

NEW ZEALAND ACTION RESEARCH NETWORK

Consumer Participation in the Project to Counter Stigma and Discrimination Associated with Mental Illness

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This is a five-year project (1996-2001), purchased by the Health Funding Authority, implementing a recommendation of the Mason Report¹ for a public awareness campaign to educate the public about mental health and mental illness. The report identified negative public attitudes towards those with experience of mental illness as a barrier to recovery from mental illness and accessing services at an early stage.

Although some other countries are attempting to address these issues (the World Psychiatric Association has ten pilot projects under way, including Australia), and New Zealand has some experience of changing public attitudes and behaviour in relation to other sensitive issues (e.g. homosexuality, domestic violence), the project largely explores uncharted territory. Furthermore, it is doing so in an environment in which the delivery of health services is politically sensitive, while mental health services, in particular, are experiencing intense media scrutiny.

The project consists of two major components: firstly, developing networks and activities at community level to empower consumers/tangata whaiora² and change attitudes and behaviour in the mental health sector; and secondly, to support these community initiatives with a national programme of policy development, media and public relations. Each of these objectives involves significant social change. The first of these - empowerment of consumers and changing attitudes and behaviour in the mental health sector - challenges traditional relationships between patient and professional that have persisted for centuries and are deeply entrenched in our culture. The second is an equally radical attempt to change popular conceptions of 'madness' in a world dominated by myths and stereotypes of people with a mental illness as 'dangerous' and 'unpredictable'. These myths and stereotypes are regularly reinforced by media reporting of exceptional tragedies and criticism of the adequacy of mental health services.

Independent researchers have been engaged to carry out formative, process and outcome evaluation of regional activities, including the planning process, cultural appropriateness, and impact on consumers. In addition, the impact of the mass media campaign will also be evaluated in September 2001. While consumers may be involved as key informants in these evaluations, it is also necessary - to be faithful to the project's intention "to empower consumers and increase consumer involvement in the project" - that consumers decide for themselves whether the process of involvement in the project is empowering, and to make their own decisions regarding the nature of their participation.

WHAT IS MEANT BY CONSUMER PARTICIPATION?

Definitions

A consumer/tangata whaiora is defined, in the Health Funding Authority's National Plan for The Project to Counter Stigma and Discrimination Associated with Mental

¹ Report of the Inquiry under Section 47 of the Health and Disability Services Act 1993 in respect of certain mental health services (The Mason Report) 1996:164.

² 'Consumers' are people who have experienced mental illness and have used mental health services. 'Tangata whaiora' is a preferred term for Maori consumers and means 'people seeking wellness'.

Illness (April 1999), as people who have 'experience of serious mental illness and have used mental health services'

Consumer participation is any activity done by consumers where they have power or influence on the systems and services that affect their lives. 'Consumer participation', like the concepts of 'love' and 'democracy', is an overarching term with many different shades of meaning and expression. It can mean many types of activity by many types of consumers. It can happen in any type of service or system, at every level from government policy development to the one-to-one relationship between a service user and service provider.

One of the major forces that brought about consumer participation was the development of the consumer movement in New Zealand in the late 1980s. The consumer movement began in the 1970s in Europe and North America but did not develop in New Zealand until the late 1980s. The consumer movement is based on a similar world view to the feminist, gay rights and civil rights movements. The underlying principle of all these movements is self-determination. In the last ten years this principle has begun to influence the way services in New Zealand are delivered to people with mental illness. Government policy now requires services to involve service users at all levels.

Government policy and consumer participation

Standard Nine of the National Mental Health Standards (2) prepared by the Ministry of Health states that 'consumers are involved in the planning, implementation and evaluation of the mental health service'. The standards are specifically aimed at mental health services but are also relevant to the discrimination project, particularly as Standard 20 refers to the mental health services responsibilities in promoting mental health and community acceptance. The Ministry of Health's Guide to Effective Consumer Participation in Mental Health Services was written for mental health services as well as 'mental health promotion and education'. It is clear that government policy requires the discrimination project to involve consumers.

The HFA's commitment to consumer participation

The HFA's draft national plan, prepared jointly by the Public Health and Mental Health, recognises the importance of consumer participation in the discrimination project. One of the guiding principles is to 'ensure project activities are consumer-focused'. In the 'health sector development' component of the project, the HFA 'will focus on ensuring consumer involvement and making consumers more visible and comfortable participating in the project'. It plans to do this through incorporating consumer advice into the project, organising local consumer hui and developing consumer networks for the project. The plan is clear that both the HFA and national and regional providers share responsibility for developing consumer participation. The HFA's Mental Health Operating Group is developing consumer networks and processes for consumer participation in the HFA organisational and policy directions. When this has been set up, the networks and processes developed for the discrimination project will be incorporated into the overarching HFA consumer participation activities.

Issues unique to the discrimination project

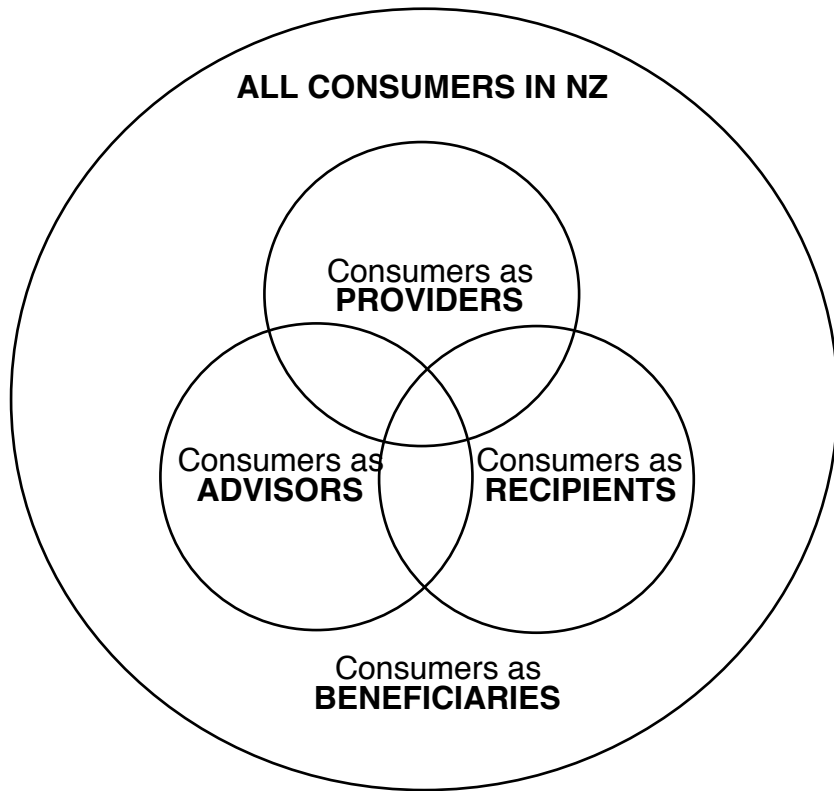
Consumer participation in the discrimination project differs slightly from consumer participation in personal mental health services. Consumers are the main beneficiaries and the main recipients of mental health services. While they are also the main beneficiaries of the discrimination project, they are not its main recipients. The project's main recipients are the people who discriminate against people with mental illness. This means that others, such as the recipients, public relations, public health and community development experts may have as good an understanding of effective ways to deliver the project as consumers do. Consumers still need to be involved in decisions about the delivery of the project but we need to remind ourselves that we do not walk in the shoes of the main recipients of the project, as we do walk in the shoes of those who are recipients of mental health services. In every other way consumer experience and expertise is as fundamental to the success of the discrimination project as it is to the success of mental health services.

The primary purpose of the discrimination project is not to develop the consumer movement - it is to reduce discrimination against consumers. The consumer movement is the responsibility of the whole mental health sector, not just the discrimination project. However, a well developed and coordinated consumer movement is crucial to the success of the project.

CONSUMER ROLES IN THE DISCRIMINATION PROJECT

People with experience of mental illness could have any role in the project whether the role is specifically created for consumers to fill or not. But there are four major roles consumers can have in the project - as beneficiaries, advisors, providers and recipients. Other roles they could fill are as funders or monitors of the project.

There is some overlap between the four major roles - some consumers will be in some or all of these roles over the time of the project. All the consumers who are providers, advisors and recipients are also beneficiaries. This situation is made more complex by the overlay of ethnic and regional differences. These roles cannot be considered without taking into account the four HFA regions and the main ethnic groups including Maori, Pakeha, Pacific people, Asians and others.



The different types of participation in the discrimination project

The four major roles all require the involvement of different groups of consumers to participate in different ways, as expressed in this table.

ROLE	WHO	EXAMPLES OF PARTICIPATION	WHY
Consumers as Beneficiaries	All consumers who stand to benefit from the project, or in parts of it	Survey of kinds of discrimination that affect consumers, for planning purposes	To understand the experience of the consumer population
		Evaluation of the effectiveness of the project	
Consumers as Providers	Consumer organisations that are providers in the project and consumers employed by other providers	Information to consumer population on the project eg leaflet, website	To inform the consumer population of the project
		The work they are contracted or employed to do on the discrimination project	To ensure consumers have a high profile in the project as role models and change agents
Consumers as Advisors	Consumers who give advice on the project as representatives	Representatives on advisory groups with a consumer mandate and processes for eliciting consumer views	To ensure breadth of consumer influence in the project
	Consumers who give expert advice on the project as individuals	Individual consumers on advisory groups or consulting to providers or HFA	To ensure depth of consumer expertise used for the project
Consumers as Recipients	Consumers who directly use a service provided by the project	Consumers receiving training to be providers eg media training, Speaker's Bureau training	To develop consumers to become advisors or providers in the project
		Consumers using resources provided for them by the project eg book of retorts, leaflet on using the Human Rights Act	To assist consumers deal with discrimination

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Some issues need to be noted here:

Consumer providers have as much obligation to seek consumer information, advice and feedback as other providers.

Providers and the HFA need to be clear whether they need individual expert advice or representative advice. People in a representative advisory role need to have a mandate from a group of consumers and show they have processes for finding their views, such as consultation meetings or focus groups. Consumers giving expert individual advice should have the confidence of consumers but they do not need a formal mandate and will not always need processes for getting broader consumer views, though they often do.

The experience of mental illness alone is not sufficient for many forms of participation. If the project is short of consumer providers and advisors it needs to address this shortfall through active recruitment and/or training.

CONSUMER PARTICIPATION IN THE PROJECT SO FAR

There is a long history of consumer efforts to change the way in which mental health services are delivered, and especially to counter stigma and discrimination. A consumer group, the Aotearoa Network of Psychiatric Survivors (ANOPS), was funded by the Ministry of Health from 1988, and consumers were among those who made submissions to the Mason inquiry, calling for a public awareness campaign. Subsequently, ANOPS was involved in the original project plan, "Time for a Change", which anticipated consumer involvement/leadership in delivering the project activities.

The first major set-back to consumer hopes for the project occurred early in 1997, when then Minister of Health, Hon. Bill English, decided to postpone the mass media component of the campaign, and pass the funding from the Ministry of Health to the Regional Health Authorities (RHAs). The purpose for this was to ground the campaign in community level activities before taking it to the wider public through the mass media, and the RHAs were considered to be the appropriate government agencies for putting a more comprehensive health promotion plan into place.

However, the decision was something of a shock to consumers, since, although ANOPS had formed a working relationship with the Ministry, the decentralisation of funding required them to be represented in every region of the country. ANOPS did not have the infrastructure for this, so that, as funds were dispersed to public health service groups throughout the country, consumers often found themselves left out. The issue was confronted at a conference in Rotorua in March 1998. Consumers, angry with the way they had been side-lined by the dispersal of funding, confronted well-meaning, but puzzled project providers, who had become unwittingly part of the problem, rather than as they had intended, contributors to the solution.

Fortuitously, at the same time, the RHAs were in the process of re-structuring as one agency, the Health Funding Authority (HFA). The single funding authority was better able to bring all the parties together and develop a comprehensive, coordinated approach. The Rotorua conference proved to be a major expression of the power of the consumer movement, as it was able to gain from the fledgling HFA a commitment to fund a series of regional hui for consumers leading to a national hui a year later, in which consumers were able to reconsider their role in the project, their relationships with other participants in the project, and to re-organise themselves.

New regional consumer representatives became members of the stakeholder group which then met with the HFA to develop a new plan for the project, which was referred back to the national consumer hui in March 1999. In addition to approving the HFA's new project plan, the hui also

formally established a new Consumer Advisory Group (CAG) to the Project, and produced guidelines for consumer involvement. To symbolise the new relationship between the HFA and the CAG, a consumer-designed logo - 'Like Minds, Like Mine' - was unveiled and blessed.

By this stage, regional project providers were also re-negotiating their relationship with consumers actively involved in delivering the project, reflecting the varying roles that consumers wished to occupy. In some cases, consumers were delivering specific activities, such as 'Hearing Voices'³ workshops, or held leadership roles within a local organisation. In other places, a local consumer advisory group was formed outside the project, in partnership with it.

Nationally, the focus had returned to the mass media campaign, now scheduled for early 2000. The national CAG was represented on the HFA's selection panel for a new national project manager, and the selection panels for an advertising agency and independent evaluator.

So, without setting out to be an action research project, a classic pattern of planning, action, reflection and review has emerged. The time is now opportune for consumers involved in the project to make this pattern more intentional.

THE GAPS IN PARTICIPATION IN THE PROJECT

Anyone involved in the discrimination project will see that there are some large gaps in consumer participation. The HFA plan in its 'Achievements to date' section gives the impression that the HFA and many providers are behind schedule in their obligations to involve consumers. No-one has systematically identified the gaps in consumer participation but this needs to happen. Some of the following statements have been framed as questions because not all the information on the gaps is available.

Consumers as beneficiaries

- Have any surveys, literature reviews etc been done to determine levels and types of discrimination consumers experience?
- Have any evaluations of the discrimination project, or parts of it, been planned to determine if it has had a beneficial effect on consumers?
- How many consumers know about the project?

Consumers as providers

- There is no longer a national consumer provider.
- There are very few regional consumer providers.
- Should more consumers be employed by other providers?
- Do these providers know how to ensure the safety and accountability of their consumer employees?

Consumers as advisors

- There has been some ongoing national consumer advice which needs to be strengthened.

³ 'Hearing Voices That Are Distressing' is an experiential workshop designed by Pat Deegan, Director of Training for the National Empowerment Centre, USA. With the voice-hearing experience simulated through headphones, the workshop gives participants a personal insight into some of the challenges faced by people with a psychiatric disability.

- There is no independent advisory or advocacy body.
- Consumer advice at the regional level has been extremely patchy.
- Consumer advice to individual providers has also been extremely patchy.

Consumers as recipients

- Are enough consumers being trained to be providers in the project?
- Is there enough focus on assisting consumers to deal with discrimination?

Evaluation of consumer participation: some thoughts on methodology

The problem

Consumer participation is a key feature of the project but there is evidence that it has not always happened or been done effectively.

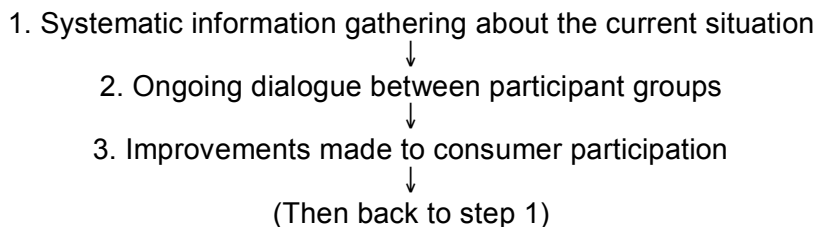
An evaluation is needed to identify the strengths and weaknesses in consumer participation and to enable people to collaborate on equal terms to improve it.

The participants

The groups who need to participate in the evaluation are:

- consumers
- funders
- providers
- Maori
- Pacific nations.

The process



Evaluation of consumer participation: some thoughts on the role of consumers

Any research methodology needs to be consistent with the values of the consumer movement and consumer participation - human rights and self-determination.

The project is built on the principle of consumer participation so any evaluation needs to actively involve consumers

This means consumers need to have some control in all stages of the evaluation:

- consumers need to lead the evaluation
- informed consent becomes informed participation
- consumer experiences have as much credibility as anyone else's
- the process and outcome should benefit consumers

Evaluation of consumer participation: some thoughts on questions

Some of the questions have been partially answered in this presentation.

All participants need to be asked and discuss with each other:

1. Questions on principles

- Why should consumers participate?
- In what roles do they need to participate?

2. Questions on current situation

What consumer participation has developed in the project

- regional level
- national level
- Maori consumers
- Pacific nations consumers

What has worked well and why?

What hasn't worked well and why?

Where are the gaps in consumer participation?

- regional level
- national level
- Maori consumers
- Pacific nations consumers

Why do these gaps exist?

3. Questions on future directions

What needs to change so the gaps are filled?

Which gaps need to be given priority?

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