



Coming in from the margins: people with an experience of mental illness and their allies work for change

Arana Pearson and Ruth Gerzon

Serious Fun 'N Mind Trust mission statement

To achieve sustained respect for people with an experience of mental illness

Whakatauki

Ma tini, ma mano, ka rapa te whai.

By many, by thousands, the vision, the goal will be attained.

Abstract

Inclusion in a community is necessary, essential, and crucial, to mental health, yet people with an experience of mental illness are excluded from communities by both a high level of discrimination in communities, and the nature of mental health services.

The Aotearoa / New Zealand government has funded a national project to spearhead political and social actions to counter stigma and discrimination associated with mental illness. Unlike traditional mental health services, this project is working with the strengths rather than perceived deficiencies of people with an experience of mental illness, raising awareness through supporting labelled people to be visible and be heard. In the Bay of Plenty a community development process has been adopted. This has led to the formation of a community trust, the Serious Fun 'N Mind Trust. The objective of this trust is to support people with an experience of mental illness to network and develop skills and resources, workshops, art, music and street theatre; recruits community leaders to support the movement; and works with the media.

Discrimination is best tackled through people learning to live alongside one another. Both the project to counter stigma and discrimination associated with mental illness and the mental health services need to employ people skilled in supporting people to develop their strengths and linking them to their communities of choice.

The ideas in this paper were presented in an interactive workshop format with dialogue, music, art and street theatre.

1. What is the nature of the problem?

Just like physical illnesses, there are many kinds of mental illness, each differing in its effect on people's lives. Some illnesses are relatively less intrusive through a person's overall life span, others are extremely debilitating in a person's life and long term functioning. As Julie Leibrich noted:

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

The diagnosis of mental illness is a complex matter. Even though there are standard criteria for diagnosis, not everyone would agree with the validity of this system, which tends to be categorical. Some people prefer to describe mental illness in terms of the dimensions of human experience

(Leibrich, 1999, p. 7)

Mental illness in all its forms is part of society. It affects people of all cultures and classes. Mental illness is significantly different from physical illness, in that physical health needs escalate as people age, with public health funding accommodating this. Whereas mental illnesses such as schizophrenia primarily start in late adolescents and can be a life long health issue for some individuals.

No one has yet found a way to prevent mental illnesses, nor effect complete cures, but it is known that early support leads to better outcomes with people enabled to continue to lead a healthy life, contributing to their community of choice.

Given these facts, what do people who use mental health services want from them?

The Aotearoa Network of Psychiatric Survivors said this:

There is a remarkable consistency in service users' views about the [mental health] services throughout the world and between cultures. People want services that will restore them to full citizenship and enable them to participate in the community of their choice. We want services to facilitate opportunities to regain the social and material opportunities we have lost rather than to just treat our illness. Most of our needs are identical to everyone else's – a liveable income, secure housing, work, friends, intimate partners and self-esteem.

(The Mason Report, 1996, p. 89)

Yet in spite of these clear objectives, in most contemporary Western societies, as in Aotearoa / New Zealand, both professional services and community responses lead to exclusion, abuse, harassment and ridicule of people who are ill and vulnerable.

This harsh response induces fear, a fear that prevents people acknowledging their illness to themselves and others, prevents people reaching out to family and community for support before the mental health issues escalate.

How did this situation come about?

Communities are more than just places. At their core are connections made by people working together to solve common problems (McKnight, 1995). Such groups can be formal, such as service or sports clubs, political groups, business associations or unions, organisations focussed on preserving the environment, or ethnic groups focussed on maintaining culture. Others are informal - a gathering of neighbours, meeting in a coffee bar. In all these settings problems are discussed, opinions are formed and group actions are taken.

In Aotearoa / New Zealand early European settlers risked isolation moving far from extended families of their home. These associations therefore became central to their communities. More recently, with increasing mobility within Aotearoa / New Zealand, the associations remain vital pathways linking new arrivals in a town into a community

Technology has also created new ways for people to connect. Excellent transport networks enable people to meet with regional interest groups beyond the confines of their local town. Internet chat rooms offer new ways for people to meet, share ideas and take action well beyond the boundaries of countries.

Cultures have different approaches to community building. Maori are born into an extended family. A whanau or hapu often acts as a group coming together to solve problems. Yet to solve some of the complex difficulties arising from being marginalised, in a racist society and living in urban areas away from tribal lands, Maori developed new community groups through the Maori Women's Welfare League, and Kohanga Reo (Maori language pre-schools).

Mental Health Services and Communities

Only a couple of decades ago, services in New Zealand removed people far from home to large institutions for long periods. Now brief interventions of treatment closer to home are standard and the average length of in-patient treatment is now only ten days.

Once labelled and hospitalised, even for short periods, it is difficult for an individual to re-connect with a community that can be highly discriminatory. Individuals can frequently respond by hiding their experience, not telling employers or even friends that they have an experience of mental illness. Others leave hospital, having lost family, friends and work and move into staffed residential homes. Professional employees are paid to be friendly, and service users / tangata whai ora may see them as 'friends', as their 'community'. A professional/client relationship where an individual is employed to spend time with a person experiencing mental illness differs from our connections with true friends. Friendships are two-way relationships, supporting one another. People do not have to be paid to want to spend time with us.

Yet the reality for many people who have been institutionalised, or have a serious mental illness is that their primary social contact can end up being health workers or other clients with mental illness, separating them from the community at large.

Most people in staffed homes are encouraged to become more independent and 'graduate' to living on their own or with one or two others. Some services have begun to develop ways to link people in recovery to communities and there are some excellent examples of people being supported back into work, but in many services these crucial links to community are not made.

Too many people fail to make meaningful work or leisure or community connections in our hostile communities, and become ill and dependent on services once more, going back into hospital and then residential services, in a never-ending cycle.

There are often unexamined side effects to the ways mental health services have developed that hinder community connections.

Three of these are:

1. Professionalism.

For people with a disability or mental illnesses, the mechanism for their exclusion and disempowerment has been the rise of professionalism. As in many Western countries, professionals have labelled and excluded those whose presence is in some way difficult or disruptive to economic production.

Traditionally medical professionals have assumed the right to define the problem, and from their viewpoint this resides in individuals (Ballard 1994 p 18).

People enter services in the role of 'consumer', 'client' or 'service user', defining them in relation to the service, and denoting their inability, and that of their family and friends, to find answers to their problems. In these roles people leave behind their active citizenship and become passive clients; their abilities and attributes no longer acknowledged. The focus becomes their illness, their perceived deficiencies.

John McKnight (1995), American analyst and defender of community, articulates clearly the effect of this idea on communities:

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

McKnight (1995) sees services as taking from community capacity to look after their own. Care comes to be seen as something better done by professionals. As grief counsellors come into town so people will eventually lose faith in their own abilities to support one another at times of loss.

2. Boundaries

Along with professionalism come issues of relationships and 'boundaries'. Professionals keep their distance and their power through a careful maintenance of boundaries.

Boundaries can be self-protective and reduce exploitation. But they can also be used to distance people from each other. Boundaries make people less real and more 'God

like', and powerful. At a recent community meeting a psychiatrist spoke of his own life and concerns, and the effect was palpable. People who had used mental health services for years responded, saying they had never experienced this level of honesty and openness about his own vulnerability from a psychiatrist before and how they felt now that he was 'more human' and more approachable.

In some areas of community mental health services, in Maori services, and sometimes in residential and day services boundaries are often less distinct. Staff and 'clients' or 'residents' share stories, spend time together and connect on a deeper level. Yet there is still a barrier and that barrier is that for one person this is their work, for the other this is their life.

3. Individualism

The individualistic nature of western (Pakeha) culture is another unexamined assumption behind mental health services. The individual is the site of treatment, and achieving independence seen as mentally healthy. Like professionalism this runs counter to community health, which thrives on our need for interaction and a more natural and achievable interdependence.

Some treatments touch on the need for individuals to connect with one another. For example, self-esteem is seen as an issue for services to address. In Pakeha culture this is often treated with individual counselling or psychotherapy directed at our 'self-talk', when self-esteem is often gained most speedily through recognition for our abilities, through positive contribution to the lives of others, in community.

There are signs of small changes. Some mental health services support people into real work and some excellent individual staff members use their knowledge of community and their connections to link people back in. But real progress in the for all service users / tangata whai ora needs more than small and ad hoc efforts.

2. What is being done about the problem?

Many groups have been oppressed in Western societies since industrialisation. There is a long history of removal and disempowerment of people who are different past decades have seen the rise of gay, disability, women's, and anti-racism movements. In their experience of exclusion, people with an experience of mental illness have much in common with other marginalised groups.

Although there has been over one hundred years of mental health patients rights and consumer rights activity (Clinton, & Olsen, 1998), widespread community awareness of the movement for inclusion and rights for people with an experience of mental illness is recent. However, being a latecomer to recognition by communities gives the mental health rights movement an opportunity to learn from other groups' tactics and strengths.

Significant change in policies and recognition of rights has begun. During the past decade within mental health services, there have been moves towards recognition of the voice and rights of service users / tangata whai ora. 'Consumer advisers' have been appointed to most hospital based services to work alongside professionals, and

legislation now asserts 'consumer' rights to partnership within all health services (Health and Disability Services Consumers' Rights Act, 1996). Ministry of Health policies (1997 & 2001) also call for services that will work in a way that is participatory and will lead to community connectedness.

Another major factor in this movement's favour is that in Aotearoa / New Zealand the government has given support through funding the *Project to counter stigma and discrimination associated with mental illness*. This project, established in 1996 for five years, has recently been extended until mid 2003.

This significant commitment stems from a government inquiry into mental health and mental illness, the Mason Report (1996), which identified the importance of community inclusion.

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

The report led to the establishment of the Mental Health Commission, with oversight over the development of mental health services, staff training and a campaign to reduce stigma and discrimination associated with mental illness.

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

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

Only one of the seven destinations focuses on mental health services. Others are public health issues, moving public health away from its traditional focus on working with communities to improve conditions leading to poor physical health, to focus on creating environments in which people feel easily able to access mental health services without fear of stigma and where people with an experience of mental illness are supported, included, and have their needs understood.

In contrast to mental health services, whose goal is to change people perceived as 'having a problem', this project aims to change the attitudes and behaviours of whole communities: employers, landlords, government agencies, journalists and community

leaders, whanau, family, friends and neighbours as well as those of mental health service staff.

No longer just passive, people 'receiving services', services users / tangata whai ora, are not only beneficiaries of the project but people with gifts and abilities to contribute to its delivery, through both directing and supporting change. As McKnight has said,

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

Within the project this has begun to happen with the voice of tangata whai ora growing stronger. A national advisory group was established a year ago and is involved in determining the project's direction.

Initially, in 1996 project was planned to be a national television advertising campaign with supporting documentaries. However, preliminary research showed the need for grassroots community action to be firmly embedded to ensure any national advertising would be effective. There were also political considerations. Government sponsored advertisements are often viewed as propaganda by the general public. Their impact would be minimal without follow up by visible community action.

The focus turned to contracting local organisations to provide public health education for mainstream (Pakeha), Maori and Pacific Island communities. These 'local' providers were encouraged to demonstrate evidence of service user / tangata whai ora involvement in the planning and implementation of their programmes. These were to be supported by the 'national project to counter stigma and discrimination associated with mental illness', co-ordinating media advertising, training, advocacy, and the production of resources.

Most contracts went to existing public health or mental health service organisations. Only here, in the Bay of Plenty, was a new approach taken. A group of six organisations in the Bay came together to plan for the mainstream Bay project work. The organisations were:

- a consumer advisory group,
- a consumer run centre,
- a mental health service,
- the public health unit and
- two family support groups

The group employed two researchers (one a service user / tangata whai ora) to consult mental health service user groups and related agencies, discovering how discrimination and stigma affected people in the district, and collating ideas on how this might be addressed. From this 1998 report *Planning for Empowerment*, an action plan was developed.

The plan proposed the establishment of a new entity as no regional agency had a strong service user / tangata whai ora focus. To be really effective in tackling discrimination on all fronts a new way of working was needed. In 1999 a trust was set up named "Serious Fun 'N Mind". Initial trustees were a mix of service users / tangata whai ora, staff of mental health services and families and a kaumatua.

Arana Pearson: When I initially became involved, my previous experience as a user of mental health services was accepted as my perspective and contribution in the group. During the planning phase I became aware there was potential for service users / tangata whai ora to model a new form of partnership and leadership in the work of tackling discrimination in the communities about the Bay of Plenty.

After the research report came the time to action its recommendations. At first I held the contract myself, with the responsibility to form the trust and subsequently became the first chair of its board.

However, this work was not without challenges. During this time I was also working part time in a mental health service in the role of consumer support and liaison. Once that service understood my involvement in this other community development role issues of 'conflict of interest' arose. The real test and challenge was whether I, a person with a service user / tangata whai ora background, could effectively manage a variety of roles in service development and community development. Sometimes it appeared these two focuses were diametrically opposed and in competitive conflict.

We did work it through partly through the acceptance of members of the trust board who were senior managers of both public and hospital based services. The balancing act is to really involve everyone, and this includes professionals alongside family, Maori, and service users. We had achieved this at the outset of the establishment of the Trust. It was clearly a team effort and we could not have been effective without the team support of the entire working group and especially with the support and resources freely offered by Public Health (Toi Te Ora) and Lakeland Health.

Ruth Gerzon: Two years ago this week I began work as the first employee/co-ordinator of the Serious Fun 'N Mind Trust. I had worked for two decades on issues of racism and disability rights. I am a Pakeha (NZ European) finding a way to live in a society, which marginalises the indigenous peoples of Aotearoa

I have not yet had a disability, intellectual or physical

I have not yet experienced a mental illness.

My journey has been as an outsider to those directly experiencing the pain of exclusion and has been an exploration of the role and ethics of the outsider, perhaps, at best, but not always, an ally.

Looking back I see what a leap of faith trustees took to put me in the role of co-ordinator, and feel immensely privileged to have been part of the early stages of this momentous journey.

When I began work I knew nothing about mental illness or the stigma and discrimination associated with it and carried deeply implanted within me both unexamined stigma and behaviours of discrimination.

Service users / tangata whai ora were my first mentors and guides, sharing their stories and understanding. Arana and his friend Geoff Harman, later joined by Jennie Hawira, Jane Barron, Catherine Dickinson, Chris Hansen and many others who became part of the Trust's Seriously Open Minded advisory group or individually supported project work. I deliberately avoided the traditional medical perspective on

mental illness as I believed a broader view would enable me to be more effective in working in the field.

I was constantly surprised at the depth of discrimination. I once spoke to Geoff about the need to 'avoid images that give rise to pity and charity' – something other disability groups have been moving away from for sometime. His response: '*pity would be a good start*' gave me a wake up call. In this field we deal with a different and much stronger basis for exclusion. Exclusion of people with an experience of mental illness is based on fear, a primeval emotion, harder to dislodge than pity.

The aim of the Trust was to promote sustained respect for people with an experience of mental illness. One person, two cities, four towns, and many smaller places in between and up the Coast. A total population of 280,000.

As I made my way around service user / tangata whai ora groups and services I found many talented people keen to support change. The role of the Trust became to network, bringing people together, providing training and resources to enable them to use their gifts to advance the cause, providing vehicles for them to express themselves. The driving force and enthusiasm was provided by service users / tangata whai ora, but they were joined in this network by some mental health service staff and family members, learning to work alongside service users / tangata whai ora as equals. It turned out the movement to promote respect for people with an experience of mental illness was an idea whose time had come.

Within six months, by the end of the first Mental Health Awareness Week in October 1999

- There were four committees in different towns: over 45 people actively organising events, running workshops, writing their stories, speaking on radio, devising puppet shows for schools, orchestrating street theatre.
- Over 400 people had attended a workshop or other public event
- More than 1400 column centimetres of newspaper space had been devoted to positive articles and advertisements about mental health and mental illness.

Looking back I can see some things were especially significant in those frenetic first few months of activity.

1 Service user / tangata whai ora support groups throughout the Bay actively joined in the work against discrimination. The activities gave people in existing service user / tangata whai ora networks a vehicle for speaking out and many showed immense courage in doing this. In a climate that remains highly discriminatory, they gained both visibility and a voice.

The two most effective events that first year brought tangata whai ora and high profile members of the community together. Each took place in four different towns.

Awards for Respect. Service users / tangata whai ora in each town selected their champions: people in the community and in mental health services and government agencies that had shown them sustained respect. Some people selected were well known, such as a mayor; others were 'the person at the corner store', a general practitioner or mental health service worker. The

ceremonies differed: sited on marae or in mayoral chambers, all with speeches, some with song, but all bringing together tangata whaiora and high profile people in the community.

Breaking the Stigma Wall. A two metre high and four metre long artwork was made for this street theatre, a wall of stigma along with a pathway to respect and many banners. In the wall's centre is a broken mirror with the words 'Face the Stigma'. Each town developed its own 'kawa' or ceremony surrounding its demolition. In some towns a haka was performed. In others karakia (prayers) were said before the symbolic journey began down the yellow brick road to respect. Mayors, psychiatrists, police, politicians and tangata whai ora carried out wall demolition with style. The activity involved many people, and invariably gained good coverage on radio and in the press.

2 People gained self-esteem and a renewed sense of purpose through participation. The movement against stigma and discrimination associated with mental illness has opened up new and valuable roles for people, contributing to their recovery. The impossible began to feel possible. To gain momentum the movement needs all the people it can gather and here there is a place for everyone, from facilitating a group to joining a walk, handing out leaflets, nominating someone for an Award.

3 In *Planning for Empowerment* it was said that
'The turning point is very personal. No one can make it happen for you.'
(1998, p32)

New people with an experience of mental illness joined the movement, people not previously active in service user / tangata whaiora networks. Some were people embedded in community with paid work and family, yet living a life where their illness, a significant part of their lives, remained hidden from those around them.

For one woman in a small town the symbolic demolition of the stigma wall and her walk down the pathway to respect became a personal breakthrough.

I felt I had broken down my own wall...walked down a pathway to freedom. It was like a rebirth.... for 13 years my illness had been a secret to myself and I had not been able to talk about it to anyone.

(personal communication to author)

Since then this woman, a member of a service club has courageously played an active part in the project, using her gifts and strengths to speak publicly about her experiences and the pain of stigma and discrimination.

As New Zealand author, Keri Hulme, wrote in *the bone people*

*They were nothing more than people, by themselves.
Even paired, any pairing would have been
nothing more than people by themselves.
But all together, they have become
the heart and muscles and mind
of something perilous and new,
something strange and growing and great.*

*Together, all together they are
instruments of change.*

(1983, p 2)

4 Only during the subsequent reflection and celebration meals held with committees in each town did I become aware of the importance of the breaking of boundaries. In the initial research it was noted that

...there is a very strong 'them and us' mentality between 'consumers' and professionals that cannot be denied. Some of the boundaries created by this 'them and us' mindset, whether they be real or imagined, as long as they are perceived to be there, they will remain a major hurdle to over-coming discrimination and misunderstanding between 'consumers' and professionals.

Planning for Empowerment (p 14)

For many professionals and service users / tangata whai ora the committees gave them their first chance to work as equals in pursuit of a common goal. Some barriers dividing these groups began to crumble.

Becoming visible and 'out' takes a great deal of courage in communities where fear and misunderstanding are still rife. The woman who walked down her pathway to freedom later recalled feeling very tender and exposed. We have learnt that people need to consider the implications for themselves, their families and their health before they take this journey. But for those who wish to do this there is now support.

Since those first few months many more activities have occurred that both support labelled people to be heard and recruit new allies to the movement.

We have organised workshops in writing, art, public speaking, and facilitation so that the voice of tangata whai ora gains strength. Tangata whai ora now run workshops for mental health services, government agencies and social work students throughout the Bay of Plenty, and there is now a demand for these further afield. We have also produced resources: the music CD 'I'm Just a Little Mad', badges, the wall, banners, street theatre, displays, and held many public events.

Recruiting allies to work alongside labelled people in the project has not proved as difficult as I had anticipated. Not everyone who attends a workshop later joins in project work but significant numbers now actively support the project and others have gone away with more understanding of mental illness and an understanding of discriminatory behaviours.

- Hundreds of mental health service staff have attended workshops facilitated by service users / tangata whai ora, others have offered to join them in speaking to community groups; many have joined in street theatre and walks for wellness, manned stalls and displays
- The business community: chambers of commerce have joined in promotion of mentally healthy workplaces
- A puppeteer has worked with staff and tangata whai ora to produce a puppet show and tour schools promoting 'healthy minds';

- And with a bit of lateral thinking we even persuaded the Australian children's TV character friends: Bananas in Pyjamas to join the cause, promoting a stress free lifestyle.

Yet there is a wild card that can undo in an instant all the work of a year or two. I refer here to the media. This powerful mechanism of community exclusion well known to all marginalised groups has been used with particular potency against people with an experience of mental illness. In *Planning for Empowerment* it was noted

‘As long as the media highlights the ‘crazy’ ones we all suffer.’
(1998, p 69)

The media, with its penchant for headlines that frighten and intensify stigma, its quick and simplistic views of complex issues continue to do much damage. Horror films use images and story lines that link mental illness and dangerousness.

Mental illness is rarely out of the news for long but the perspectives, the voices we hear are those of politicians, professionals and frightened members of the public. Even now, if an event is inaccurately reported or blown out of proportion, their voices can drown out those of service users / tangata whai ora, linking violence and mental illness and adding to stigma.

Alongside our other attempts to spread the message we have worked with the media. Nationally, the project's TV advertisements began just over a year ago and raised the profile of the campaign and awareness of discrimination. Regionally we have worked closely with media, training people in the project to contribute positive articles, informing reporters of resources that help ensure they do not add to stigma and discrimination through their writing and broadcasting. A Media Madness workshop brings the point home to trainee journalists and a prize for journalism students who write positive articles will be offered this year.

3. HOW EFFECTIVE HAS THIS APPROACH BEEN?

For all our work the reality is that the wall of discrimination has only been symbolically smashed: a very few bricks removed. It is crucial to reflect on this, to work out how to use limited resources to the greatest effect.

1 It takes a few key people to spread new ideas (Gladwell, 2000) and here is where we have made most progress. People with an experience of mental illness have always lived, worked and contributed to our communities. One in five of us have an experience of mental illness every year. But many are invisible. The campaign has encouraged more people to ‘come out’ and describe their experiences through poems, stories and songs. Like a pebble that ripples in a pond, these people are spreading the word and this will make a difference, for research shows that

‘People who have had contact with people with a mental illness have different attitudes to those who have had no such experience’
(BRC 1997 p 108)

2 We have begun to find effective vehicles to express our ideas in ways that help people both receive and remember the message:

The Stigma Wall and Pathway to Respect,

A powerful drama used in our Tangata Whaiora Experience workshop

The national advertisements, showing high profile people, known for their positive contribution to our communities, 'coming out' about their own experience of mental illness.

The simple telling of stories by tangata whaiora.

The simulated experience of Hearing Voices that are Distressing

The music CD '*I'm Just a Little Mad*'

3 Some people, not receptive to the soft sell of educational approaches, need clear indicators that certain behaviours are no longer acceptable. Even if we think people with a mental illness are lesser beings we are unlikely to say so, or refuse to employ them if we know these behaviours are illegal or unacceptable to people around us. Research (e.g. Eagly & Chaiken, 1993), indicates that behaviour change precedes attitude change. A climate of 'zero tolerance' for discrimination is needed to push through change.

We have begun this through the

Promotion of human rights, and rights to good health service

Challenging councils who refuse people the right to live or meet in certain parts of the community,

Support for people denied work because of the label they wear

Letters to editor to complain when negative language is used

If inclusion in a community of your choice is essential to mental health, then will these tactics, given time, demolish the rest of the stigma wall and enable inclusion for everyone with an experience of mental illness?

Will they bring what service users / tangata whai ora wish: full citizenship and participation in the community of their choice?

Coming from a community development approach, the Trust work has been effective, building on people's strengths. But the project has only tackled one half of the equation: stigma and discrimination in the community. Also needed is a change of mental health service practices towards community building, using people's strengths to help them regain or retain connections with communities of their choice. Services must see their role as supporting the capacity of communities to care and to include service users/ tangata whai ora.

As noted by Tessa Thompson (2000), "work to promote social inclusion is fundamental to recovery ...(it) is not a sideline to mental health services - it is the Heart".

Public and mental health services need to work together to promote the linking of people to communities, cementing in new ways for people who have not yet experienced a mental illness to relate to those who have.

Community connections bring a double benefit: promoting mental health for labelled people, and reducing the stigma and discrimination, through the people contact that has been shown to be so effective. (Business Research Centre report, 1997)

Active involvement in communities, through paid work, membership in sport, leisure, service clubs, and inclusion in activities on marae, needs to be viewed as essential to recovery. To enable this to happen for everyone, some service users / tangata whaiora will need staff skilled in linking them to communities. In this way people can leave behind their passive 'patient' roles in services focussed on their perceived deficiencies and build the self-esteem that brings emotional health.

If inclusion in a community is crucial to mental health, then care in the community for people with an experience of mental illness needs to become true community care.

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