

People with experience of mental illness were enabled to put their own case for partnership, with their expertise giving them added authority. One facilitator, Chris Hansen, was seen as especially credible as she had been a mental health service manager herself. However, participants not open to the messages can always find a way to discount expertise. Maybe Chris did not have a 'real' mental illness. One interviewee said

I talked to people at work and they still think 'that'll never happen to me'. They see Chris as having had a temporary illness, someone who got over it and now copes.

3 Raised expectations

A second and unexpected side effect was raised expectations by participants for the people with experience of mental illness they supported. Following Workshop One a respondent said,

I was sceptical at first and when I saw them [the facilitators] I was surprised...to me tangata whai ora were people who were unwell...we learnt so much...never in my life did I think tangata whai ora would be able to...we talked about that and thought about the people we work with... if they can do it, then here in [our service] they can do it too, with a lot of work of course, not overnight.

Although one in five of the population experience a mental illness, and three in a hundred experience an on-going and serious mental illness, many who learn to cope with an on-going illness regain work and avoid discrimination by not openly identifying as a person with an experience of mental illness. The lack of positive role models of people who have an illness and live well in recovery, leads to low expectations by staff.

DECISION

During the early discussions a reference group member said: 'There may be gains and losses whatever option we choose', and as the study progressed this was very evident.

In summary, issues of safety were not as important as originally feared; and the effect of the presence of people with experience of mental illness on participants' ability to ask questions was also less than anticipated. Techniques had been found to deal with both these issues.

- Safety: the identity of facilitators should be clear in advertising and brochures so people could make an informed decision to attend.
- Setting a climate of openness and developing techniques to encourage open debate would encourage open questioning.

Three positive gains from having people with experience of mental illness as facilitators were also noted:

- Intrinsic behaviour change – participants having to listen to people with experience of mental illness
- Added credibility
- Raised expectations for clients

Finally examination of the issues of dual and hidden identity had shown that separate workshops by and for staff were not feasible and banning of people with experience

of mental illness from workshops (either as participants or facilitators) was seen as discriminatory, working against inclusion - a basic principle of the project itself.

With all these factors considered the decision to continue with facilitators who have experience of mental illness was affirmed after Workshop One and became a key and distinctive feature of workshops offered by the Trust.

I now turn to the first cycle of the research.

REFLECTION ON PREVIOUS WORKSHOPS

This section examines the action research processes of observation and reflection that informed the first workshop of this study. The initial reflections were based both on the facilitators' experience of previous workshops held for students on social work and mental health support work courses and a further literature review to examine questions raised. It is structured chronologically in terms of the action research processes used.

Two five hour workshops facilitated by the Trust team which had been held early in 2000 for students of social work, were planned to meet objectives set by their course module on marginalisation. Information on the causes of mental illness was followed by a facilitator's personal story of her experience of mental illness; group work on stigma and discrimination, and an early version of 'The Cape Drama' (Appendix Three) was performed after lunch.

Following these a workshop was held for students of the Certificate in Mental Health Support Work, many of who were already working in the residential services. This had more emphasis on stigma and discrimination in services and did not include information on mental illness itself, covered elsewhere in their course.

These workshops were named 'Discrimination Awareness' workshops. The team was not comfortable with this name. Although technically discrimination can be positive, in this case it referred to negative behaviours. A name that referred to a positive goal or vision was seen as preferable and more likely to attract participants, but one that was both positive and an accurate description of the workshop was yet to be found. Since recruitment was not necessary for these workshops, which were an integral part of year long certificate courses, the name Discrimination Awareness was retained.

All three workshops used experiential learning techniques of drama and group discussions involving reflection on people's previous understanding of the issues.

Evaluations on these workshops showed their effectiveness. Most participants found them enlightening and challenging, were motivated to learn more, and noted their awareness of the issues had been raised. Feedback also showed that strong emotions were aroused by the Cape Drama (see Appendix Three) and students needed more time to process these. Two comments were "The Cape activity made me think about the feelings mental patients must have" and "I enjoyed it but found labeling the Cape hard as I was conscious that a person was underneath". Facilitators noted that some participants and their family members have had experiences of mental illness themselves. This might have triggered strong emotional reactions to the Cape Drama, which needed addressing. Students found it important that people with experience of mental illness facilitated the workshop, and said the personal stories told by facilitators were especially effective.

The workshops were clearly valuable in raising awareness, but facilitators still had two main concerns. Firstly participants did not leave the workshops with a clear view of actions they could take as a result of their new understanding. Secondly participants returned to environments (both in workplaces, within the tertiary institute and in communities) where discrimination was rife, and needed tools to help them maintain positions of sustained respect.

Workshop One of this study was the first to be developed specifically for mental health service staff. It was the introductory day of a three-day workshop for staff wishing to speak publicly about mental illness. It was chosen for two reasons:

Firstly, participants were from a variety of services: hospitals, residential services, rehabilitation programmes, both Maori and mainstream, rural and city based so responses from staff from these different settings could be gauged. Secondly, participants self-selected to attend because of their interest in the campaign against stigma and discrimination. It was felt this would make them more open to learning and taking part in the research.

Since the group had yet to find a positive alternative name, the name 'Discrimination Awareness Workshop' was used.

PLANNING FOR WORKSHOP ONE

AIMS

The full three-day workshop aimed to give participants "increased confidence about speaking publicly about mental health and mental illness, and skills to deliver positive and consistent messages that promote sustained respect for people with experience of mental illness".

The objectives for the first day (the Discrimination Awareness workshop) were stated fairly simply. Participants would

- gain further understanding of stigma and discrimination associated with mental illness
- gain knowledge of how to advocate with respect and understanding

LITERATURE SEARCH

A further literature search was undertaken to find resources or tools to support professionals to maintain anti-discriminatory behaviours after the workshop.

One of the central tenets of experiential learning is that learning is life long and occurs inside and outside classrooms. Workshops provide only a very small part of participants' experiences of mental illness. Until workshops are run in conjunction with organisational changes in procedures and practices that promote recovery, participants will both come from and will return to workplaces where discrimination still occurs. What learning can help them hold on to practices that promote hope and recovery in the face of the predominant medical model?

A useful approach was found in the work of Mezirow (1993). He applied the ideas of discourse analysis and experiential learning to professional practice. People's structure of cultural and psychological assumptions (their 'meaning perspectives') were originally acquired through cultural assimilation rather than intentional learning. Through critical reflection these assumptions can be changed.

Mezirow critiqued major learning theories in psychology for giving limited attention to the habitual ways in which people symbolically categorized and interpreted reality. He advocated identifying the structures and assumptions that influence the way people perceived, thought, decided, felt and acted on experience. This critical reflection of the meaning perspectives and paradigms by which professionals understood their experience led to 'transformative learning'. Facilitators of learning needed to create an environment where this could occur.

The question of how to practically accomplish this within the scope of a one-day workshop remained until a useful model was found in Joyce Stalker's (1996) writings. She put Mezirow's theory into practice and developed a model of ideological systems to uncover political assumptions and dominant discourses. She used the model in her university lectures to encourage students to confront and challenge the hidden

curricula and power relationships they encountered in the classroom and in their wider lives.

This provided students with a framework revealing different paradigms and their underlying assumptions, which they could use independently to understand, critically reflect on and analyse, their own and others' experiences. The relevance of the model of ideologies was demonstrated in practice, with students asked to identify and respond to problems from each perspective. She noted the framework reduced confrontational debates within the classroom as students learnt to understand the different assumptions behind the discourse.

Stalker's model (1996) looked at four paradigms, which she named the consensus, conflict, interpretive, and 'new right' perspectives. To encourage honesty and openness in her teaching she revealed her own position on these perspectives. She noted students living where there was on going and very visible dialogue about issues of domination and oppression (in Aotearoa/New Zealand compared to Canada) found this model easier to understand and use. Student feedback was positive, indicating the model helped them classify their readings and understand the tension between different views.

RESOURCE DEVELOPMENT

Based on Stalker's concept, we developed a model to trial in Workshop One. Categories were based on differing relationships between people with and without an experience of mental illness with both negative and positive relationships included. Early drafts were gradually refined and simplified, until a four category framework evolved. In the first category relationships were based on fear, with a resulting need to control people with experience of mental illness. The second category, with relationships based on pity, made explicit the more subtle discrimination resulting from paternalistic behaviour often experienced in mental health services. The third category was based on respect, and rights. A fourth category of 'citizenship' was a

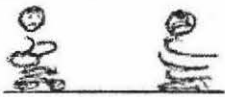



vision for a future where labels and an emphasis on rights would be no longer needed. Finally sketches were added, representing the physical and emotional distancing that occurred within different relationships (see table below).

Three other sections were added to the model, but left blank for participants to fill in:

1. Words/signs: Through discourse analysis the more subtle forms of discrimination, not adequately addressed in earlier workshops, would be made explicit. The way discourse could justify discrimination would show how, for example, a publicly professed stance of 'understanding' and 'good will' masked paternalism.
2. Effects: To show the power of discourse, participants were asked to consider the effects on service users of commonly used words and signs.
3. Actions: Examples of staff actions or behaviours were to be added to reveal the links between discourse and behaviours.

One concern about this model arose from Wetherell and Potter (1992)'s examination of discourse associated with racism, which had shown its elusiveness. This understanding was at odds with the concept of discrete categories of discriminatory and non-discriminatory relationships. The possibility of using a continuum instead of categories was discussed. However it was felt that this would add further complexity and reduce clarity.

Stalker (1996) had also noted this problem and in her teaching admitted her model was reductionistic. She helped students understand 'these are four ideal, falsely tidy categories which are culturally bound' (p.71). The facilitators decided to follow her lead and use the model on this basis.

<u>RELATIONSHIPS</u>				
Relationship based on	Words/signs	Effects on consumers	Action	Distance
FEAR				
PITY, BENEVOLENCE PATERNALISM				
RESPECT AND RIGHTS				
CITIZENSHIP				
Table Two: A framework for understanding relationships				

The need for people to leave workshops with concrete goals was one of the key findings of the ILO study (1999) on anti-racism workshops. The framework would support this, helping participants move beyond 'attitude change', giving them a vision of behaviours and discourse that promote respect for people with experience of mental illness.

In Workshop One further work on behaviour change would then focus on the ethics and behaviours of respectful interaction when speaking publicly alongside people with experience of mental illness. Although this new model was trialled in Workshop

One, the other workshop content (the Cape Drama and exercises) followed previous workshops.

WORKSHOP ONE DELIVERY

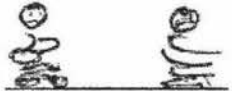



This workshop was the first day of a three-day workshop on public speaking for staff of mental health services. Staff from a variety of services had chosen to attend. The two facilitators for Workshop One, Chris Hansen and Jennie Hawira, had facilitated the previous workshops. The processes they used were those retained from previous workshops, based on a combination of experiential learning and Maori kawa. The reference group supported the practice of having Maori and Tauwi co-facilitators and the addressing of Maori cultural needs through the use of karakia and mihi.

The climate was set through opening karakia and gaining participants' shared agreement on ground rules stressing the confidentiality of people's stories. Participants were given the course aims and objectives and also discussed their own goals with each other and the facilitators.

All elements of Kolb's (1984) experiential learning cycle of observation, reflection, planning and action were included in the timetable (for complete timetable see Appendix Three). In the first exercise the whole group reflected on their previous understanding and experiences of stigma and discrimination. The model was then introduced with discussion about how they manifested through the ways people use to distance themselves from tangata whai ora. Participants shared discourse familiar in their workplaces and in community environments. Discussions clearly showed the links between discourse and behaviours.

Completed by the group the table showed the following:

Table Three: A framework for understanding relationships: participant responses

<u>RELATIONSHIPS</u>				
Relationship based on	Words/signs	Effects on consumers	Action	Distance
FEAR	escape, parole, don't, unacceptable awol non compliant risk management	lack of trust withdrawal alienation lost rejection feel blamed anxious lonely ashamed controlled	out of sight, out of mind isolation punishment removal of rights institutionalisation	
PITY, BENEVOLENCE PATERNALISM	inappropriate allow snap out of it turoro condescension sympathy	patronized belittled vulnerable devalued child-like over helped	speaking for people, telling people what to do lack of own voice advocacy	
RESPECT AND RIGHTS	tangata whai ora individual to fore empathy	independence equal warmth empowers self-acceptance choice	consumer voice self advocacy growth meaningful jobs and relationships	
CITIZENSHIP	no labels	openness about illness is possible okay to be different	everyone has a voice and is valued	

After the lunch break the Cape Drama was presented. The participatory drama began with a simulation of one of the experiences of people with a mental illness admitted to hospital. Returning to the room from lunch participants were stopped at the door and asked to give over something of value to them (watch, wallet, jewelry), in return receiving a positive label. Then the drama itself began, acted by the facilitators. One sitting, had a large black cape placed over her, a Cape that represented mental illness. Then the negative labels, words associated with stigma were added, until she threw back the Cape, denying the force of the labels and regaining her power. Participants were then invited to give their positive labels to the facilitator, to strengthen her for

the journey towards recovery. The facilitators concluded the drama with a song of strength and mutual support, 'E Tu Kahikatea'.

Both whole group and small group discussions were used to reflect on this experience, with sharing of emotional reactions and previous experiences of stigma and discrimination triggered by the drama.

Issues raised during this period of reflection formed the basis for the planning and action parts of the experiential cycle, in the final exercise. Because this group had enrolled for the following two-day workshop on public speaking, this discussion focused on the issues arising when people speak on behalf of others. Issues covered were of ethics, permission to use people's stories, the implicit message that results when people speak on behalf of others; the role participants can play when speaking in partnership alongside people with experience of mental illness; and the role of 'allies'. These participants all then carried this learning through to the next two days of training on techniques of public speaking.

EVALUATIONS AND INTERVIEWS FOLLOWING WORKSHOP ONE

QUESTIONNAIRE RESPONSES

There were 13 participants in Workshop One. The 11 participants who arrived on time, and were present when permission for the study was sought, agreed to take part in filling in pre and post workshop questionnaires. All 13 filled in the usual evaluation sheets at the end of the workshop. Nine participants took part in the post course interviews held 8 - 10 weeks later.

Identical questionnaires (Appendix One) were designed to be used at the beginning and at the end of the workshop to test its effectiveness in terms of the first objective: to see whether there was an increase in participants' awareness of stigma and discrimination in the field of mental illness. A ten point continuum (1= none to 10 =

a lot) was used for participants to mark their views on three questions. A comparison of differences between the pre and post workshop responses showed only minimal change in views. The three questions are below. At the end of each is the average difference recorded in responses made at the end of the workshop.

How much stigma and discrimination exists in the community?

+ 0.41

How much stigma and discrimination exists in mental health services?

+0.96

How often do you hear discriminatory language used?

+ 0.04

A fourth question was designed to see whether the workshop supported participants to become aware how much stigma could affect their own thoughts and actions. Participants were asked,

How often does the widespread stigma around mental illness affect your own thoughts and actions?

Responses were to be marked on continuum with 4 marks: 'daily', 'once a week', 'once a month', 'never'. There were some changes in individual responses pre and post workshop in both directions, yet the average score for this question was identical: that is there was, on average, no perceived change in awareness of stigma in their own thoughts and actions.

This finding did not reflect the results of both the written evaluations filled out in the workshop and the later interviews where participants clearly identified the way stigma and discrimination had influenced them. This variation in responses could have resulted from the complexity of the issue. It may have been too ambitious to use a single question and continuum to accurately measure a complex idea that required considerable reflection.

A continuum from 1 (not at all) to 4 (very much) was used for the answers to question

five:

How able do you feel to counter stigma and discrimination when it occurs?

The average score increased 0.6, indicating some small gains practical skills and knowledge. Interviews showed much greater gains, with participants reporting actual incidents where they worked to counter stigma and discrimination after attending the course, in some cases attributing their ability to skills gained on the workshop.

A sixth more open-ended question was designed to see if there was a change in the relationship participants envisaged having with tangata whai ora.

What words best describe the role you feel mental health service staff might play in the movement to reduce stigma and discrimination associated with mental illness?

Pre and post course answers both included such words as:

kaha, nui, strong; an important role; become more aware, breaking down the barriers

Post-course answers had stronger wording such as:

to check own value and belief system; more ... workshops, on-going, compulsory; heaps of discrimination amongst mental health professional/support workers; educate the public, colleagues, whanau I come in contact with about how normal people experience mental illness from time to time.

The information gained from this attempt to gather quantitative data through pre and post questionnaires was seen by the reference group as of little use. The process also intruded considerably on the limited time available for the workshop. Facilitators requested that this be discontinued, and only post workshop evaluations and interviews be used to gather information on Workshop Two.

EVALUATION FORMS

The post workshop evaluation form had open questions, examining workshop content and processes, and the impact of facilitator identity and issues of safety that had arisen.

FACILITATOR IDENTITY

The first two questions were designed to gauge whether participants had previously been to a workshop facilitated by people with experience of mental illness and how important (on a scale of 1 – 10) it had been to their learning that this was facilitated by tangata whai ora. Just over half had attended a workshop facilitated by people with experience of mental illness before, mostly to the half-day workshop 'Hearing Voices That Are Distressing' that had been delivered throughout the region over the past couple of years.

On the scale of 1-10, the average score was 9.3, indicating that this had been seen as important. The reason for this was later explored in interviews with most people seeing this as giving the information greater credibility.

CONTENT

In the third question of the evaluation participants rated various sections of the workshop according to how much each helped them improve their skills and knowledge. Rating was on a 1-5 scale (0 = not at all, 5 = a great deal). The highest average (4.5) was for the Cape Role Play, and second came the framework or categories of discrimination (4.2), with two other topics: a facilitator's story (3.7) and discussion on ethics of advocacy practices (3.7) coming close behind.

A fourth and final question asked:

What changes might you make to your language or practices as a result of attending this workshop?

Answers ranged from:

Working to avoid labels, to avoiding negative words like 'loopy' in general conversation.

INTERVIEWS

PROCESSES

All interviewees were asked whether they felt safe to say how they felt within the workshop. All but one said they felt very safe, one naming the emphasis on the confidentiality of stories early on in the workshop as helpful. One participant said she had felt unsafe because of the presence of a participant she had clashed with in the past who was in a small discussion group with her. She was then asked if it would have felt safer if participants had been enabled to form their own groups, rather than being given numbers and allocated to a group by the facilitators. She responded:

I think you numbered us off...in a way that was good. If we speak publicly that may happen and I have to be sure I can ...we have to be more accountable.

Although this participant reflected that her discomfort had some positive aspect, she did raise an important safety issue. It is hard to speak openly when people present have been critical of ones past work practices. The practice of allowing people to choose their own groups, previously only used by the facilitators in situations where emotional issues are discussed, should become standard throughout the workshop. Facilitators can never know, nor account for difficulties in pre-existing relationships.

Interviews also highlighted the issues faced by participants with an undisclosed experience of mental illness themselves. One participant said

By lunchtime it seemed almost everyone had questioned their own practice and more than half admitted to being tangata whai ora.

This participant had disclosed her identity to the group during the morning session and others had spoken to her confidentially over lunch about their past experiences.

She said that the courage shown by the facilitators in publicly owning their identity had given her courage to do the same. Since the workshop she had chosen to

challenge discriminatory remarks in a way that she would 'probably not' have done previously.

I was in a social situation recently in a group of about seven women and one of them said (about people with experience of mental illness), 'I would line them up and shoot them.' I replied 'Would you shoot me?' That turned the conversation around and there was an open discussion of the issues.

CONTENT

Near the beginning of interviews, participants were asked what they remembered of the day. This question aimed to find out which part of the workshops were retained in people's minds: or in Gladwell's (2000) terms were 'sticky'. All but one person interviewed first mentioned the Cape Drama and four spoke of how they had talked to other people about the experience. Some responses were:

The Cape thing...I felt like crying for her. I was telling people the other day about it.

The Cape giving Jennie back her dignity and her life.

The Cape was very emotional. It had a strong impact. Seeing it there visually, with the stigma attached. It was powerful.

One participant made the link with other forms of oppression

The stigma is associated with other things too, with racism and I looked at that as well. Since I came back from overseas I have felt the racism in New Zealand very strongly.

It also helped most participants reflect on their practices

My attitude was not different to those putting labels on when I started, four years ago.

I thought, how you start to act like that...to use labels, when people put labels on you.

Within the workshop, towards the end of the Cape Drama one participant expressed how hard she had found it to see someone under the Cape.

It was not just (the facilitator) there, but also her tipuna.

A final question whether participants had changed their behaviour as a result of attending the workshop. Defensiveness can result when people are asked to disclose behaviour changes as to do so implies previous behaviours were less than ideal and, in this case, may have been discriminatory, yet all participants reported either changes or intentions to act to reduce discrimination, whether a change in language used or 'talking about it (stigma and discrimination) to others'. Three mentioned having challenged others in services and the community about their use of language. Comments from four of the interviewees were

I'm not so patronising. It made me aware I could be. It opened my eyes to that.

It has given me a hunger to do something about it. I plan to work with my church. The church support the residential home but the people do not mix at church, nor visit. There is still a fear. People think, 'how do I talk to them?'

I think more carefully about things now. ... we can use inappropriate words... but when I heard tangata whai ora say how they made them feel...

I have started speaking to organisations... previously I had not asked tangata whai ora to come with me. Now I would.

When asked who else might benefit from the workshop, an interviewee said:

I would absolutely recommend it (to mental health service staff). There is nothing more powerful than having it come from people with experience of mental illness. ... If someone tells another's story it doesn't have the same emotional depth.

One commented:

You would get resistance from some. But it would give them a chance to reflect on their practices and attitudes. That's what I got out of it mostly.

Although resistance and defensiveness were minimal in this workshop, this highlighted the possibility of considerable resistance in workshops where attendance is compulsory. There is always a risk that people may react negatively to events. All

learning implies change and people attending experiential workshops designed to engage emotions, are more at risk than people attending lectures, which engage them only on an intellectual level. Careful planning means risk can be minimised but not eliminated. A workshop aiming to reduce workplace discrimination must challenge staff. Finding ways to maximise learning for people who may be resistant to such challenge became an issue to be addressed before the second workshop.

To summarise, data gathered following Workshop One confirmed that

1. Some behaviour changes could result from a one-day workshop, at least when participants were willing and open to change.
2. It was important to have people with experience of mental illness facilitate workshops, not only because of their expertise in their perspectives on services, but also because their wellness confirmed to participants that recovery was possible.
3. The Cape Drama was a valuable tool, bringing the 'stickiness' that results from emotional engagement.

and raised new questions and concerns

1. The need to ensure emotional and spiritual and cultural needs are met.
2. What further techniques could be found to reduce possible defensiveness and resistance.
3. How to apply the 'stickiness' evident in the Cape Drama to other sections of the workshop.
4. How to more actively involve participants throughout the workshop.

In addition, there was still a need to find a positive name for a stand-alone workshop.

REFLECTION AND REDESIGN FOLLOWING WORKSHOP ONE

In the 8 months that elapsed before the second workshop that was a focus for this study, issues that had arisen in the evaluations for the first workshop were addressed through

1. A further literature review.

2. Two workshops held for the group on experiential training techniques.
3. Reference group discussions/meeting/email debates.

I have grouped the findings from these into key topics to show how they informed the changes we made for the second workshop.

1. **Processes:** reflection based on meeting emotional, spiritual and cultural needs; reducing defensiveness; issues of language and the workshop name.
2. **Content:** reflection based on issues of 'stickiness': retention of new learning; translation of new knowledge into action – discard categories, bring in sociogram Action orientation: final activity (force field) and own action plan

PROCESS

EMOTIONAL AND SPIRITUAL NEEDS

Considering experiential learning, Julie Wylde (cited in Weil & McGill, 1989) reflected on her personal experience of the link between emotional states and learning:

...I have learnt that I cannot learn when I am tired, confused, angry or nervous. I cannot experience something new, outside of myself as interesting and challenging, if the interest and challenge is already being channelled towards a quite separate, prior, and more powerful internal experience. (p.115)

From Western cultural backgrounds most early writers on experiential learning based their ideas on scientific approaches to learning which emphasised cognitive processes, mirroring the way Western schooling extolled academic learning and paid scant attention to students' emotional needs. Kolb (1984) wrote about feeling, perceiving, thinking and behaving, but did not define feeling, nor explore the role of emotion, intuition and imagination in learning.

Later writers, such as Boud and Miller (1996) and Heron (1996), emphasised the importance of the social-emotional context in which learning occurred. They acknowledged that emotions and feelings played a key role in either enabling or acting as barriers to learning. Strong emotions influenced peoples' choices and if these were not addressed people could not learn. Boud and Miller suggested the affective experience of learners maybe the most powerful. All significant events gave rise to emotion. Indicating where people might wish to focus attention, they were a necessary part of the way they made choices. Such expression of emotions may be uncomfortable for facilitators, especially when differing from their own emotional reactions. They may be set aside temporarily because of immediate circumstances, but must be given attention during the learning process.

In Boud and Miller's (1996) collection of essays, Johnson argued that understanding and dealing with fear - one's own first and foremost - was of primary importance in bringing about personal change. Establishment of trust through setting a safe learning climate could allay fear. In a review of research based on Mezirow's transformative learning, Baumgartner (2001) noted several studies had pointed to the importance of processing feelings.

Heron (1993), who emphasised holistic learning and a consideration of spirituality, further developed elements of emotion and intuition in his workshops. He saw much experiential learning as ignoring vital parts of the 'whole person'. The 'shallowness' of some experiential learning missed potential learning power. Learning should involve the whole person - physical, perceptual, affective, cognitive, social and political, psychic and spiritual. Heron's workshops invited learners to 'celebrate, affirm and develop the positive emotional responses'; and 'resolve the negative by dissociation, cognitive reframing, emotional discharge or meditative transmutation' (p.65).

Influenced by Maori during work in Aotearoa/New Zealand, Heron (1996) noted the value of

the use of ritual for affirming spiritual integrity and solidarity of human beings; respect for the spirit of the place and living presence of nature; the concept of mana, personal charisma and power; the continuity of life beyond death and the relevance to human society of natural light; the importance of community, collective support...
(p. 76)

This need to address the spiritual elements in our workshop was evident in participant feedback immediately after the Cape Drama. A Maori participant said she felt 'maemae' (sorrow). It was not only the facilitator playing the part of the Cape, but also 'her tipuna' (ancestors) who were present. The group decided to strengthen support for participants' spiritual and emotional safety in this Drama, adding a prayer after the song used at its conclusion. This prayer would not just be for the facilitator who wore the Cape, but also for all people with experience of mental illness who had faced, or continued to face, stigma and discrimination.

To directly address emotional needs, during the reflection following the Cape Drama we decided to trial a resource I found valuable in Treaty workshops. Participants selected from over 100 cartoon pictures of positive and negative emotions, ones that reflected their own feelings, and discussed them with other participants in self-selected pairs. Later some shared emotions with the rest of the group. This part of the activity was voluntary but triggered a wide discussion of emotions and their influence on our thinking. Maori words and phrases developed by a Maori facilitator of Treaty workshops had been added to the original English language cards.

THE IMPORTANCE OF LANGUAGE

The workshop name

The workshop name was finally set before the second workshop. Within the Like Minds, Like Mine national movement to counter stigma and discrimination associated with mental illness, during this period there was a gradual increase in usage of the term tangata whai ora to refer to people with experience of mental illness. Although some people with experience of mental illness in the movement still have reservations about this term, and it is not officially endorsed by the Like Minds, Like Mine, Like

Mine national advisory group (Chris Hansen, national advisory group secretary: personal communication Oct 2001), it is now widely used.

This increasing acceptance of 'tangata whai ora', coupled with the decision that it was safe and effective for people with experience of mental illness to facilitate the workshops themselves, led to the new name: "Tangata Whai Ora Experiences". Evaluations for the first workshop showed few staff had attended a workshop facilitated by people with experience of mental illness, so a distinctive feature of this workshop had become the open identity of the facilitators. This name also promoted a central theme of a non-discriminatory approach, the importance of the voice of people with experience of mental illness being central in relationships that lead to recovery. The plural term 'experiences' was chosen to reflect the wide and varied nature of people's experiences both of mental illness itself and of the accompanying stigma and discrimination. Locating the workshop in individual experiences also reflected a post-modern approach implying many valid experiences, truths, and perspectives. It was hoped this would reduce defensiveness that can result when people feel one viewpoint is being pushed at the expense of others.

Discourse

An email debate held among people involved in the movement during June 2001 also dealt with the issue of language and emotion in the field. This began when a woman involved in project work searched for a word to describe people who fear, hate and discriminate against people with mental illness: i.e. a word parallel to 'racism' and 'homophobia' as descriptions of stigma and discrimination in other fields. Responses included 'mentophobic', 'psychophobic', 'mindist', 'mentalist' and 'psychist'.

However Tessa Thompson, then working in the Mental Health Commission objected to the use of the term 'phobic'

... we should not put a "quasi- medical" label on bigotry of any kind. It would be a very sad day if the anti discrimination project started labelling any type of bigotry , as a mental illness!!!! To consider bigotry as a phobia, degrades people who have serious mental health problems related to phobias, and also gives bigots an excuse.

A cautionary note was sounded by Jim Crowe, who works both nationally and internationally in education and advocacy on issues of mental illness. He noted the negativity and polarization that can arise with such terms,

To label those who have already labelled people with a mental illness may only cause them to strengthen their views. It may cause them to think that they are getting to you and now you're fighting back. ... positive everyday action and ongoing positive education will cause the change you seek .

Warren Lindberg, former director of the Aids Foundation and national project manager of Like Minds, Like Mine, endorsed this:

The concept of homophobia has not been particularly helpful to the gay rights cause. If our aim is to break down the barriers between people a new label isn't going to help.

However another commentator (Tessa Castree, Mental Health Commission) thought the negative label might act as a wake up call in some cases:

I can see Jim's point, but on the other hand, no-one likes to be called racist, sexist, homophobic, etc, so having a word to describe these unfortunate characteristics may be of some use.

My own experience of teaching Treaty workshops bore out the need for caution in the use of negative terms that might seem to be blaming. The words 'racism' and 'oppression' introduced after information on the history of colonisation had been presented were more readily accepted than if they were presented earlier in workshops. A link to structural analysis and systemic issues, also reduced perceptions of personal blame for oppression and racism, and made the words more acceptable.

DEFENSIVENESS

People's emotional reactions within the workshop continued to be a central concern. There have always been debates in Treaty education as to why some people become defensive and resistant to the content of the workshops. Dominelli (1997) noted that it was natural for people to feel extremely uncomfortable when they realised they

were playing the role of the oppressor. People developed several strategies to avoid having to hear and respond to information about racism. Some key ones were: denial - refusal to acknowledge the problem or an acceptance that racism exists out there (e.g. apartheid S Africa) but not here, and the 'dumping' approach that blamed the victims. These seem to be paralleled in discrimination against people with experience of mental illness. Some staff would see their role and power under the medical model as essential, and people with experience of mental illness not well enough to be able to be partners in recovery.

After confrontation by participants, facilitators may label those who become upset as fundamentally 'racist'. Derman-Sparks & Brunson Phillips (1997) found themselves 'writing off individual students too soon, rather than searching for ways to get past their resistance and defensiveness' and 'closing some students up by expressing anger too early' (p.146). Clearly participants arrive with different understandings and some are more or less open to the messages. However, labelling people who object to course content or processes as racist, can lead to a reluctance to examine the ways in which changes in processes and content can be made to support even the more reluctant participant to gain some new information and make some changes in attitude and behaviours. Heron (1993) notes that negative emotions

may be anxieties and disquiets that point to some fundamental flaw in the structure of the exercise, or in the concepts on which it is founded. It is important to differentiate between negative emotional responses that are blocks to learning and those that indicate ways in which it needs to be reorganized, either practically or conceptually or both together. (p.77)

In her work on learning processes, Barer-Stein (1987) observed a realisation of dissonance in learners, when their familiar 'tools' used to interpret situations suddenly no longer worked. Some people chose to be passive and ignored the new information, or engaged in verbal or physical battle to prove there was really no differing reality, or withdrew to their familiar world. For some people withdrawal seemed easier than forging into the unknown.

Anti-racism work has led me to view most discrimination as based on ignorance rather than malice. Teaching history and helping people analyse the effects of racism helped nearly all participants see the need for change without either battles or withdrawal. However there were occasional participants (where workshops were compulsory) who very quickly became oppositional. Adorno et al.'s (1950) theories on the effect of personality on discrimination may point to a reason for this. Over many years of Treaty work I have observed that many people resistant to new ideas seem to feel a need to be in control and hold onto authority.

A search was made for techniques to reduce withdrawal, battles or other defensive reactions. The likelihood of defensive responses is exacerbated by common western cultural thinking styles that tend to be oppositional or dualistic, with things seen in all-or-nothing or either-or terms (Hodge et al., 1975). Within this thinking style if any two things are in conflict, one must be good, the other bad. A person must pick one side and oppose the other, and their choice is then identified with the good, or closer to good. As Hodge et al. (1975) wrote: 'Complex problems requiring a balance of views and complex solutions often get reduced to the simple notion of victory versus defeat' (p. 225).

This thinking style can lead people to be defensive when new ideas presented conflict with their own. When people feel their ideas or behaviours are being criticised a cycle of self-protection arises and they close down. Fearing attack, they become less able to listen and learn. The workshop aimed to change people's ways of working, originating from professional training that emphasised the medical model, and practiced for many years. Resistance may be a natural and expected response in such circumstances. People, particularly those 'sent by management', and used to holding unquestioned authority under the medical model, may take an oppositional stance. The barriers they raise inhibit learning.

Eitington (1997, p.89) cited a classic 1961 study into defensiveness by psychologist J. Gibb identifying behaviour that can trigger either defensiveness or feelings of rapport, mutuality and support. He found people were more likely to become defensive if they

felt they were controlled, manipulated, criticised, and if communicator emphasised his/her superiority, or appeared to be certain they were right and was not empathetic. Of specific application to this study is that messages that implied a need for people to change in some way were perceived as an attempt to control them. Instead issues should be presented as problems. This communicated a flexible, open-ended approach without attempting to impose a solution. This approach was mutual and collaborative rather than unilateral and controlling.

Wadsworth and Epstein (1996) suggest that the culture of mental health services itself enables staff to ignore feedback and reflection on their practice, as it explicitly allows for staff to make decisions on others' behalf, often against their wishes, for the 'greater good' of improved health later.

In such a culture where it is permissible to put aside the 'now' it can also become possible to put aside the 'impact of the 'now' on the later lives of individual consumers. At the same time it is possible to see feedback as an artefact of the symptoms of illness rather than a genuine comment about the quality of the service. (p.39)

In one of their training manuals for facilitators, Hope and Timmel (1984b) wrote about the 'creative use of opposition'. They noted the emotional aspects that arose when people's ideas were opposed as people often saw such opposition as a personal attacks. Three responses are possible to opposition: to resist it and meet hostility with hostility; to avoid it and ignore the person; or to use the opposition creatively. To do the latter facilitators must acknowledge the person's dignity and worth, taking into account their feelings and ideas. By accepting their way of seeing a situation and enabling freedom to express it, dialogue can begin and everyone (including the facilitators) can learn. This stance was risky and required courage. Facilitators needed to be open to compromise and to accepting correction when it was justified.

The key facilitators decided to trial three strategies to reduce defensiveness. Firstly they would acknowledge the difficulties inherent in adult learning: "We acknowledge the courage you have to come here. All learning leads to change and takes courage. We want this to be a safe place for learning so we need some ground rules....".

Ground rules would then include supporting open and honest debate, with no put downs or personal attacks.

Secondly, they wished to signal a postmodern stance. Postmodernists view knowledge as tentative and multifaceted and always subject to challenge, for there are many 'truths' (Kilgore, 2001). Truth is seen as relative, seen from many viewpoints, and this relativism has been challenged as leading to a position where all viewpoints can be seen as equally valid or useful and where, in contrast to dualism, there is no right or wrong. For example, discriminatory beliefs about people with experience of mental illness could be seen as just different ways of viewing the world and therefore 'okay'. Yet human rights legislation in our culture reinforces the idea that discriminatory behaviours are 'wrong'. Do we have a right to challenge the worst excesses of institutionalisation or current services? I believe we do as aspects of the medical model and misuse of professional power lead to the imposition of people's views on people with experience of mental illness. However it is important to make such challenges without reverting to dualism. If common goals are recognised (such as recovery or respect for people with experience of mental illness) a variety of views can be discussed about how to reach those goals. If we do not stereotype the medical model as 'all bad' then we avoid possible defensiveness and can acknowledge aspects of treatment developed under the medical model, such as some medications, that are seen as useful by people with experience of mental illness.

After ground rules were set in Treaty workshops I had developed a statement to show that our intention was for a variety of views to be put forward safely. Facilitators would speak as individuals without generalising, and acknowledge there were many histories. This also pre-empted any challenge that facilitators' viewpoints might not be representative.

This practice was adopted in Workshop Two, with the following version used:

- We are not here to tell you what to think but we will encourage you to think outside the square.

- We are not here to tell you what to say, but we will encourage you to consider the effects your words have on others.
- We are not here to tell you what to do, but we will encourage you to consider how your actions can accord with your beliefs and values.

Another Treaty facilitator who trialled this in cultural safety training reported it helped reduce defensiveness, with students giving an almost audible sigh of relief after she read it.

The third change to reduce resistance was the inclusion of a safe way to open up discussion on contentious issues. A continuum was drawn with cards denoting 'agree' at one end and 'disagree' at the other. Controversial statements on cards were presented, such as 'People who are unwell should be made to take their medication'. Participants were asked to consider their own views and, in accordance with these, move the card to a place on the continuum. They were then asked to say why they had placed it there. This gave everyone a chance to participate and a variety of viewpoints on fundamental issues of control and rights to be expressed and considered. It was likely that some staff would agree with non-discriminatory statements, so this was unlikely to become an 'us' and 'them' dualistic debate, but rather give everyone a chance to note the complexity of the issues. Facilitators could make their own views explicit, without dominating the discussion. This technique was likely to be effective in producing lasting attitude change. Research findings supported by Eagly & Chaiken (1993, p. 499) showed people became more resistant to counter-argument after hearing two sides of an issue, and feeling their own viewpoint was heard and accepted.

Research also showed that people changed their beliefs more towards a position advocated in the persuasive messages when they had delivered the communication themselves rather than listened to another person deliver the communication Eagly and Chaiken (1993, p. 501). This technique could also be used in small group discussion where most participants would be able to take part.

CONTENT

Workshop Two aimed to support participants to:

1. Define stigma and discrimination associated with mental illness and its effects.
2. Recognise beliefs and attitudes leading to discriminatory behaviours: dangerousness and unpredictability (control); incompetence (paternalism).
3. Understand how attitudes and beliefs manifest themselves in behaviours.
4. Identify discriminatory behaviours in various settings: community, services, family relationships, employment.
5. Identify non-discriminatory attitudes and behaviours that promote respect for people with experience of mental illness.

One issue for the reference group was retention of learning. The model used in Workshop One, designed to support people to evaluate actions and discourse after the workshop, had not been retained. Facilitators decided the ideas were too complex to develop in a one-day workshop. Alternative ways were needed to show the links between attitudes, language and action, and the subtle discrimination of paternalism.

This was addressed in a revision to the Cape Drama. Facilitators now made clear that the Cape did not represent mental illness itself, but the stigma and discrimination accompanying it. Labels were introduced in the context of sentences, (Appendix Four) more clearly showing the links between discourse and behaviours that distanced and isolated people. Different segments highlighted, in turn, discrimination based on fear and on pity, and reactions of staff, family and community (neighbour, employer). Nursing notes were contrasted with the thoughts and reactions of the 'patient' (facilitator wearing the Cape), to the distancing behaviours.

Two new exercises were found and trialled in Workshop Two, both introduced by a Like Minds, Like Mine, Like Mine project worker, Debbie Hager of Framework Trust during a workshop for the facilitation team. Taking Steps (Appendix Four), actively involved all participants in delineating discriminatory behaviours and linking those

associated with mental illness with other grounds of discrimination. This exercise showed that some people faced discrimination on two or three counts: as Maori, or as women as well as on grounds of an experience of mental illness. Secondly a sociogram gave a powerful visual representation highlighting the distancing behaviours and resulting isolation faced by people who become unwell. This actively involved participants representing the different people involved in the life of a central character. Once the central character became unwell they moved physically to represent the change in their relationship. Finally facilitators noted that for some people who became unwell the only people in their lives were people paid to be there.

With the framework there had been discussion of non-discriminatory relationships and how these could become part of daily practice. Without the framework a different way was needed to link learning with actions that could be implemented in daily practices. A new interactive technique was used for this: Force Field Analysis - a shared assessment of the forces working for and against respect for people with experience of mental illness (Barndt 1989, Hope & Timmel, 1984a). This was followed by paired work filling out a handout, asking participants to consider what they had learnt and to make a commitment to change (Appendix Four).

Table Four: Summary of changes for Workshop Two

	Issue	Considerations	Plans
1	Emotional and spiritual needs	Importance of openly acknowledging participants' emotional and spiritual needs	Additional prayer after the Cape Drama; 'emotions' cards to debrief it.
2	Climate	Ensuring there is safety necessary for open debate	Facilitators 'postmodern' statement to set open climate Agree/disagree discussion
3	Reducing defensiveness	Supporting people who might be resistant to open themselves to new learning	Acknowledge courage Avoid use of negative/blaming terms
4	Workshop name	Facilitator identity credibility; postmodern approach	Tangata Whai Ora Experiences
5	Retention of learning	Framework not used; experiential techniques retained longest	Discard framework and change Cape to highlight discourse and paternalism
6	Action orientation	Without the framework how can we make this relevant to practice?	Force field analysis; individual commitment handout

WORKSHOP TWO DELIVERY

Workshop Two was facilitated by the same two key facilitators, Jennie Hawira and Chris Hansen, who had facilitated Workshop One, assisted by Barbara Hart, who facilitated one exercise. Participants were 27 mental health staff, from hospital and community based services, both mainstream and Maori.

After setting the climate the facilitators began with the new Taking Steps exercise that set stigma and discrimination associated with mental illness into a context of discrimination on many grounds. This was followed by the Cape Drama – brought into the workshop earlier to hook in participants with its emotional impact. After a discussion of the learning from this drama there was a focus on the emotions aroused. Following lunch there was a discussion on key issues of debate in the field. Using the agree/disagree cards to facilitate this many people offered differing opinions so a variety of responses to issues often debated in the field of mental illness were considered.

Working in groups, participants then completed a Force Field Analysis to focus on factors that helped or hindered moves towards sustained respect for people with experience of mental illness. Following this they were asked in pairs to make a personal commitment to achievable goals for themselves that would support this change. A full timetable is in Appendix Four.

EVALUATIONS AND INTERVIEWS AFTER WORKSHOP TWO

The information gained from evaluations and interviews is grouped into issues explored. Interviews were conducted with all eight participants who gave permission, 10-12 weeks after the workshop. This was two weeks longer than the gap allowed after Workshop One due to illness.

PROCESSES

RESISTANCE

Attendance had been made compulsory for some in-patient staff, which led to some resistance. A member of the management team explained:

Some from the ward were directed to go. It is so important for in-patient nurses to get a perspective on recovery and make them think beyond the ward. Some get burnt out a little, and get cynical and say things like 'she's always carrying on'. ... There is no recovery focus in the ward. They need to know who the patients really are.

Resistance among these participants was evident through body language such as crossed arms, and facial expression, and a reluctance to participate. None agreed to take part in interviews, and not all completed their evaluation forms, so the reasons for their behaviours can only be surmised. However one participant wrote on the evaluation form

Watch that an 'us' (mental health workers) and 'them' (clients) situation is not set up. We are always working towards the same end result (a person functioning as well as possible). Please be more positive about the intervention of staff, particularly those on the floor during acute periods of illness.

This was a wake up call to continue to search for ways to avoid slipping into a dualistic frame, even when participants come with a negative attitude.

One participant interviewed said

...some did not look interested, they looked out the window. Some quite high up [positions]. A couple said to me later, 'What is the point of doing that, it's a waste of our time'. They did not want to learn. Their positions are to look after people, but for some it's a job and that's it.

A staff member reported some negative feedback later:

One nurse from the inpatient unit said it was a load of rubbish... 'why do we have to have all that politically correct nonsense...it was a lot of gobbleydoock. They should try working in the unit with all these mad people'. She's one I'd like to see change, she's so parental in her manner. Another one...said it was okay but she

didn't really enjoy it, and didn't really get anything out of it. But she's always negative.

It may well be unrealistic to expect success with every participant, yet people holding such discriminatory attitudes, and exhibiting accompanying behaviours such as paternalism, can diminish people's chances to recover. We cannot dismiss this group of people but need to continually work to find ways to get through the barriers they set up.

SAFETY

The issue of safety was raised again during interviews, and no one reported having felt anything but safe to speak out. Participants were positive about the emotional climate set.

[It was] emotional and spiritual. I feel my eyes have been opened.

One exercise that promoted safe discussion (using the Agree/Disagree continuum) was clearly recalled during interviews. It had enabled everyone to have a say and be listened to respectfully. It also clearly showed the complexity of issues. Some comments were:

I couldn't get over how difficult the questions were.... My own thoughts on where it would be were totally different to others.

The questions help people listen to each other's viewpoints. I was amazed at the response to the question on medication. The head nurse got up and said she strongly agreed that people should be forced to take medication.

[The statements] generated lots of discussion.... I would think – that's where it should go – and then listen and change my mind -

EMOTIONAL ENGAGEMENT

Participants clearly recalled parts of the workshop that affected them emotionally.

I was moved by Chris's story – where she came from – nearly losing her house and children. She was really brave to be so honest.

I was amazed. It changed a lot of nurses' views on how they treated tangata whai ora. One of the big battles is getting through how people feel. I saw a lot of tears flowing. It was a realization, an awakening for a lot of people.

The revised Cape Drama proved effective in showing how services act to distance staff from people they support:

I saw how dark and lonely they can feel even with all the staff around them.

I've been 12 years in mental health and some things like that just get taken for granted. You forget about the people with lives and treat the illness.

I remember how we had to hand in our possessions. That made me realise how it was for them in the ward, when their possessions are taken away because they are unwell. It felt wrong – they should be allowed to keep something. It helped me understand how they feel.

Facilitators felt the use of the emotions cards to debrief after the Cape Drama helped participants cope with its emotional impact. One person interviewed said

I remember the cards with the emotions on them. I was going through a bad patch at work.... I felt my vulnerability.

As in the first workshop, interviewees were first asked what they recalled. Responses were more varied, showing that it was not just the Cape Drama that was 'sticky' but also some new exercises:

...the sociogram – that was quite good – people standing around and how friends stepped out and health people came in, how that affected tangata whai ora.

One of the facilitator's personal stories was especially helpful in making staff realise their own vulnerability, as she had been a mental health service manager before becoming unwell. One participant said

I thought I could have a nervous breakdown tomorrow and go into the ward and experience the same thing. I know they do some good work but some clients I work with are terrified to go there.

One participant found Chris' story had more impact for her than the Cape Drama which was

... interesting but not as real as someone's real story and having empathy with someone.

But participants can find ways to discount challenging information. Maybe Chris did not have a 'real' mental illness. Referring to her story, one interviewee said

I talked to people at work and they still think 'that'll never happen to me'. They see Chris as having had a temporary illness, someone who got over it and now copes.

LEARNING

Emotionally engaged, the next question became 'What did participants learn?'

Reported self-evaluation showed that most participants felt they had learnt much. Asked whether they had gained more understanding of discrimination within the community four out of 23 participants marked the 'not much' (1-2) end of a continuum. In contrast the other 17 marked the high end of the same continuum (7-10). Asked about improvements in understanding of discrimination within mental health services there was a similar gap, with seven marks towards the 'not much end' (1-4), and 16 from 5 – 10, with a median of 8. Comments indicated at least some felt they did not learn much because they already had a good understanding of the topic:

[It] was a good reminder about nursing practice, as [I] work with acutely unwell people mainly and I believe I have an awareness of this,

In evaluations immediately after the workshop, fifteen participants asked what changes they might make to their language or other practices, one commented “not much” and fourteen gave examples of positive changes such as:

Own discrimination; use positive and uplifting words and not label people; being with and not doing to; equal, adult, non-paternalistic, respectful; treat others the way I would like to be treated. Who knows what may happen down the track – the tables may turn...

All eight interviewees reported some changes in behaviour since the workshop, such as:

I probably listen more now...to the emotional part of their conversation and understand now why they feel that way.

Overall the results of these evaluations and interviews was positive, yet they showed further work was needed to ensure that people who arrived feeling defensive were hooked into learning and to further reduce any chance of a dualistic ‘them’ and ‘us’ climate developing.

CHAPTER FIVE: REFLECTION AND REDESIGN

In the months following Workshop Two several more issues were identified and further changes are now being implemented or planned.

1. THE RECOVERY MODEL

Following this workshop a key new resource became available: the Mental Health Commission's Recovery Competencies, published mid 2001. Developed for all mental health professionals these described 'best practices', and listed the attitudes, skills and knowledge required of the mental health workforce. The document noted that they signalled a fundamental change to all aspects of the education of mental health staff. Linking the workshop to practices acknowledged as supporting recovery would give it more credibility. Supported by both professionals and people with experience of mental illness, the recovery model has the potential to reduce 'them' and 'us' impressions. People with experience of mental illness and mental health services staff need to work in partnership in this new paradigm.

2. CLARIFYING CULTURAL CHANGES

A new framework was developed to clarify the cultural changes needed as services move towards the recovery model. A useful table developed by Marsh et al. (1997, p.360) showed the paradigm shift in professional practice needed to move from what they termed the 'pathology paradigm' to the 'competence paradigm'. This would give participants a tool to evaluate their practices and judge new information acquired after the workshop. Through face-to-face and email discussions within the reference group the original table was substantially modified and simplified to make a framework for Aotearoa/New Zealand:

Table Five: A draft framework to show cultural change in services

<u>A CULTURAL CHANGE IN MENTAL HEALTH SERVICES</u>		
	Medical model	Recovery model
Overview is a... (paradigm)	disease based medical model	health based developmental model
Services...	treat individuals	support people to live well in their community
People with experience of mental illness are...	mentally ill passive patients	unique individuals active partners
Services emphasise...	problems and limitations	strengths and resources
Expertise lies in...	professionals only	partnership led by people with experience of mental illness
Services model is...	hierarchical 'power over'	power sharing 'power with'
People assessed on...	clinical diagnosis	strengths and needs
Key methods are...	medication, psychotherapy	building on strengths, linking people to community
Cultural perspectives are...	monocultural	cultural safety
Role of community is...	none - exclusion	essential - inclusion

Early versions were trialled in two presentations: one to first year nursing students; another to participants at a mental health conference and feedback has been positive. The current draft is being more widely circulated for comment within the mental health field.

If this can engender discussion and enough staff buy into this vision then they can work with people with experience of mental illness to plan how to move towards a recovery model. The workshop can only be a first step to enlist people on this journey. As the Melbourne study (Wadsworth & Epstein 1996) on consumer involvement in psychiatric services noted:

We found that in the supremely sensitive area of acute psychiatric services, no deep cultural shifts of the kind that both consumers and

staff want are likely to take place unless committed staff and consumers who want there to be change, [can] come together to re-envision the culture they daily enact. (p. 40)

New resources (a series of cartoons and quotations from people with experience of mental illness) are being developed to engender reflection and discussion on the way

- the paradigms are reflected in the experiences of service users;
- the paradigms are reflected in both discourse and other behaviours of staff

These will also increase the diversity of 'voices' heard during the workshop and help make the vital link with practices. Ideally once enough have been gathered, these could be used to illustrate each area in the framework.

Recently the Mental Health Commission (2001) has published a booklet to celebrate the stories of mental health service staff who show sustained respect for people they support and use a recovery approach in their work. This booklet, and a number of posters that accompany it will be useful resources.

3. AVOIDING DUALISM

Such a model is in danger of becoming dualistic, highlighting two extremes with the implications that practices swing between extremes: irredeemably bad or perfect. In reality most staff practices are somewhere on the journey between one extreme and the other. A dualistic model, contrasting the medical and recovery models, could lead to defensiveness by participants whose work has predominantly been within the medical model. It would be necessary to acknowledge that many staff in medical model services, in spite of the service culture, have worked positively to support recovery and save lives. To show the journey between one model and the other it may be helpful to develop a continuum of behavioural changes identifying stages on this journey. Participants could then see both where they are personally on such a continuum, as well as where their organisation is placed, and what changes might be needed by individual staff and for the service as a whole.

4. CREDIBILITY

Linking the workshops to the recovery model promoted by the Mental Health Commission will add to their credibility. In addition it would be useful to also have workshops identified as a normal part of the reflection necessary for good professional practice, as promulgated by Schon (1983). If the workshop process is seen as an essential component of good practice, a positive attitude to participation, listening and reflection may follow. This emphasis can be made in leaflets and flyers advertising the workshop.

5. RESISTANCE AND THE TRANSTHEORETICAL MODEL

Interviews and evaluations pointed to the variety of attitudes and beliefs people brought to the workshop, with some participants more open to change than others. A model was found that enabled these differences to be taken into account in planning workshops. This was the Transtheoretical Model of change used extensively in health promotion and organisational change (Prochaska et al, 2001). In this model behaviour change was a process or journey, not a single event. This reinforced the need for training to be part of a larger process, such as changes in organisational policies and procedures.

People were at different stages of readiness to undertake such a journey. The stages, most often applied to smoking cessation, were

1. Precontemplation – where people were not intending to make any change. They were unmotivated and either did not see a need to change, or had tried without success. This would equate to reluctant workshop participants ‘sent’ by their managers.
2. Contemplation – where people intended to change within the next 6 months. This group were becoming aware of the positives of change but also were acutely aware of the negatives (possibly difficulty in implementation, lack of skills needed, loss of professional power inherent in the medical model). Prochaska noted the importance of the ‘decisional balance’. The crucial move from stage II, contemplation, to stage III, preparation, happened when the gains to be made by change were seen to outweigh the losses. To be motivated

to change people need a reason that resonated with them. What reasons to change work practices in line with the recovery model might appeal to mental health service staff? Staff motivated to help others, would welcome change if convinced practices of the recovery model were effective. A barrier could be a lessening of their professional control and authority. It was also helpful if people were given choices at this point, to avoid feeling backed into a corner.

3. Preparation – people intended to take action in the next month and were looking for ideas on how to behave, how to plan for success. These people were seeking concrete examples of changes they could make.
4. Action – people had made specific changes in the past six months and vigilance against relapse was critical. Here workshops could support them to continue with their new behaviours, and encourage their colleagues to make changes too.
5. Maintenance – by now people were increasingly confident in new behaviours. In mental health services improved relationships with service users should help maintain behaviours. Post workshop support materials would be useful e.g. discussion topics for staff meetings, posters etc. Linking new behaviours to performance appraisals and other internal mechanisms would reinforce maintenance.

In this model it was noted that some regression was usual though people rarely went right back to the beginning. Regression by mental health staff to previous medical model behaviours (such as authoritarian attitudes and unnecessary use of coercion) might happen when they were under stress. Change in a service's policies and procedures would encourage and support new behaviours and make regression less likely.

The transtheoretical model examined both experiential and behavioural processes of change. The experiential ones were more important in the early stages (pre-contemplation, contemplation, preparation) and the behavioural ones in the later stages of change. In brackets are some thoughts on how these could apply to education for change in mental health services.

EXPERIENTIAL (PROCESSES SUITABLE FOR WORKSHOP SETTINGS)

- Consciousness raising increased awareness (understanding impact of discrimination)
- Dramatic relief – emotional reaction (personal stories, the Cape Drama)
- Environmental reevaluation- social reappraisal (positive and negative role models, peer pressures)
- Social liberation – more acceptable to be non-discriminatory (cultural change that recognises and supports positive behaviours)
- Self Reevaluation – self appraisal (encourage awareness of impact of behaviour on others)

BEHAVIOURAL (MOSTLY OCCURRING IN THE WORKPLACE)

- Stimulus control – remove triggers to old behaviours; include triggers for new behaviours (posters, policies, guidelines and expectations about what is acceptable)
- Helping relationships – supporting (buddy systems, staff meetings)
- Counter conditioning – substituting (practising new behaviours until they become ‘second nature’)
- Reinforcement management – rewarding (consequences for the changes made, group rewards)
- Self liberation – commitment to change (for example: public statements supporting recovery practices)

6 SYSTEMIC CHANGE

Although in the field of mental illness individual interactions are key to good practice and within the power of each person to change, there are also systemic changes needed. As Gladwell (2000) noted, small changes in the context in which people work can make a big difference. Individuals working in mental health services can encourage changes in policies and procedures to increase the voice of people with experience of mental illness. The need for systemic changes was introduced briefly using the exercise called Force Field Analysis in Workshop Two. These cannot be adequately addressed in a one-day workshop, but can be introduced so participants

leave knowing there are ways they can support systemic change. It would also be important to work with mental health services on designing a longer workshop or a follow up one.

Table Six: Summary of Changes planned following Workshop Two

	<u>Issue</u>	<u>Considerations</u>	<u>Plans</u>
1	Mental Health Commission's Recovery Competencies	Linking the workshop to these will enhance its credibility and hook people in.	The workshop can be marketed as an introduction to the recovery model; all exercises and handouts can be linked to this theme.
2	Clarifying cultural changes	Support participants to reflect on and interpret their experiences (Mezirow, Stalker)	A new framework developed and trialled.
3	Credibility	Normalise and add value to the process of reflection in the workshop by linking it with good professional practice	Advertise workshops as reflection common to good professional practice.
4	Avoiding dualism	Avoid extremes, to reduce defensiveness and enable realistic steps to change to be identified.	Present cultural change as a journey with signposts to be identified by participants.
5	Resistance	Accounting and allowing for differences in participants willingness to contemplate change.	Explore implications of the transtheoretical model of change
6	Need for systemic change	Show participants how they can support systemic change	Discuss ways individual staff can support improvements of policies and procedures within their organisation

CONCLUSION

Action research by its very nature is designed to be specific and this research informed the design of a workshop for mental health services.

In spite of its specific nature I feel the research has raised a number of issues, listed below, that are worth considering when designing workshops focusing on other forms of discrimination.

CONSIDERATIONS FOR THE DESIGN OF WORKSHOPS ON DISCRIMINATION

1. It is important to pay equal attention in workshop design to content and process.
2. In setting the climate, it helps to use a postmodern approach, openly acknowledging different perspectives.
3. Learning needs to be made relevant to individuals, so participants who wish to change know what steps to take. Support them to work out for themselves the steps they wish to take.
4. Ensure participants understand the institutionalised nature of discrimination and its effect on individual interactions
5. It is helpful to give participants tools to evaluate their actions and any further information they acquire after the workshop
6. Discrimination can be overt and covert. Show the various ways it manifests through an analysis of discourse.
7. Ensure participants are aware of the benefits of change; and these benefits appeal to people at different stages of the journey.
8. Drama and other techniques that arouse participants' emotions are very effective, but there needs to be time to discuss their emotional effects.
9. Use opposition creatively, to reduce possible feelings of criticism and blame.
10. Moving towards a position of respect is a journey. Support participants to work out for themselves steps on a journey, where they are now and what their aims might be.

The action research methodology proved worthwhile enabling me to reflect on practices, search the literature from a variety of different disciplines for ideas, sharing ideas with the reference group, applying them and trialling and evaluating new

techniques. Previously elements of workshops I planned and facilitated were based on what seemed 'politically correct', their consequences and effectiveness unexamined. This study has afforded me a rare privilege, as facilitators do not often get time to examine issues from many angles and trial new techniques.

I considered the implications of theories and ideas from several disciplines on the design of workshops to reduce stigma and discrimination within mental health services. We have developed a more postmodern approach, welcoming discussion and differing opinions, acknowledging that there are many truths. This fits well into a workshop that primarily is about the viewpoints of people so often silenced by the practices of the medical model. An unknown source provided an apt quotation cited in Wadsworth, & Epstein, (1996): "If you want to know how we are repressed, listen carefully to what we are not allowed to say". (p. 153)

The trap of extreme relativism, of all seeing viewpoints as equally valid, was circumvented, for discrimination, in its essence, acts to silence people and deny them access to choices and opportunity. This workshop is centred on ensuring that 'truths' that have been suppressed are heard so dialogue, participation and partnership can begin.

Through our observations and reflection on facilitator identity we developed a clear stance on this issue. We examined issues of safety and effectiveness, but found it important that facilitators do identify as having experience of mental illness. If others facilitate there is an implicit message in direct contradiction to the central premise of the workshop.

During the study I became increasingly aware of the extent of stigma and discrimination in services. For example this manifested in the low expectations of staff, evident in the expressions of surprise that people could become well enough to facilitate workshops. The journey between wellness and unwellness went one way only. People irredeemably became 'other'. Firmly attached, their label would not be

easily dislodged. Changing the discrimination that accompanies it will need sustained work on many fronts.

I noted that, although there are similarities between anti-discrimination movements, generalizing from one kind of discrimination to another is not always useful. Fundamental differences became apparent such as the inextricable and intimate links people with experience of mental illness have with the staff of mental health services whose organisations were seen as the site of discrimination in this study.

In terms of the processes used, the workshop evaluations gave me an opportunity to reflect on the participants' differing reactions and to look for ways workshops can be delivered to meet more of their diverse needs and viewpoints. People will only make changes if they see a reason that makes sense to them, and they have to be at a stage of readiness to receive the message.

Frustratingly it was not possible to gain first hand viewpoints from all participants. Most useful would have been the opinions of those who were most defensive, yet these people did not wish to be interviewed and their viewpoints could only be surmised from their behaviours or comments during workshops and comments from their colleagues. The strength of opposition to change must be taken into account.

Key highlights were

- the development of a more 'postmodern' workshop looking at different paradigms and welcoming viewpoints and dissent
- the further inclusion of ways to meet the spiritual and emotional needs of participants
- the development of a framework to clarify the new paradigm of recovery
- growing awareness of the importance of having facilitators identifying as people with experience of mental illness

The next step must be to integrate this workshop into other techniques which organisations can use to bring about change, such as revamped policies and procedures, and opportunities within the workplace for reflection on practices. An

ideal follow up study would be a longitudinal action research on a service promoting change to evaluate the effectiveness of this workshop and other factors promoting change can work together.

APPENDICES

APPENDIX ONE

ETHICS

Included here is the original application made to the Massey University ethics committee.

The committee requested some minor amendments before final approval was given.

Following the application are the final approval letter and a sample of the amended information and consent forms.

MASSEY UNIVERSITY HUMAN ETHICS COMMITTEE
ALBANY CAMPUS

APPLICATION FOR APPROVAL OF PROPOSED RESEARCH
PROCEDURES INVOLVING HUMAN SUBJECTS

Name: Ruth Gerzon

Contact numbers: email: gerzon.r@xtra.co.nz; Cell: (025) 308 149 Ph (07) 312 5310

Address: P O Box 3017, Ohope, Whakatane

Status of Applicant: M. Phil student

Department: School of Social Policy and Social Work

Current Employment: Executive Officer, Serious Fun 'N Mind Trust, Bay of Plenty

Project Status: M. Phil thesis

Funding source: No funding sought

Clinical Trial Status: No

Supervisors: Marilyn Waring, Associate Professor, School of Social Policy and Social Work; Massey University, Private Bag 102 904, North Shore Mail Centre, Albany
(09) 443 9665 email M.J.Waring@massey.ac.nz

Carole Adamson, Lecturer, School of Social Policy and Social Work; Massey University, Private Bag 102904, North Shore Mail Centre, Albany
(09) 443 9771 email C.E.Adamson@massey.ac.nz

Title: Changing the paradigm? Reflections on the learning and experience of participants in workshops to reduce stigma and discrimination associated with mental illness

Attachments:

- ☐ Four Consent Forms (for interviews/tape recordings, participants managers, reference group)
- ☐ Three information sheets (for participants, managers, reference group members)
- ☐ Draft sample questions for questionnaires, evaluations and interviews

Signatures:

Applicant:.....

Supervisors:.....

.....

Date: 12 April 2000

1. Description:

1.1 Justification

Currently the national Like Minds Project is working on measures to reduce the stigma and discrimination associated with mental illness. Workshops are being set up around the country for mental health service staff, government agencies, and the general public, using a variety of techniques. Part of my work is to co-ordinate the development of resources and training of facilitators for these workshops in the Bay of Plenty. To ensure the effectiveness of the workshops it would be useful to examine current theoretical knowledge and the effectiveness of adult education practices in this and other anti-discrimination areas.

I plan to use action research to directly inform and improve the work in progress. Following the work of Carr and Kemmis (1986) I see this as enquiry in an educational setting in order to improve the effectiveness and justice of educational practices. Alongside me will be a reference group of people with an experience of mental illness who are facilitating the workshops. Information gathered from the participants will be used to improve the planning and delivery, and production of resources for further workshops.

1.2 Objectives

I am aware that participants can find anti-discrimination courses difficult and challenging for a variety of reasons. I wish to examine how participants respond to various techniques used, explore possible blocks to learning and then focus on improving the workshop experience, resource materials and learning outcomes.

1.3 Procedure for Recruiting Participants and Obtaining Informed Consent

1.3.1 Reference Group

The focus of the research will be on the participants attending the workshop, but consent will also be needed by workshop facilitators. These facilitators will be the reference group working with me on this action research, and their concerns and questions will become part of the study. In this way they will be not only fully informed but will also contribute to the direction of the research.

1.3.2 Participants

- Workshops may be held on a number of sites: offered to the general community and to organisations whose personnel or students come into contact with people with an experience of mental illness. Where workshops are held for organisations I will begin by obtaining the consent of the relevant organisation. I will give the manager a copy of both the manager's and participant's information sheets, discuss the

research and ask him/her to sign a consent form, if s/he is willing for the research to take place in their organisation.

- Recruitment and informed consent for the use of pre and post course questionnaire and evaluation sheets. I will give out and discuss the attached participant information sheet at the beginning of each workshop, and ask participants to sign a consent form if they wish to take part. I will make it clear that this is voluntary and that there will be no negative repercussions for those who decline to take part.
- Recruitment and informed consent for post-course interviews. At the bottom of each workshop evaluation form, participants interested in taking part in an interview will be asked to include their names and phone numbers. They will be offered an option of a small group or individual interview.

1.4 Procedures in which research participants will be involved

When gathering data from participants the exact nature of the questions used will vary according to the objectives and length of the workshops.

I propose to gather data in the following ways:

- by asking participants to complete both brief pre and post-workshop questionnaires designed to assess their knowledge and attitudes. The questionnaires will vary over time as each set of new data may bring up new issues.
- through post-workshop evaluation forms to assess participants' immediate response to the workshop.
- workshops may be video or audio taped in order to record events for later analysis
- a small number of participants will be invited to take part in a short interview 3-6 weeks after a workshop to examine whether the workshops have resulted in changes in practices.

2 Ethical Concerns

2.1 Access to Participants

2.1.1 Each organisation will be asked to give consent to the research being carried out within their organisation. The information sheet and consent form are attached.

2.2 Informed consent

All participants will be adult volunteers. The information sheets and consent forms will be fully explained to them.

2.3 Anonymity and Confidentiality

All written material will be kept in a locked cabinet in my office sited at my home. I will not divulge the identity of participants in writing up or publishing the research. The only exception will be oral discussions held about participants views and needs with members of the reference group present during workshops. In my thesis I will quote from the interviews to enhance understanding of the

viewpoint of the participants concerned. Names and identifying characteristics will not be used in this or any part of the project. Where participants consent to small group interviews all members will be asked to maintain complete confidentiality of information given in interviews. Any participant may have an individual interview if that is preferred.

Members of the reference group may choose whether or not to have their contributions acknowledged or kept anonymous.

2.4 Potential harm to participants

In the interview process I will take care of the needs of participants. Interviews will not be an occasion to debate issues. The purpose of the interviews will be clearly stated as being to gain the opinion and thoughts of the interviewees, and I will accept all opinions and ideas as valuable. I believe that psychological effect on people interviewed will be positive. This will be an opportunity for them to be heard and have their views accepted and taken seriously. However, as a safeguard, if participants show any discomfort they will be reminded that they can opt out of participation at any point. They will also be reminded at the beginning of the interviews that they may decline to answer any question.

2.5 Potential Harm to the Researcher. No harm is anticipated.

2.6 Potential Harm to the University. No harm is anticipated.

2.7 The right to decline to take part.

Each participant will have the right to decline to take part, and the right to decline any questions they do not wish to answer; to decline an interview even if they have previously agreed to such an interview, and to withdraw from the process at any stage. Finally they can refuse to allow information they have provided to be used.

2.8 Uses of the Information

The information is to be used to improve workshops and will be shared with the critical reference group and other facilitators of workshops aimed at reducing stigma and discrimination associated with mental illness.

2.9 Conflict of Interest

The rights of participants will be protected at all times. I have no position that gives me an on-going relationship with workshop participants. Participants work in the courses will not be assessed.

However the information gathered will directly improve the workshops provided by the Trust of which I am the executive officer and I will use it to influence the further production of workshop materials and training of facilitators who are members of the reference group.

2.10 Other ethical concerns. I believe all ethical concerns have been covered.

3 LEGAL CONCERNS

3.1 LEGISLATION

3.1.1 Privacy Act 1993

All participants will be offered access to the transcript of any interview held with them, copies of any written material they provide, and access to the final thesis. Their names and identifying features will not be used in the final report.

3.2 OTHER LEGAL ISSUES. I do not believe there are other legal issues.

4.0 CULTURAL CONCERNS

I am a Pakeha. Workshop facilitators and participants will be Maori and non-Maori, as are members of the reference group guiding the research. I will be studying mainstream workshops, not those being prepared for marae settings. However I recognise the importance of being guided by Maori members of the group as to ensure resources and techniques produced are appropriate for people of both Maori and non-Maori cultures who attend mainstream workshops.

5.0 OTHER ETHICAL BODIES RELEVANT TO THIS RESEARCH

This application is not being referred to other ethics committees. It is not subject to any professional codes.

6.0 OTHER RELEVANT ISSUES

If there are other relevant issues which I need to discuss with the committee, I am available by telephone.

Draft questions that may be used in evaluation, interviews, questionnaires

Note: The exact questions need to be worked out in conjunction with the reference group and may vary as the research proceeds. They will also vary according to the objectives of each workshop.

Pre workshop questions:

What did you learn about mental illness as you grew up?

What did you learn about mental illness from books, films and TV?

From all these messages and experiences what are your beliefs about people who have a mental illness?

Pre and post workshop questions:

Mark on the comfortable/uncomfortable continuum to show how comfortable you feel when you meet someone new who has a mental illness.

Mark on the comfortable/uncomfortable continuum to show how comfortable you would feel about having someone with a mental illness as a neighbour.

Mark on the comfortable/uncomfortable continuum to show how comfortable you would feel about having someone with a mental illness baby-sit your children.

Post workshop evaluation/interviews

Circle one:

Was the workshop: enjoyable useful too short
too long(write your own)

What are the most important ideas or thoughts that you will take away from this workshop?

What exercise/video/role play did you find most helpful to your learning?

How important was it that the workshop was facilitated by people with an experience of mental illness themselves?

What did you dislike or find least helpful?

How do you feel now: challenged, motivated, less anxious, more anxious, enlightened?

What further learning would be useful to help you develop a positive and supportive attitude towards people with a mental illness?

Do you feel you might now make changes to the way you interact with people with an experience of mental illness?

If yes, what ways might your interactions change?

Massey University

13 July 2000

Ruth Gerzon
C/O Marilyn Waring/Carole Adamson
Social Policy & Social Work
Massey University
Albany

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Dear Ruth

**HUMAN ETHICS APPROVAL APPLICATION – MUAHEC 00/027
CHANGING THE PARADIGM? REFLECTIONS ON THE LEARNING AND EXPERIENCE OF
PARTICIPANTS IN WORKSHOPS TO REDUCE STIGMA AND DISCRIMINATION
ASSOCIATED WITH MENTAL ILLNESS**

Thank you for your amended application details, which we recently received and have been placed on our files.

The amendments you have made now meet the requirements of the Massey University, Albany Campus, Human Ethics Committee and the ethics of your application, therefore, are approved.

Yours sincerely



Dr Mike O'Brien
**CHAIRPERSON,
MASSEY UNIVERSITY, ALBANY CAMPUS
HUMAN ETHICS COMMITTEE**

cc. Marilyn Waring, School of Social Policy & Social Work, Massey University, Albany
Carole Adamson, School of Social Policy & Social Work, Massey University, Albany

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Changing the paradigm?

Reflections on the learning and experience of participants in workshops
to reduce stigma and discrimination associated with mental illness

Information sheet for members of the reference group

Researcher: Ruth Gerzon is the executive officer of the Serious Fun 'N Mind Trust, which is developing workshops aimed at reducing the stigma and discrimination associated with mental illness. This research is aimed at improving the effectiveness of the workshops. She will also submit this research as her thesis for her M. Phil degree at Massey University.

Ruth Gerzon can be contacted at: P O Box 3017, Ohope, Whakatane
mail: gerzon.r@xtra.co.nz

The supervisors of this study are:

Marilyn Waring, Associate Professor, School of Social Policy and Social Work,
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(09) 443 9771 email C.E.Adamson@massey.ac.nz Fax: (09) 443 9767

What is the study about?

This is a study aimed at improving workshops designed to reduce the stigma and discrimination associated with mental illness. During courses there is only a limited time for listening to the viewpoints and concerns of participants. I would like to hear more from them about their needs and what their reactions are to the style and content of workshops. The information will be used to design further resources and teaching techniques to improve the effectiveness of workshops.

Who will take part?

- Participants on workshops designed to reduce the stigma and discrimination associated with mental illness can opt to take part if they wish. It is their choice. Anyone who takes part has the right to refuse to answer any questions and to withdraw from the study at any point until one week after the gathering of their information; ask any questions about the study; and to confidentiality. All information will be carefully stored and will be collected anonymously. It will not be possible to identify participants in any reports prepared from this study.
- People facilitating the workshops who agree to be part of the reference group. It is your choice. Whether or not you agree to be part of the research will have no bearing on whether you facilitate workshops.
- If you take part you have the right to refuse to answer any questions and to withdraw from the study at any time; to ask any questions about the study; and to confidentiality. All information will be carefully stored. Although you may withdraw from further participation in the study at any time, the information and ideas you have already contributed will remain part of the research.
- If you agree to take part you may choose whether you wish to have your contributions attributed to you or kept anonymous.

If you agree to be part of the reference you can support this research through

- enabling the researcher to distribute and gather questionnaires from participants who agree to this;
- when facilitators and participants agree, enabling her to observe workshops
- when facilitators and participants agree, enabling her to audio tape workshops
- when facilitators and participants agree, enabling her to video tape workshops
- helping determine the information to be gathered that will be most useful to evaluate the effectiveness of workshops
- sharing ideas in debrief sessions on how the information can be used to improve resources and teaching techniques that will enable workshops to be more effective.

How will the views and ideas of the reference group be gathered?

If you take part you can contribute in one or more of the following ways:

- Debrief sessions held after workshops that examine the processes that occurred. These may include viewing videotapes or listening to audiotapes of sessions.
- Participation in meetings to critically discuss findings and to share ideas for further resources and teaching techniques

What can the reference group expect from the researcher?

- To have your views respected
- To be given copies of minutes of meetings.
- To have access to a copy of the final report
- To choose whether to be identified or have your contributions anonymous

Who will have access to the contributions of the reference group?

The material gathered will be shared with

- people involved in funding, designing and producing further similar workshops and resources
- the researcher's supervisors at Massey University
- people assessing the research.

Note: This information sheet was only slightly amended for other people advising on the research (cultural advisers etc).

Changing the paradigm?

Reflections on the learning and experience of participants in workshops
to reduce stigma and discrimination associated with mental illness

Information sheet for workshop participants

Researcher: Ruth Gerzon is the executive officer of the Serious Fun 'N Mind Trust, which is developing workshops aimed at reducing the stigma and discrimination associated with mental illness. This research is aimed at improving the effectiveness of the workshops. She will also submit this research as her thesis for her M. Phil degree at Massey University.

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What is the study about?

This is a study aimed at improving workshops designed to reduce the stigma and discrimination associated with mental illness. During courses there is only a limited time for listening to the viewpoints and concerns of participants. I would like to hear more from you about your needs and how you feel about the style and content of workshops. The information will be used to design further resources and teaching techniques to improve the effectiveness of workshops.

Who will take part? Participants on workshops designed to reduce the stigma and discrimination associated with mental illness can opt to take part if they wish. It is your choice.

Anyone who takes part has the right to:

- refuse to answer any questions and to withdraw from the study at any point until one week after the gathering of their information.
- ask any questions about the study.
- confidentiality. All information will be carefully stored and will be collected anonymously. It will not be possible to identify you in any reports prepared from this study.

If you do not wish to take part you are still able to participate in the workshop and your decision will have no bearing on your role in the workshop.

How will your views and ideas be gathered?

If you wish to take part may contribute in one or more of the following ways:

- Filling out a short questionnaire before and after the course. This should take about 5 minutes for each of the two questionnaires.
- Post workshop questionnaires to be filled in by participants.
- Agreeing to have the course audio-taped. This will only happen if all participants and facilitators of a course agree.
- Agreeing to have the course video-taped. This will only happen if all participants and facilitators of a course agree.
- Interviews 3-6 weeks following a course. If you wish to take up this option you can be interviewed alone, with friends or in a small group. You can decline to answer any questions or withdraw at any point up to one week after the interview. If people interviewed agree, these interviews may be taped to help the researcher recall exactly what was said. These interviews will take about half an hour.

What can you expect from the researcher?

- To have your views respected
- On request, to be given copies of any of your questionnaires and evaluation forms, and transcripts of interviews.
- To have access to a copy of the final report
- To have your contributions kept confidential and anonymous.

Who will have access to the information you provide?

The information gathered will be shared with

- a reference group of facilitators of workshops designed to reduce the stigma and discrimination associated with mental illness
- where a workshop is held for an organisation, the managers of the organisation concerned will have access only to collated anonymous comments from evaluations (names will not be used)
- people involved in funding, designing and producing further workshop resources
- the researcher's supervisors at Massey University
- people assessing the research.

Note: This information sheet was only slightly amended for managers of organisations holding workshops.

CONSENT AND CONFIDENTIALITY FORM

for the reference group

Changing the paradigm?

Reflections on the learning and experience of participants in workshops to reduce stigma and discrimination associated with mental illness

I have read the information sheet about this study and have had the details explained to me. I agree to be part of the reference group to this research, participating in discussions about the issues involved under the conditions set out in the information sheet.

I agree to keep confidential all personal information discussed at debrief sessions after the workshops that might identify individuals involved in this research.

Name..... Telephone number.....

Address.....

Signature..... Date.....

CONSENT FORM

for participants who agree to fill out questionnaires

Research: Changing the paradigm?

Reflections on the learning and experience of participants in workshops to reduce stigma and discrimination associated with mental illness

I have read the information sheet about this study and have had the details explained to me. I voluntarily agree to take part, understanding that I may agree to withdraw at any time up to one week after the information is gathered. I agree to provide information to the researcher on the understanding that it is completely confidential. I agree to fill out the questionnaires on this basis and under the conditions set out in the information sheet.

Name..... Telephone number.....

Address.....

Signature..... Date.....

Note: These consent forms varied only slightly for the other groups involved in the research, for participants being interviewed etc.

APPENDIX TWO

QUESTIONNAIRES

Identical questionnaires were given out at the beginning and end of the first workshop only.

EVALUATIONS

Evaluations for both workshops are included since the questions were changed for the second workshop.

INTERVIEW QUESTIONS

These are a sample and guide only as the interviews were informal with specific questions added at times to elicit more in-depth information.

questionnaire for Discrimination Awareness workshop
Speakers' Training Programme (mental health service providers)

This questionnaire is part of Ruth Gerzon's research. The information gained will be used to improve these workshops. **This is voluntary. You do not have to answer any questions at all.**

The initials of your mother's maiden name:.....

Mark the lines below to show how much stigma and discrimination associated with mental illness you feel exists in the following areas:

1 Within the community

0 1 2 3 4 5 6 7 8 9 10
none a little quite a bit a lot

2 Within mental health services in general

0 1 2 3 4 5 6 7 8 9 10
none a little quite a bit a lot

3 How often do you hear discriminatory language used?

0 1 2 3 4 5 6 7 8 9 10
never occasionally quite a bit a lot

4 How often does the widespread stigma around mental illness affect your own thoughts or actions?

1 2 3 4
daily once a week once a month never

5 What words best describe the role you feel mental health service staff might play in the movement to reduce stigma and discrimination associated with mental illness

.....
.....

Would you be willing to be interviewed 6 weeks after this course to see how it has impacted on you and your work? ☐ yes ☐ no
If yes, please give your name and phone number to Ruth Gerzon at the end of this course.

Evaluation for Discrimination Awareness workshop
Speakers' Training Programme (mental health service providers)

1 Tick one: Have you ever attended a workshop facilitated by people with an experience of mental illness before? ☐ yes ☐ no

2 How important was it that the workshop was facilitated by people with an experience of mental illness?

0 1 2 3 4 5 6 7 8 9 10
| | | | | | | | | | |

not important

a little

quite

very important

3 Did the workshop help you improve your skills and knowledge?

Consider the value of different parts for your learning.

Put numbers beside the list below, using this scale in each case:

0 1 2 3 4 5
not at all a great deal

- Discussions of categories of discrimination (.....)
- Cape Role Play (.....)
- Chris Hansen's story (.....)
- Ethical issues in advocacy (.....)
- Handouts (....)

4 What changes might you make to your own use of language or practices as a result of attending this workshop?

.....
.....
.....

5 How able do you feel to counter stigma and discrimination when it occurs

1 2 3 4
| | | |

not at all

very much

6 What did you like or find most helpful to your learning?

.....

.....

.....

.....

7 What did you dislike or find least helpful to your learning?

.....

.....

.....

.....

8 Would you recommend this workshop for other groups? Tick one: ☐ yes ☐ no

If yes, name the groups that you feel might benefit from it

.....

9 Did this day's training meet your expectations?

Not at all		yes		exceeded them

Any other comments?

.....

.....

.....

Kia ora. Thank you very much for taking the time to fill this out
and helping us improve our training.

Tangata Whaiora Experiences Workshop

May 01

Participants Evaluation

1	<p>Tick one. Have you ever attended a workshop facilitated by tangata whaiora before? <input type="checkbox"/> Yes <input type="checkbox"/> No</p>
2	<p>How important was it to your learning that the workshop was facilitated by tangata whaiora?</p> <p>1 2 3 4 5 6 7 8 9 10</p> <p>_____</p> <p>not important a little quite very important</p> <p>If you found it important can you explain why?</p> <p>_____</p> <p>_____</p>
3	<p>Did the workshop improve your understanding of discrimination in the community?</p> <p>1 2 3 4 5 6 7 8 9 10</p> <p>_____</p> <p>not much a little quite heaps</p> <p>Comments? _____</p> <p>_____</p>
4	<p>Did the workshop improve your understanding of discrimination within mental health services?</p> <p>1 2 3 4 5 6 7 8 9 10</p> <p>_____</p> <p>not much a little quite heaps</p> <p>Comments? _____</p> <p>_____</p>
5	<p>What did you like, or find most helpful to your learning?</p> <p>_____</p> <p>_____</p> <p>_____</p>
6	<p>What did you dislike, or find least helpful to your learning?</p> <p>_____</p> <p>_____</p> <p>_____</p>

Tangata Whaiora Experiences Workshop -

May 01

Participants Evaluation

7	<p>Consider the value of different parts of the workshop to your learning? (refer to the timetable on board for ones not listed below) Put numbers on the list below, using this scale in each case</p> <div style="text-align: center; margin-bottom: 10px;"> ←—————→ </div> <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 15%;"></th> <th style="width: 20%;">1</th> <th style="width: 20%;">2</th> <th style="width: 20%;">3</th> <th style="width: 20%;">4</th> <th style="width: 20%;">5 a great deal</th> </tr> </thead> <tbody> <tr> <td></td> <td colspan="5">not at all</td> </tr> <tr> <td>1.</td> <td colspan="5">Chris Hansen's story _____</td> </tr> <tr> <td>2.</td> <td colspan="5">Cape Role Play _____</td> </tr> <tr> <td>3.</td> <td colspan="5">Discussion on paternalism _____</td> </tr> <tr> <td>4.</td> <td colspan="5">Sociogram _____</td> </tr> <tr> <td>5.</td> <td colspan="5">Discussion on language _____</td> </tr> <tr> <td>6.</td> <td colspan="5">Forces of change _____</td> </tr> <tr> <td>7.</td> <td colspan="5">Other parts or aspects....._____</td> </tr> <tr> <td>8.</td> <td colspan="5">.....</td> </tr> </tbody> </table>		1	2	3	4	5 a great deal		not at all					1.	Chris Hansen's story _____					2.	Cape Role Play _____					3.	Discussion on paternalism _____					4.	Sociogram _____					5.	Discussion on language _____					6.	Forces of change _____					7.	Other parts or aspects....._____					8.				
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8.																																																												
8	<p>If we were to make any changes,</p> <ol style="list-style-type: none"> 1. What should be left out? _____ _____ 2. What should be added? _____ _____ 																																																												
9	<p>What changes might you make to your own use of language or other practices as a result of attending this workshop?</p> <p>_____ _____ _____ _____ _____</p>																																																												
10	<p>Any other comments?</p> <p>_____ _____ _____ _____ _____</p>																																																												

A SAMPLE OF INTERVIEW QUESTIONS USED

1. Firstly, what do you remember of the day?
2. Have you been to a workshop run by people with an experience of mental illness before? If yes – is that Hearing Voices or others?
3. Do you remember the Cape Role Play?
4. Do you remember any of the other exercises?
5. Any other impressions, emotions?
6. Did you feel safe to speak and say what you felt?
7. Do you notice much stigma and discrimination within the community?
8. Do you notice much stigma and discrimination within mental health services?
9. Is there anything we should do differently if we run this workshop again?
10. Is there anything in the way you work or the language you use that you have changed as a result of the workshop?

APPENDIX THREE

WORKSHOP ONE TIMETABLE

- 10.00 Welcome
- Karakia
 - Introduce workshop:
How it fits into SFNM Trust aim of promoting sustained respect for people with a mental illness.
 - Introduce team and research.
- Participants introduce selves
- Name
 - Service they are from
 - Why they came
 - What they wish to learn at this workshop
- 10.45 Cup of tea
- 11.00 Handout folders. Course aims and objectives. Participants to discuss their goals (and how they will know when they have reached them) with neighbour and then fill in section in workbook.
Put up timetable
- 11.20 Brainstorm words that are stigmatising. Write up on chart paper – when finished take off, tear up and throwaway
- 11.30 More subtle discrimination: introduce idea framework and ask for group to brainstorm a few situations/ways people distance themselves in services
- 11.40 Divide into groups of 4-5 to discuss and fill in handout
- 12.0 Group feedback on this shared and charted
- 12.15 Lunch – half hour
- 12.55 Cape Drama (instructions at end)
- 1.20 Chris Hansen tells her story
Followed by: tangata whai ora definition of mental illness
- 1.45 Tea break
- 2.00 Ethical and respectful practices in when speaking alongside someone who is tangata whai ora
- 2.40 Questionnaire, evaluation
- 2.55 Wrap up and karakia

WORKSHOP ONE EXERCISES

CAPE DRAMA

PROPS: black hooded cape.

Positive (Green) labels: courageous, respected, creative, sensitive, strong, manaaki, honest, strong, confident, reliable, supportive, confident, conscientious, humble, joyful, good friend, awhi, aroha, supportive, compassionate, responsible, hard worker, passionate, informed, professional, leader, intelligent, educated.

Negative (Red) labels: dangerous, drama queen, uncontrollable, trouble, invalid, highly strung, poor thing, unpredictable, crazy, porangi, beneficiary, incompetent, frightening, friendless, strange, psycho, victim, turoro, manipulative.

Action: As participants return to the room from lunch a facilitator stops them at the door and asks them to give up something of value to them. They are then given a green (positive) label.

Scatter red (negative) labels on floor.

One facilitator (Jennie) sits on a chair in the centre, in front of the rest of the team.

The other facilitator (Chris) begins:

- indicate that this is an experiential workshop
- ask participants how they feel about wearing the green labels.
- talk to the red labels on the floor...comment on power of labels and how the stigma relates to behaviours (discrimination)
- The Cape is introduced and put on Jennie who sits on a chair. This represents all those who have an experience of mental illness. By putting it on the green labels describing who she is as a person, and her role in the community are lost.
- From here the facilitator on the chair (Jennie) is only referred to as 'The Cape'.
- Facilitator (Chris) picks up labels and talks to them. Start with 'dangerous' label. Speak to this and uses statistics etc to add to the information.
- The final label is 'victim'. Each group can feel like a victim. This is not about blame or not taking responsibility. Victimhood and 'learned helplessness' can result from well meaning health/social work staff.
- As the victim label is offered to 'The Cape' Jennie rejects it and stands up in her own power and throws back The Cape. She then speaks about refusing to take on labels any more.
- . Then give a green label each and give it to Jennie, saying 'Jennie, I acknowledge your (e.g. wisdom, good parenting). Jennie can respond if she wishes.

Participants are asked to give their positive green labels to Jennie as a person who has to withstand significant pressure.

- At end facilitators stand and sing a waiata.

WORKSHOP ONE HANDOUTS

SPEAKERS' TRAINING

**A course for staff of mental health services
wishing to speak publicly about mental health and mental illness**

Welcome to this programme, a vital part of the movement to promote sustained respect for people with an experience of mental illness.

This programme, in keeping with others offered by the Serious Fun 'N Mind Trust, paves the way for a partnership where people with an experience of mental illness, families, allies and staff of services can work together, promoting change.

By joining the programme staff stand alongside consumers/ tangata whai ora, showing their understanding of the effects of stigma and discrimination.

- 1 If we visualise a gradual move to a world where there is less discrimination towards ... people with mental health problems, the first staging post would be a place where people are listening to what those 'on the edge' are saying.*

*To have power, users' and allies' voices need to reach further beyond the circle of survivors and mental health professionals to wider public and decision-making audiences. **

This training is linked to the speakers' programme being set up in the main towns of the Bay of Plenty by Ki Te Ao Marama: The Open Minds Project of the Serious Fun 'N Mind Trust in conjunction with consumers/tangata whai ora, whanau and mental health services. It is hoped that people who have received this training will offer to join in this co-ordinated approach.

Speakers who help the movement to promote sustained respect in this way will speak to organisations or community groups as individuals, and not represent Ki Te Ao Marama: The Open Minds Project.

**Sayce, Liz, (2000). From Psychiatric Patient to Citizen: overcoming discrimination and exclusion. England: Macmillan Press.*



Speakers' Programme August 2000
Ki Te Ao Marama - Open Minds Project of the Serious Fun 'N Mind Trust

Ethical Issues for Speakers

INTRODUCTION

WHO SPEAKS FOR WHOM?

For centuries people with an experience of mental illness have been spoken and written about, often in derogatory ways.

In many cases people are still speaking about or on behalf of people with an experience of mental illness.

Yet people have the right to tell their own story. They have the right to withhold participation in another's story about them. The recent catch-cry in consultation has been:

Nothing about us without us

The role of allies and supporters of the movement

What is required of people who have not yet used mental health services, who wish to join tangata whai ora in promoting change?

- 2 A strong belief in the rights of people with an experience of mental illness to
 - speak for themselves,
 - be full members of their communities,
 - have an excellent standard of service,
 - always be treated with respect.
- 2 Actions:

Stigma and discrimination come in many forms and constantly surround us, tainting our own thinking, our own actions. We need to monitor ourselves and each other, challenge ourselves and each other, and remain open to challenges from tangata whai ora. You must have an open relationship with tangata whai ora in order to speak on their behalf. Consider these situations

Speaking for people If we stand up and speak 'on behalf' of a group what does that say about their ability to speak for themselves, their ability to tell their own story? We may say people with an experience of mental illness are capable, contributing members of our community, but standing up there alone tells a different story. Our credibility and their credibility may suffer for 'actions speak louder than words'.

Within our own work If we truly believe tangata whaiora have been denied a voice, then we must make every effort ourselves to really hear what they say within our services, even if when the messages are sometimes hard to hear. Anything less is patronising.

Responding to issues Staff have to be especially careful since they always have their own version to 'sell'.

We have all seen situations where mental health service staff seek to prevent the service being blamed for problems by blaming tangata whai ora instead – 'they won't take their medication'; 'they need to take individual responsibility'.

We need to get beyond this blame game and find positive ways to respond to challenging and difficult questions without adding to stigma and discrimination.

A positive and ethical approach means we must

- Tell true, good and helpful stories, revealing the complexity of issues
- Regularly check both what we say and how we say it with tangata whai ora
- Help defend the space tangata whai ora may claim for themselves

Speaking without tangata whai ora support is okay when:

- you have their endorsement
- you have made every effort to support tangata whai ora to speak for themselves but they are not able to join you
- they have said they would prefer not to go to a speaking engagement.

Telling someone else's story is okay when:

- the story has been already gifted by tangata whai ora to be used publicly (for example quoting from published books that were produced ethically)
- the person has asked you to do so and has given you written permission, clarifying what it is okay to say, and what must not be said; issues of confidentiality and whether they wish to have it presented anonymously etc. We suggest you use the form included in this programme.

Speakers' Programme August 2000



KI TE AO MARAMA - OPEN MINDS PROJECT OF THE SERIOUS FUN 'N MIND TRUST

Rules for Telling Stories

Some stories enhance life; others degrade it. So we must be careful about the stories we tell, about the ways we define ourselves and other people. A worker taught to expect 'violent monsters' may eventually encounter or create them.

A Those about whom stories are told have:

- The right to tell their *own* story. A person has the right to claim they are Napoleon. Children have the right to 'explain' themselves with whatever fantasies they find useful.
- The right to have *true* stories told. Every human being is entitled to the story that they are valuable.
- The right to *good* stories. You are entitled to stories which confirm your value. Even criminals are entitled to stories which do not deny their value as human beings.
- The right to withhold participation in another's story about them and thus the right to stick to their own story. I am what I am!
- The obligation to live up to good stories. Parents try to live up to their stature as parents as children attempt to live up to parents' expectations.

B Those who would tell stories about others must respect these rights.

They have the obligation to:

- Listen to the stories of those about whom they tell stories. Professionals must be especially vigilant, because they always have their own versions to 'sell'.
- Tell good and helpful stories. Of course there is always the question, 'Help whom? And how?'
- Tell true stories. We must be vigilant because professional truths tend to be irrelevant and are usually sterile. More often than not, the injuries we inflict are by neglect and not by design.
- Take responsibility for the stories they tell. Professionals don't always enjoy such responsibility. We blame 'syndromes' on our victims.

C Those who hear stories by or about others must:

- Distrust bad or destructive stories
- Seek to *know* the *truth* of stories, and to *understand* the *good* of stories. Knowledge and understanding can be entirely different matters.
- Remember that they become (we become) the sum total of stories that they (we) believe. It becomes their (our) story.
- Dismiss any story presented as finished. Even dead peoples' stories are not ended. There are stories that need to be told about Hitler, about Moses, and about the billions of 'ordinary' people who left legacies and lessons to be learned.

(Slightly adapted) from writings by Burton Blatt
in *The Conquest of Mental Retardation* (1987) Pro-Ed: Austin, Texas pp 142/3



Speakers' Programme August 2000

Ki te Ao Marama - Open Minds Project of the Serious Fun 'N Mind Trust

APPENDIX FOUR

WORKSHOP TWO TIMETABLE

Key objectives

- Define stigma and discrimination associated with mental illness and its effects
- Recognise beliefs and attitudes that lead to discriminatory behaviours: dangerousness and unpredictability (desire to control); incompetence (paternalism)
- Know how attitudes and beliefs manifest themselves in behaviours
- Identify discriminatory behaviours in various settings: community, services, family relationships, employment
- Identify non-discriminatory attitudes and behaviours

<u>Time</u>	<u>Content/Exercises</u>	<u>Resources</u>
9.00	Welcome – Karakia Jennie introduces self – says other facilitators will introduce selves later	Name stickers register.
9.05	Group introductions <i>Line up in order of your birthdate (without using words). People who have birthdays in January will be at this end, people with birthdays in December at that one.</i> Check – can you say your birthdates, starting here.... Introduce yourself to someone nearby who you don't know. Remember what your partner says as you will introduce your partner to the whole group later. Tell them your name, your workplace and one thing you hope to learn today. Then partners are introduced to the whole group	List on board: ○ Name ○ Workplace ○ One thing you hope to learn today
9.35	Climate setting: <i>We acknowledge the courage you have to come here – all learning leads to change and takes courage.</i> We want this to be a safe place for learning so we need some ground rules. Can anyone suggest ones they would like to see? List these. Include: confidentiality of personal stories; respect for each other; Responsibility for own learning – ask questions if you do not understand Right to 'pass' Facilitators' commitment to participants: ○ <i>We are not here to tell you what to think but we will encourage you to think outside the square</i> ○ <i>We are not here to tell you what to say, but we will encourage you to consider the effect your words have on others</i> ○ <i>We are not here to tell you what to do, but we will encourage you to consider how your actions accord with your beliefs and values.</i>	
9.35	Timetable introduced and handout objectives	Handout 1
9.50	Other facilitators introduce selves and Chris tells her personal story.	
10.15	Taking Steps – see instructions at end of timetable After debrief read 'ups and downs'	Role descriptions. Ups & downs.

10.30	Morning tea	
10.45	Cape Drama	
11.05	Five minute break	
11.10	<p>Debrief emotions using cards</p> <p><i>Choose a card or two that reflect the way you feel after hearing the Cape Drama. If you cannot find one that is appropriate for your feelings then think of another word yourself.</i></p> <p>After most people have chosen cards:</p> <p><i>Talk to one or two other people about why you chose those cards.</i></p> <p>After nearly everyone has chosen a card</p> <p><i>Come and sit down – anyone want to share with the group why they chose their the card?</i></p> <p>Note if people choose</p> <ul style="list-style-type: none"> o guilty say that is natural but we can only do what we know at the time – no use feeling guilty for past events – but we are responsible for what we do from now on with insights we have gained through this exercise. o anger talk about anger being a fire for change as long as it is focussed on ways we can change things rather than just going home and kicking the dog! 	Emotions cards
11.20	<p>Debrief learning:</p> <p>Talk to two other people about what you learnt from the Cape Drama.</p> <p>Then whole group share: points to bring out are:</p> <ul style="list-style-type: none"> o Effect of language we use and its connection with our behaviours o Emotion of fear linked to control and distancing, o Mother/child relationship and paternalism. 	Handout – If sanity & insanity exist how shall we know them?
11.45	Sociogram	
12.00	Brief overview of media and violence	Handout overheads
12.10	Lunch	
12.55	Discussion on language	
1.05	<p>Force field analysis Brainstorm areas that are sites of discrimination e.g. community, employers, mental health services, government agencies, media, tangata whai ora themselves (internalised discrimination)</p> <p>Put down the goal of respect and the line of change. Divide people into groups (number off). Each group has one area in list above and 2 arrows. They write/draw on arrows what is hindering and what is helping change in the site of discrimination</p>	Overhead Where do we go from here? Force field line respect circle Arrows
1.30	<p>Everyone walk around the work and look at what people have written.</p> <p>Whole group discussion.</p> <p>Points to make:</p> <ul style="list-style-type: none"> o It is important to start with people and organisations that have the most power to improve the lives of tangata whai ora o For change such as this the movement needs everyone who wishes to take part – whether tangata whai ora, family, employers, service staff o Everyone can play a part. o Mention some initiatives started by Serious Fun 'N Mind Trust 	
1.50	Afternoon tea	

2.05	Individual commitment – Brainstorm as whole group what individuals might do to support change at their work or in the community. Handout 'stages on the journey to respect' What is possible for you to do - discuss with one other person	Handout – journey to respect
2.40	Written evaluations Research – ask participants if they wish to volunteer for interviews.	Research forms
2.50	Round – one thing I learnt today	
3.00	Karakia	

WORKSHOP TWO EXERCISES

REVISED CAPE DRAMA

Labels: add in courage, creativity, determination, sensitivity and *tumeke*, *rangimarie*. Take out: judgmental ones that imply some people better than others: professional, leader, intelligent, educated. Leave out 'approachable' which is not positive enough.

Begin pinning 'tangata whai ora' label on facilitator two (Jennie) : and explaining meaning and use of the term. The Cape is put on her. This represents **the stigma and discrimination** faced by people with an experience of mental illness (note the Cape does **not** represent mental illness itself). From this point on Jennie is only referred to as 'The Cape'.

Four 'hats' are made for narrator to use to indicate changing roles for the facilitator who is the narrator. As she reads she stops at words that are in *italic* and pins the appropriate label on The Cape

1. Staff narrative (reading from file notes)

Patient presents as well groomed with long dark hair.

Behaviour: *unpredictable* with periods of agitation and guardedness.

Uncontrollable hyperactivity declining, but potentially *dangerous* behaviour still needs monitoring. Affect remains labile. Some perceptual disturbances, speech quite pressured. Doesn't see her admission in terms of psychiatric illness. Somatic complaint subsiding. Has little insight. At assessment she was restless, disinhibited, disorganised, agitated and unable to give account of actions. Very labile mood. Recommended and brought in by police with restraint. Patient has a history over the last nine years of multiple admissions to psychiatric hospitals with relapses similar to this one. They respond to medication, + high functioning in between admissions.

Aside (as if to another nurse):

"This one could be *trouble*, so keep an eye on her. Will attempt to *manipulate* staff and patients to meet her own ends. A bit of a *drama queen* at times.

The Cape Response (read slowly with pauses between sentences)

Do you want to know how to care for me? Can you hear me? Will you hear me? Do you want to know what makes me feel safe? Why do you judge me? Can you see me, not monitor me? How can I speak when you only ask me certain questions? How do I speak, when the way patients demonstrate insight, is to say they know they have no insight. I cannot live in this place, this hopeless place, where dreams are only disease. I have been filed, diagnosed, categorised, abused, and labelled.

2. Family narrative

She used to cope so well before she became *porangi*. Now she's a *turoro* there's not much she can do (*incompetent*). I've lost my sis. I don't really know how to talk to her now. Mum's going to take the kids and look after them for a while.

The Cape Response

My family don't visit much now. I don't have the friends (*friendless*) I had before. I don't think they understand me or my illness. I'm mokemoke, I'm lonely now.

3. Employer narrative

I was shocked to find out that this woman was *mental*. She used to be one of our best workers. She's been quite *strange* and now they tell me she's *psycho*. The other staff are *frightened* that she might talk *crazy* stuff to our customers.

The Cape Response

I got that job after years of study. I worked there for five years. I know I have done it well. I could continue to do so, but will I be given a chance? I wake up in the night and worry about my mortgage.

4. Neighbour narrative

I've just heard my new neighbour's a victim of mental illness. *Poor thing*. She must be a bit *highly strung*. She'll be on a *benefit*. I'd better keep my distance - I don't need someone like that on my doorstep day and night.

The Cape Response

My poor neighbour. She thinks I'm nuts and tells her kids to keep away. I suppose I give her nightmares. I'd like to be able to help out with the kids, when I hear them having a domestic.

5. Narrator, taking off her last 'hat' now adds

You are of no value. You are an *invalid*, you are in-valid.

The Cape Response - throw it off saying:

I reject the Cape. I reject the labels that bruise and limit me. They are not me. I am a loving daughter, friend, mother, worker and member of your community. I am valuable.

Waiata and karakia: the karakia is for all the people, past and present, who have been bruised by stigma and discrimination associated with mental illness

TAKING STEPS

Participants gather at one end of room with clear space in front. Each is given a role. Instructions are to take one step forward if, in your role, you think you could answer 'yes' to any of the questions.

Roles (one per participant)

1. Maori Woman, 45, married with 4 children. Separated from partner. Severe post natal depression. Beneficiary.
2. Maori man, 35. Gay, living with partner. General practitioner. Good mental health.

3. 21 year old male Pakeha. Studies law. Lives with parents. Hears voices
4. 60 year old male psychiatrist, Indian, in good mental health. 2 grown up children. Married Earns \$90,000 per annum.
5. 40 year old Pakeha executive man with bouts of severe depression. Married. 3 children. Earns \$50,000 per annum.
6. 25 year old Samoan woman. Single. Hospital registrar, no history of mental illness Earns \$60,000 per year
7. 25 year old Fijian woman diagnosed with schizophrenia at 18. Lives in supported accommodation (P.I service.) Beneficiary.
8. Pakeha man, 43, beneficiary, living with wife and two teenagers. Anxiety disorder.
9. Chinese woman, 19, engaged. Working in a café. No history of mental illness.
10. Pakeha man, 75, beginning stages of Alzheimers. Living with his son and daughter-in-law.
11. Pakeha woman, 23, just released from an acute care unit. Diagnosis was drug-induced psychosis. Living on the streets. Back on the drugs
12. 56 year old Pakeha man, mild intellectual disability. Institutionalised for twenty nine years, now in supported accommodation. Beneficiary No history of mental illness.
13. English woman, 30, lives with her female partner. Works 2 days per week Diagnosed with bi-polar disorder.
14. 23 year old Samoan car painter. Earns \$38,000 per year. Single. No history of mental illness
15. Pakeha woman school principal aged 47. Lives on own. No history of mental illness.
16. Pakeha man, 35, a school guidance counsellor. Married to a nurse. One child of their own and two foster children. No history of mental illness.
17. Pakeha woman living with woman partner. Age 45. Runs successful business marketing herbal remedies. No children. No history of mental illness
18. Pakeha man age 21. Never worked. Beneficiary. Flatting. Many convictions for drunk driving and speeding. No history of mental illness.
19. Maori teenage girl with one year old child. On DPB. Lives with parents who are also beneficiaries. No history of mental illness.
20. Maori woman, 32, executive in Maori mental health organisation. Earns \$45,000 per year. No history of mental illness. 3 children. Supportive partner.
21. Pakeha woman age 35. Married to a lawyer. Full time caregiver for three children. Had post natal depression four years ago.
22. Maori teenage girl age 19. Working one year in a supermarket. Living with flatmates.
23. 45 year old Pakeha man. Separated. Full time caregiver to two children. Has bipolar disorder. Beneficiary.
24. Maori man aged 45, with intermittent work on the wharves. Four children. Wife works full time. No history of mental illness
25. Maori kuia aged 69, active on marae, severe asthmatic. Has three grandchildren living with her. Superannuitant. No history of mental illness.
26. Pakeha widow age 65, living on her own now children have left. Recently retired from school teaching career. No history of mental illness.
27. Pakeha policewoman, 30, married with two children. Partner is a lawyer. No history of mental illness.
28. Pakeha man. Executive earning \$75,000 a year. Married with two children. Uses wheelchair. No history of mental illness.

Questions

- Do you see positive images of people like you in the media?
- Are you confident of being short-listed for good jobs?

- Do you feel welcomed and valued in your neighbourhood?
- Do you feel that you are sympathetically listened to by your GP?
- Do you think you will ever own your own home?
- Would you be able to get a bank loan?
- Would people ask you to baby sit?
- Would you be welcomed as an in-law?
- Are you likely to be invited onto the board of trustees at your local school?
- Do you feel comfortable talking about your achievements at job interviews?
- Do you feel that you will be taken seriously if you complain about bad service?
- Do you think you would be welcomed as a tenant?

SOCIOGRAM

An exercise about community supports for people with an experience of mental illness.

1 Clear space in centre of room and people sitting or standing around edges.

A volunteer participant is asked to come forward and stand about a third of the way from the front of the room

Now this is ..., a member of the community.

Now who are the people close to you?

Other participants are asked to come forward to be partner, children, parents, siblings, in laws and gather around him/her – the distance they stand indicates the closeness of their relationship with the key person.

Then add other people – friends, employer, workmates, neighbour, sports mates, social friends, drinking buddies, fellow club members, doctor, lawyer, shop assistants,

Then add in one or two who represent people you don't know well but who are part of your life such as the IRD, dentist etc.

2. Facilitator explains that this is called a sociogram. It shows people's relationship to

Participants who have joined in are asked to consider their positions and relationship with ...

3. Participants are asked to imagine Jane/ John has an experience of serious mental illness and to move to where, in their roles, they might move in this situation.

Now bring on other people: psychiatrist, mental health worker, Work and Income.

4. Debrief. Ask people why they moved, what their relationship is now, how it is changed. Ask how the key person how they feel about the way their friends and family moved.

This is what happens to people in our community with an experience of mental illness. Note: Sometimes providers of mental health services become more important than family. Not by choice but because there often isn't anyone else. For some people who have been institutionalised the only people in their lives are people who are paid to be there.

WORKSHOP TWO HANDOUTS

Tangata Whai Ora Experiences

*If we visualise a gradual move to a world where there is less discrimination towards ... people with mental health problems, the first staging post would be a place where people are listening to what those 'on the edge' are saying.**

Welcome to this course, designed to increase understanding and reduce barriers between people with an experience of mental illness and those who have not yet had such an experience. In keeping with other training offered by the Serious Fun 'N Mind Trust, it paves the way for a partnership where people with an experience of mental illness, families, allies and staff of services can work together, promoting change.

Key objectives

1. Define stigma and discrimination associated with mental illness and its effects
2. Recognise beliefs and attitudes that lead to discriminatory behaviours: dangerousness and unpredictability (desire to control); incompetence (paternalism)
3. Know how attitudes and beliefs manifest themselves in behaviours
4. Identify discriminatory behaviours in various settings: community, services, family relationships, employment
5. Identify non-discriminatory attitudes and behaviours

Facilitators

Chris Hansen (BSW, NZASW, CQSW) Chris weaves the threads of her tangata whai ora experience together with 20 years in social work and as a mental health professional. She is mother of two teenage sons, a musician and a writer. She works at a local, regional and national level for the Like Minds Project and for various service providers as a consultant and educator.

Jennie Hawira, Te Arawa, Ngati Pikiao. Jennie has built on her tangata whai ora experiences, completing the Certificate in Mental Health Support Work, working in mental health services as a consultant; as a member of the national advisory group to the Like Minds Project. She is a mother to her 11 year old son.

*Sayce, Liz (2000) From Psychiatric Patient to Citizen: overcoming discrimination and exclusion, Macmillan Press, Hampshire, England



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Stages on the journey to respect

What is required of people who have not yet used mental health services, who wish to join tangata whai ora in promoting change?

1 Beliefs:

A strong belief in the rights of people with an experience of mental illness to

- speak for themselves,
- be full members of their communities,
- have an excellent standard of service,
- always be treated with respect.

2 Actions:

Make every effort to really hear what tangata whai ora say, even if when the messages are sometimes hard to hear. Anything less is patronising.

Challenge ourselves and each other. Stigma and discrimination come in many forms and constantly surround us, tainting our own thinking, our own actions. We need to monitor ourselves and each other, and remain open to challenges from tangata whai ora.

Consider our language. Just as we have rid our language of offensive terms such as 'nigger' now we must learn to avoid terms such as 'nutter' and put downs such as 'drama queen'

Avoid blaming tangata whai ora when things go wrong. *'They won't take their medication'; 'they need to take individual responsibility'*. We need to get beyond this blame game and find positive ways to respond to challenging and difficult questions without adding to stigma and discrimination.

Commitment. We must not look the other way when discrimination occurs. People with an experience of mental illness need allies in their efforts to reduce stigma and discrimination.



THE ISSUE OF VIOLENCE

Misinformation and stereotypes are major contributors to the problem of discrimination. And one of the most destructive examples of stereotyping is the belief that if a person has received a diagnosis of a mental illness then they are more likely to be violent. This stereotype is perpetuated in films, literature and in the media and leads to fear, a strong emotion that causes people to distance themselves from tangata whai ora.

VIOLENCE IN SOCIETY

We live in a society where violence happens and no one can predict this violence with any great certainty. Violence is never acceptable. While it is a reality that most violence is by males against people they know, we are more fearful of 'stranger' or random acts of violence. Most random acts of violence are done by people who do not use mental health services or have a diagnosis of schizophrenia, but there is a widespread belief to the contrary.

Locking up or blaming people with mental illness will not make the streets safe or our homes safe from violence. It will however needlessly exclude many people from positively participating in the community.

VIOLENCE AND MENTAL ILLNESS

Some psychotic illnesses, like schizophrenia can contribute to violent behaviour if a person is not treated or misuses drugs and alcohol. However, the vast majority of crimes of violence are committed by people who **do not** have a mental illness and the vast majority of people who have a mental illness **do not** commit violent crimes. Moreover an act of violence by someone with a mental illness may have *nothing* to do with their mental illness it may be for the same mixture of reasons that other violent crime is committed.

Unless we deal with discrimination, it will not be possible to deliver mental health services which support recovery and prevent illness.

Useful statistics

- * 65,000 NZers use mental health services
- * 2,500 live peacefully in supported housing in the community
- * approximately 3% of adults in NZ have serious, ongoing and disabling mental illness requiring treatment from specialist mental health and alcohol and drug services



If sanity and insanity exist, how shall we know them?*

What is viewed as normal in one culture may be seen as abnormal in another.

How do we know whether behaviours we observe and label as 'insane' result from

- a person's inner being,
- from their environment, or
- from our own inner prejudices, colouring the way we view labeled people?

In 1973, eight people, with no history of mental illness, checked out the accuracy of diagnoses by getting admitted to psychiatric hospitals to see whether they would be discovered to be 'sane' and, if so, how.

The eight 'pseudopatients' were varied and included a painter, a housewife, a psychiatrist; three women and five men. Those in mental health professions said they had another occupation as they did not want to receive 'special treatment' that might be accorded by staff to ailing colleagues. A variety of hospitals were chosen, some with good staff-patient ratios, others understaffed.

All pseudopatients complained they had been 'hearing voices' that were unfamiliar, unclear but said 'empty', 'hollow' and 'thud'. Apart from this all the pseudopatients gave their real personal history, events and circumstances (relationships, children, frustrations, joys etc).

Immediately upon admission to the wards the pseudopatients reported the 'voices' as having ceased. Medication was not swallowed. All felt stressed by being there and wished to get out but were told they would have to convince staff that they were well first. They spent an average of 15 days before being allowed out. (this was in 1973!)

None were ever detected as 'pseudopatients' by staff and all were eventually discharged with a diagnosis of 'schizophrenia in remission'. However 35 out of 118 patients voiced their suspicions 'you're not crazy, you're a journalist checking up on the hospital'.

Behaviours and personal history were seen in light of their diagnosis.

- Pseudopatients took many notes and this was recorded as 'patient engages in writing behaviour'.
- Staff notes on the pseudopatients showed a man with a close relationship with his mother and this was seen as ambivalent in his current family.

...1

* Notes from Rosenhan, D. On Being Sane in Insane Places, in Science, 179. Jan 1973, pp 250-58



Behaviours caused by the environment are attributed to the patient's disorder.

- In many circumstances when patients were treated badly by a staff member and became upset, their upset viewed as resulting from their illness.
- When patients were waiting outside a dining room half an hour before lunch this was seen as oral-acquisitive behaviour not that there was little else to do in that environment .
- One patient paced up and down the corridors and was seen as 'nervous' when his pacing resulted from boredom.

A psychiatric label has a life, an influence, of its own. The label becomes a self-fulfilling prophecy and the negative attitudes also affect professionals. Staff and patients are typically separated, with staff emerging from their 'space' primarily for caretaking duties – to give medication or conduct a group therapy meeting, otherwise keeping to themselves.

The average amount of time staff spent with patients was 11.3 % of their day. The people further up the hierarchy have the least contact with patients. Psychiatrists and psychologists had an average of 6.8 minutes per day with each patient, and this includes group sessions. Staff meetings and an enormous amount of record keeping take up much time. Pseudopatients all attempted to engage staff in friendly conversation but without success, being brushed off with quick answers before staff moved on.

Rosenhan notes:

- 3 *Powerlessness was evident everywhere. The patient is deprived of his legal rights... shorn of credibility by virtue of his label... his freedom of movement is restricted... personal privacy is minimal... personal history and anguish available to any staff who chooses to read his folder...*

...2



Commitment

Consider what you can do about stigma and discrimination:

- as an individual

.....
.....
.....

as a member of your whanau/family

.....
.....
.....

as a member of your community

.....
.....
.....

- within your service

.....
.....
.....

Name..... Date.....



The Parable of Ups and Downs

What makes an up an up and a down a down is that an up can do more to a down than a down can do to an up. That's what keeps an up up and a down down.

The ups tend to talk to each other and study the downs, asking the downs what's up, or what's coming down for that matter. The downs spend a lot of time taking the ups out to lunch, to dinner, to explain their downness. The ups listen attentively, often in amazement about the experiences of being a down. They contrast one down's experience with another down's experience and at times don't worry too much about what the downs are up to because the downs never get together. If they did, the ups would have to shape up.

After a while, the downs weary of talking to the ups. They tire of explaining and justifying their downness. They think, "If I have to explain my downness one more time, I'll throw up." And so they form a process which they call 'networking and support groups'. This act makes the ups nervous. Three ups together is a board meeting; three downs, pre-revolutionary activity.

Some ups hire downs, dress them up, send them down to see what the downs are up to. We sometimes call this 'personnel and affirmative action'. This creates a serious problem for the down who is dressed up with no sure place to go. That down doesn't know whether he or she is up or down. That's why downs in the middle often burn out.

Sometimes what the ups do to smarten up is to ask the downs to come into a programme one at a time to explain their downness. The ups call this 'human relations training'. Of course the ups never have to explain their upness, that's why they're ups rather than downs.

There's good news and bad news in this parable. The good news is we're all both ups and downs. There is no such thing as a perfect up or a perfect down. The bad news is that when we're up it often makes up stupid. We call that 'dumb-upness'. It's not because ups are not smart. It's that ups don't have to pay attention to downs the way downs have to pay attention to ups. Downs always have to figure out what ups are up to. The only time ups worry about downs is when downs get uppity, at which time they are put down by the ups.

The ups perception is that downs are overly sensitive; they have an attitude problem. It is never understood that ups are underly sensitive and have an attitude problem.

I used to think that when downs became ups they would carry over their insight from their downness to their upness. Not so. Smart down – dumb up.

- Dr Robert Terry



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