Service user participation in mental health services

A DISCUSSION DOCUMENT
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Introduction

Participation is about getting and sharing information, making a difference to decision-making, being treated with respect, and understanding one’s rights. Service user participation within the mental health context should improve mental health services and move the experience of services users from exclusion to inclusion. Mental health service users writing and talking about their experiences emphasise that their participation in decision-making within services must be available, real and meaningful.

This paper aims to broaden dialogue about service user participation among service users, mental health workers at all levels, providers, policy makers and funders. The paper asserts that service user participation should occur routinely at all levels.

The Blueprint for Mental Health Services in New Zealand states that service users should participate in mental health services in a variety of ways:

As individuals, [service users should] take an active part in their assessments and in decisions about their treatment and support. As a collective, they [should] be involved in the planning and evaluation of services at all levels.

(Mental Health Commission 1998a:17)

This paper provides a framework for thinking about and discussing service user participation. It is intended for mental health service funders, policy agencies, service providers and mental health workers and service users. It will help mental health organisations think about ways they can integrate service user participation more effectively into their daily business.

Service users developed this paper for the Mental Health Commission, and have drawn on service user views and experiences.

Why we need to look at service user participation

There are a number of reasons why service users should participate.

1. Service users have fundamental citizenship rights that include participation in mental health services or issues that affect them.
2. Participation gives service users an active role that is essential to their recovery.
3. The rights of service users as customers mean that they should be given choices and that services should respond to their needs.
4. Service user participation contributes to improved services.

Current discussion about service user participation shows:

• a tendency to focus on service user participation at the service or system level, rather than the individual service user’s relationships with mental health workers while they are receiving a service from them
The Commission strongly believes that service users, individually or collectively, should influence decision-making within mental health services. But opportunities for service user participation vary widely. There is little consistency in the way policy makers, funders, providers or mental health workers think about, plan for and ensure participation. Reasons for this inconsistency include the lack of conceptual clarity and consensus about what service user participation really means, and the contexts and competencies that are necessary to support it.

Scope of this paper

This paper covers service user participation in the mental health service sector only. It doesn’t cover service users participation as service providers whether independently, as part of mainstream services or as independent advocates. Nor does it cover the participation of people with mental illness in the wider society, or service user participation in other sectors (such as employment or social services), in research or in mental health promotion.

This paper doesn’t give guidelines on how to do service user participation; this paper provides a framework for thinking about service user participation and discussing it.

Use of this paper

This discussion paper provides service users with information on the scope of participation and their right to participate. Policy organisations can use this paper in the development of policy, standards, strategies and guidelines. Funders can refer to the paper when developing service specifications and monitoring services. Providers can use the paper for reviewing their existing service user participation processes and when developing new approaches.
Who is a service user?

Put simply, a service user is a person who uses mental health services. However, service users differ considerably in terms of:

- whether their service use is voluntary or involuntary
- the types of services they use
- how long or how often they have used services
- the extent their mental illness has disrupted their lives.

Unlike the users of many other services, mental health service users can be either voluntary or involuntary users of services. Individuals who are committed for treatment under the Mental Health (Compulsory Assessment and Treatment [CAT]) Act 1992 or the Alcoholism and Drug Addiction Act 1966 are not voluntary service users. Moreover, because they use a service this should not necessarily imply that the service user agrees with the service's views on the nature of their problem.

Most people who identify as service users have used specialist mental health services for their mental illness or distress. However, there are some people active in the service user movement who have only used primary health services for their mental health problems or addictions. Service users can be current, former or episodic users of services.

It is worth remembering that, ultimately, any person who uses mental health services has another much larger personal identity beyond their diagnosis or their use of services.
service user participation in mental health services
Unlike users of other health services, mental health service users can be voluntary or involuntary. Individuals can be involuntarily committed for treatment under the Mental Health (CAT) Act 1992 or the Alcoholism and Drug Addiction Act 1966. Sometimes the fundamental choice of whether or not to use a mental health service or treatment is taken away.

This can have a profound effect on participation. Being subjected to compulsory treatment may greatly impact not only on a person’s ability and willingness to participate in his or her treatment, but also on their ability to participate in and make decisions about social activities that citizens take for granted, such as employment and education (Pearson 2001).

One of the most important supports for service users’ participation is their status as voluntary users of services. Participation is a useful contributor to recovery. Important principles of common law (Legislation Advisory Committee 2000) and ethical requirements mean that mental health professionals should try to maximise the use of voluntary treatment and minimise the use of compulsory treatment.
The context of service user participation in wider society

Service user participation can be matched to historical trends of citizen participation and greater recognition of customer rights. Legislation and government policy regarding human rights and elimination of discrimination supports participation. Health sector policies require and support service user participation. The Treaty of Waitangi gives mental health organisations a basis for Māori to participate in ways that are meaningful to them.

The Treaty of Waitangi

A commitment by funders, policy agencies, service providers and mental health professionals to the participation of Māori service users must recognise Māori as tangata whenua and Treaty partners. The Treaty of Waitangi is officially recognised as the founding document of this nation and is the base from which Māori and non-Māori conduct their affairs and relationship. The government has responsibilities under the Treaty of Waitangi and has an objective to improve the health status of Māori.

The Treaty provides for separate kaupapa Māori services delivered by iwi and other Māori providers. Māori need to determine their own perspectives and practices at all levels of the mental health sector and in all phases of service delivery. Issues like health, illness, partnerships, a good service and good outcomes must be built into participation processes that Māori service users use.

The Treaty is also a good working model for thinking about both Māori and non-Māori service user participation, as its principles include participation, partnership, active protection and a duty to consult.

Before Māori service users can begin to fully participate in the decisions about their own treatment more Māori mental health workers, particularly clinicians, must be appointed. A service user cannot contribute to his or her own treatment plan when health professionals do not understand their needs.

All non-Māori clinicians need to have had cultural training so that they can have meaningful dialogue with Māori service users. They need to understand the articles of the Treaty of Waitangi in their everyday work, understand the impact of colonisation and Treaty non-compliance on Māori, and be able to help Māori service users rediscover their identity and enrich their mana. Clinicians need to have knowledge of and empathy with Māori service user recovery stories and experiences. Clinicians who do not have this knowledge take away the right Māori service users have to participate in their recovery plans.

While the number in kaupapa Māori services has grown, many of these services are residential support rather than clinical services. The clinical services for people who want a kaupapa Māori service are still largely provided by non-Māori.
Maori service users are denied opportunities to participate fully in policy-making or in decisions about the structure of systems at national or local level unless the people with whom they are participating have a proper understanding of biculturalism.

Citizen participation

The movement for participatory democracy developed throughout the western world in the 1960s. It challenged public sector agencies to show accountability and involve those sections of the public interested in and affected by their decisions. Such involvement is a key way that public sector agencies now demonstrate their responsiveness.

Service users have rights to participate in wider society and in mental health services. But the claim to citizenship rights for people with mental illness has only happened recently. Some of the main drivers of this claim have been civil rights, the closure of institutions, the service user movement, the recovery approach, and anti-discrimination campaigns. As the citizenship rights of people with mental illness have become more widely acknowledged, it is inevitable that over time the mental health sector will have to provide a full range of opportunities for service user participation.

Customer rights

Current thinking on mental health service user participation and agency responsiveness is also influenced by ideas about the rights of all consumers or customers of goods and services.

During the 1980s increasing public dissatisfaction with health care services included concern about lack of consumer control and say in how health care should be delivered. Changing consumer needs, and the needs of groups such as women and Maori were not being met by services. Management concepts such as ‘quality improvement’, ‘customer responsiveness’ and ‘cost-effectiveness’ have been increasingly employed by public sector agencies wanting to improve their services for users, and the public sector has generally adopted marketplace terminology when describing its operations.

The use of the term ‘customer’ for service users, within a mental health context, needs to be carefully qualified. When someone wants to buy goods or services they do not have the automatic right, or the ability, to control what goods and services are provided, but they do have the power to choose the options placed in front of them. Mental health service users do not necessarily have any choice about using services, for example when they are subjected to compulsory treatment.

The focus on the customer is a focus on the individual. In contrast, service user participation provides the opportunity for both individual and collective benefit. As well, a customer focus tends to concentrate on the delivery of services, whereas service user participation should happen at all stages – from design to evaluation – of mental health services.
Developments within the mental health sector

Several changes in the mental health sector have encouraged greater service user participation. These changes include a shift from institutions to community-based services, development of services focused on meeting diverse service user needs, and the development of consistency. These changes are consistent with the recovery approach (see page 14).

Policy supports for service user participation

Several New Zealand health sector documents and guidelines set out requirements for service user participation. These include:

- **the Ministry of Health's Moving Forward.** Under Objective 3.2 this states:
  
  "The main area where service responsiveness and quality improvements in mental health can be achieved is through increasing involvement of consumers in all aspects of the sector through planning, policy, purchasing and provision. (p.22)"

- **the National Mental Health Standards.** Standard nine requires consumers to be involved in planning, implementing, and evaluating mental health services

- **the Mental Health Commission’s Blueprint for Mental Health Services.** This contains many references to service user participation noting it should occur at all levels and phases of policy development, funding, and service provision (see Appendix 1)

- **the Ministry of Health’s Guidelines on Consumer Participation in Mental Health Services.**

- **The Code of Health and Disability Services Consumers’ Rights** is also highly relevant. The ten consumer rights in the Code are:
  
  - the right to be treated with respect;
  - the right to freedom from discrimination, coercion, harassment, and exploitation;
  - the right to dignity and independence;
  - the right to services of an appropriate standard;
  - the right to effective communication;
  - the right to be fully informed;
  - the right to make an informed choice and give informed consent;
  - the right to support;
  - rights in respect of teaching or research; and
  - the right to complain.

  Providers of health and disability services are obliged to take ‘reasonable actions in the circumstances to give effect to the rights, and comply with the duties’ in the Code. The Code does not override other legislation.

Eliminating discrimination

The mental health sector must also actively eliminate discrimination against service users by ensuring that people using mental health services are afforded respect, equality and rights protection; and by involving them in decisions (Mental Health Commission 1998a: 20; National Mental Health Standard, No. 8).
The recovery approach

The recovery approach can fit with a model of treatment and support that focuses on achieving wellness. The recovery approach cannot happen without service user participation. Activities to expand, elaborate and empower the roles of service users are important to a recovery approach.

"Being a support worker is part of my recovery and helps me to move forward ... I'm also a walking information billboard for other people who would like help ... I do a lot of work within the community to keep myself focused and in balance."


Services are using a recovery approach when they foster hope for people with mental illness while enlisting the resources of service users – their communities and families and mental health services – to bring about recovery. A recovery approach recognises and develops service users’ ability to participate actively in learning to live well in the presence or absence of their mental illness. This includes reclaiming one’s voice in every area of life, including the experience of mental health services.

Recovery is not only about recovering from the actual illness or distress, but also about recovering from its consequences, and the limiting expectations made about service users that are based on diagnostic labels. Reclaiming one’s voice is linked with recovering a sense of self. Recovery literature documents clearly that reclaiming of self is vital in the recovery process. Self is variously expressed in hopes, dreams, goals and choices.

Advance directives

Even in brief periods, when individual service users are in a crisis that is endangering themselves or others, there are ways to facilitate their participation. In those situations, ‘advance directives’ and crisis planning can help service users and providers make sure a person’s preferences and needs are catered for.

Advance directives come into force when someone is unable to clearly articulate his or her wishes. An advance directive is a document detailing an individual’s wishes and preferences of health care and treatment, prepared while he or she is able to articulate their wishes. An advance directive may include preferences regarding medication, preferred treatment setting, who information can be shared with, and other aspects of care and treatment.

The Protection of Personal Property Rights Act 1988 allows people to appoint someone to act on their behalf to manage their property, personal care and welfare. This is done by creating an enduring power of attorney that comes into effect if a person become ‘mentally incapable’. An enduring power of attorney can be general, limited to a specific matter, or be given subject to conditions or restrictions.
Constraints on service user participation

While it is important to maximise service users' role in decision-making, mental health organisations should be transparent about any constraints on service user participation and clearly communicate what those are. Organisations should work to overcome or negotiate around any constraints. There is no one formula for this to happen as service user decision-making will vary depending on the service user, the organisation, and the type and purpose of participation.

The power to make decisions is tipped in favour of organisations, not service users. Service users nevertheless have the right to participate in decisions affecting them. There are justifiable constraints on service user participation, as in some situations their involvement may not be feasible or appropriate. Factors influencing service user involvement in decision-making can include cost, legislation, contract obligations, ethics, safety of the individual and others, or the interests of other service users.

Most people who identify as service users have experienced crises where their ability to participate in the way they usually do is compromised. However, service providers should not use a crisis as a reason for taking away the right to participate. Part of everyone's crisis plan should include negotiated options. Thus someone whose ability to participate could be compromised during a crisis is still able to play some role.
Degrees of service user participation in decision-making

Mental health organisations vary in their approach to service user participation, from adopting practices that deny service user participation through to incorporating within organisational practice successful attempts to share power and decision-making.

No participation in decision-making: neglect and abuse

“I was treated as a condition rather than as a person.”
(Service user)

“There was not a lot of information. In fact I wasn’t told a damn thing. Looking back I don’t know how they got away with treating me the way they did. I guess the main tool they used to keep you in place was medication, but the side effects were horrendous.”
(Mental Health Commission March 2000:20)

“I’ve learned a lot about the system by now. I have learned about a lot of things I had no idea about before and I realised I did have some rights. I had never been aware that I had rights.”
(Stepping stones: a workbook for users of mental health services. Health Funding Authority 1998:45)

Mental Health workers making decisions without service user opinion has been the norm in institutional services and in many community-based services. There is seldom any justification for it in today’s mental health services.

In some situations, service users may experience neglect and abuse. This denies them any involvement in decision-making. It means services have total control over or neglect of aspects of a service user’s life. Abuse or neglect may occur when controlling a person’s care and treatment or when making decisions about their finances and housing. A service user may get no information or be treated without respect. When this happens services cannot be helpful and, in some instances, they can be harmful.

Limited participation in decision-making: paternalism and tokenism

Sometimes service user participation in decision-making occurs, but in a token or paternalistic way.

“This consumer representation process is not cheap. Some people may think you can have consumer representation by getting a few volunteers to pop in. You can’t – it will be merely tokenism, worse that useless because it can conceal the absence of real consultation with consumers.”
(Consumer participation in hospital and health services Pupu Whakaaro, No. 1 Mental Health Commission 1998b)
“Consumer advisors are sometimes like garden gnome reps ... they sit there looking forlorn on the lawn and they’re not able to do anything.”

(Service user)

Paternalism can inhibit service user participation in decision-making. A paternalist organisation makes decisions without talking with the service user and assumes that professionals know best and work in the best interests of the service user. Paternalism can be seen in some practices around committal, seclusion and medication.

Tokenism is when service users appear to be involved, while in reality no shift in power has occurred and service users are unable to influence change. There are examples of service providers who have appointed consumer advisors, yet consultation carries no real element of negotiation and the person is not given the supports required to achieve effective participation, such as information and training. The value of user participation is downplayed, with little or no payment for users’ involvement.

Another example of tokenism is where a service provider appoints a consumer advisor or consults service user representatives, but doesn’t understand the need to work collaboratively with individual service users in their treatment and support. Having a consumer advisor does not, of itself, fulfil all the service provider’s and clinicians’ responsibilities to involve service users.

Tokenism also occurs when only service users in particular services are involved, or when the same service user is called on repeatedly. Using a few well-known service users can be a safe option; it allows an organisation to canvass a limited range of viewpoints and does not challenge thinking.

“It’s important to have consultation in services. It reassures the person, who is always upset when they get into the hands of a whole lot of powerful strangers ... talk to them, let them know what’s happening.”


“If I had listened to the doctor who was keeping me under compulsory treatment, I would still be on injections, in a half-way house and on a benefit ... Initially there was no respect for my personal beliefs. I suddenly had to be reformed, reshaped, ‘we’re going to change you.’”


Some service providers have made decisions informed by service user opinion that has been gathered, individually or collectively, through consultation or through research. Although such an exercise involves service users, it is not service user participation in decision-making. Even if service providers make decisions favoured by service users, this is not genuine service user participation because the process of decision-making excludes them. The process is as important as the outcome.
Joint decision-making: partnership

“My inclusion in the management team is now something that few would question. It’s a given; it’s well established. I think it’s a very positive step for an organisation, it gives a strong signal of intent, but it wasn’t easy for some people to cope with this at first.”

(Consumer participation in hospital and health services Pupu Whakaaro, No. 1 Mental Health Commission 1998b)

Service users and mental health workers should jointly be involved in decisions about treatment and support. Both have complementary expertise that needs to be considered. Some examples where joint decisions can be made are assessing strengths and goals as well as needs, and decisions about treatment and support. The views of others, for example, those closest to the service user, may also need to be taken into account, but preferably with the service user’s consent.

There are examples of good practice involving service users in decisions about their treatment and support. One mental health service operates client files – living documents that are written collaboratively and are open to both the service user and clinicians. Service users and workers say the files are now more objective, with fewer inaccurate judgements and discriminatory comments. This approach may be one aspect in an overall improvement in the quality of records.

Mental health organisations are increasingly seeking the expertise of consumer advisors and service user groups to comment on a wide range of matters from policy development to delivery. Management should understand the benefits of incorporating the experiences of service users in decision-making.

Some service users, particularly but not exclusively Māori and Pacific service users, want the choice of including family members in their decisions. Many service users have found that involving such members has helped in their recovery. However, it must always be the service user who decides who their support people will be. The service user may want all, some, or no family members involved.

“The family is actually part of the healing process. Pacific Island parents always like to have contact, they always like to know what’s going on and what’s happening.”

(Pacific people in New Zealand talk about their experiences with mental illness. Mental Health Commission Recovery Series. Mental Health Commission April 2000:8)

“The whanau better understood what was happening for me than I knew myself, and they guided me through a process of kaupapa Māori healing.”

(Four Māori korero talk about their experience of mental illness. Mental Health Commission Recovery Series. Mental Health Commission March 2000:15)

“Partnership is about the mental health services you use allowing you choices and offering you information about the treatment and support options available to you. It is about working in unison – they provide the professional support, information and resources and you provide the direction, experience and personal input to keep yourself well.
Partnership is based on respect, upon acceptance of your rights by mental health services, and by action from you with regard to your responsibilities as consumers.”

(Health Funding Authority 1998:45)

Partnership is fundamental if service users are to be actively involved in opportunities for autonomous service user decision-making and joint decision-making.

There are many models of partnership. The Treaty of Waitangi offers an important model of partnership in New Zealand based on principles of good faith, respect, shared understandings and resourcing.

Other examples of partnership include the synergy model, where partners bring specific knowledge, skills, and resources to the relationship in order to increase the overall resources of the parties. A budget enhancement partnership model is used in some areas of health, where health providers and community-based organisations make decisions about budget allocation in partnership. A transformation model of partnership is where the parties take on one another’s world views.

Whatever model of partnership is chosen, it should involve service users. Partnership is an organisation’s commitment to share power, knowledge and resources in an ongoing way.

Partnership requires:

- real opportunities for service users to influence decision-making
- payment to service users for their participation at market rates
- recognising the validity and learnings of the service user experience
- provision of resources, knowledge, information, and supports required to facilitate partnership
- clear policies and structures for service user participation.

**Autonomous service user decision-making**

Most of us make autonomous decisions about where to live, who to work with and what work to do. Service users in particular situations should have similar freedoms to make such autonomous decisions.

Autonomous service user decision-making needs to happen in services that replace ordinary community living, such as residential services, drop-in centres, or vocational services. Service users should be free to choose who they live with, the work they do, or the people they socialise with. Sometimes individual service users will make these decisions and at other times decisions will be made collectively, e.g. if people are in supported accommodation.
“Nothing was explained to me. I had side effects from the medication, I wasn’t fully informed or a part of decision-making. I didn’t know about advocates. I didn’t know what I was entitled to. Lack of information and support for myself and my whanau definitely hindered my recovery.”


“In terms of the treatment I received in psychiatric hospitals, I found the treatment to be not only culturally offensive, but inhumane. You know, above and beyond the cultural safety and appropriateness of services, start with being humane, because we are human beings and we are existing in a way that may be different to where everybody else is at, but we still have our human rights, we still have our right to be treated with respect and in a safe way.”

(Health Funding Authority 1998:23)

From a Māori perspective, mental wellness is not just about the absence of illness. It involves a holistic view of health as expressed by the four dimensions of whare tapa wha – taha wairua (spiritual health), taha hinengaro (mental and emotional health), taha tinana (physical health) and taha whanau (whanau health) (Mental Health Commission 1998a:57). Participation for Māori with mental illness needs to happen through all these dimensions. To recover from mental illness, Māori must develop a secure identity and fully participate in society. Mental health services also need to include the active participation of service users, whanau, and their communities. Effective mental health services for Māori provide a choice of kaupapa Māori services and culturally responsive mainstream services.

Māori service users (tangata whai ora) may find that some mainstream services don’t understand the importance of whanau, whakapapa or turangawaewae in their recovery, or they interpret culturally valid beliefs as delusions. If tangata whai ora feel invalidated and alienated from mental health services they will be shut out from service user participation at all levels, including being involved in decisions about their treatment and support. All mental health professionals need to have cultural training to enable tangata whai ora to participate.

It is very important that tangata whai ora have a real choice of using mainstream services or kaupapa Māori services. This means that more kaupapa Māori services need to be available and that mainstream services need to be responsive. Kaupapa Māori services could be a model for how mainstream services provide service for Māori. Both mainstream and kaupapa Māori mental health services need to provide opportunities for tangata whai ora and their whanau to participate in decisions affecting their treatment and support. Providers also need to ensure that tangata whai ora are encouraged and supported to participate in service planning, development, and evaluation.
The types of participation that tangata whai ora need or prefer may be diverse, depending on their own particular cultural identity and preference for the use of te reo Māori and tikanga Māori. Not all people who look Māori identify as Māori, and many people who do not look Māori do identify as Māori. Mainstream and kaupapa Māori services need to be careful to find out exactly what sort of service people want and encourage their participation in any service they choose.

Ideally, kaupapa Māori services operate within a whanau model. The individual is supported by the whanau, and the service is underpinned by the Treaty of Waitangi. In kaupapa Māori services, service user participation may mean that both the provider and whanau are closely involved in making decisions jointly with the tangata whai ora. But at other times the whanau may, unintentionally, override the needs of the tangata whai ora and dismiss their opinions. For the tangata whai ora, this can lead to feelings of alienation from their whanau and the mental health workers who the tangata whai ora had hoped he or she could trust.

However, a variety of stresses may affect the kaupapa Māori ideal. Some individual Māori are dislocated from their whanau. In other circumstances whanau may lack resources to support their members and need to be strengthened. Discrimination, both as Māori and as tangata whai ora, can isolate a person from their whanau.

“Don’t make assumptions about where we feel safe and how it is best for us to heal. For some of us it’s with our whanau and for other it’s on their own. We’ve got a right to make those choices.”

“There are more options now and it is helpful for Māori to have access to kaupapa Māori services. When I was offered a place in kaupapa Māori services I refused it because it was uncomfortable for me at the time. But after I went home and reconnected with my whanau, I was more ready to access kaupapa Māori services.”


Māori advocacy and support workers are needed to work in and with mainstream services and kaupapa Māori services. They can make valuable contributions to the decisions of funders and providers, as well as help tangata whai ora and whanau to access services and to understand their rights (Mental Health Commission 1998a:62).
Issues for Pacific peoples

“I didn’t have much to say about my treatment. It was just thrown at me.”
(Pacific people in New Zealand talk about their experiences with mental illness. Mental Health Commission Recovery Series. Mental Health Commission April 2000:20)

“You lose self esteem and self confidence and that brings on the feeling of being inferior to the palagi people and feeling isolated and not being able to be part of the larger community. I really think there has to be a focus on personal needs like self esteem and self confidence – really to teach Pacific Islands people that it is okay to be a Pacific Islander in this society.”
(Health Funding Authority 1998:74)

In both mainstream and Pacific services, Pacific service users’ participation must incorporate their cultural needs and practices. Central to Pacific service users’ participation are their perspectives on health. The mental health of Pacific people is intrinsically bound to the holistic view of health captured by the Fonofale model that incorporates beliefs and values relating to family, culture and spirituality (Mental Health Commission 2001:6).

Pacific mental health service users have said access to a service run by a Pacific organisation with Pacific staff is fundamental to their recovery and ability to participate. However, in mainstream services, Pacific service users identify with Pacific staff who bring Pacific cultural understandings and belief systems to the service (Mental Health Commission April 2000:13). Pacific staff also help families to better understand mental illness because they can often communicate in their own language and ensure families are comfortable in a supportive and culturally safe environment.

“They were people who knew me, and understood my background. Pacific Islanders have more of a family approach to things, so I felt more like part of a family, rather than just a name or number on a file.”

Some mainstream mental health services fall short of providing participation opportunities for Pacific service users. A particular gap is in the lack of training available for non-Pacific staff to improve their responsiveness to Pacific service users.

Discussions on service user participation for Pacific peoples must include Pacific service users to ensure that organisations understand:

• the diversity within different Pacific cultures, with regard to language, customs, traditions, and rules of conduct
• differences between island-born and New Zealand-born Pacific peoples
• the importance of involving service users and their families in both individual treatment processes and service planning
• the barriers, such as lack of transport or information, that make it difficult for some Pacific service users to participate
• the discrimination that Pacific people can experience as Pacific people and as people with mental illness.

Service users working in mental health services can effectively aid their own and others' recovery. Some Pacific service users have found that helping others assists self-healing. Service users can work in a range of roles, including advisors, advocates and interpreters as well as providing care.
Issues for specific service user groups

While this paper focuses on what is generally required for service user participation, there are issues for particular groups across all levels of policy, funding and service delivery. Service users are a diverse group. Their experiences of the mental health system, their needs, and their family, cultural and community backgrounds differ widely. Opportunities and supports for participation, at both individual and collective levels, must take account of that diversity. Joint decision-making, partnership, and autonomous service user decision-making will be carried out differently, according to the situations and needs of the service users involved.

Participation issues are described below in:

• supported accommodation and residential services
• forensic services
• alcohol and drug services
• services for children and young people
• services for older people
• services for people with physical, sensory or intellectual/neurological disabilities
• dual diagnosis services.

Supported accommodation and residential services

The participation of those in supported accommodation and residential services is critical as they may be in those services through no choice of their own. People who make their home in supported accommodation or residential services should not be denied the freedom other citizens have to decide where to live, who to live with, and other matters of daily life. Service user participation needs to reflect and respect the living environments of service users.

Forensic services

People who use forensic services are often not heard. They are marginalised in the mental health sector as well as in the wider community. Nevertheless their experiences mirror those of many other service users, e.g. difficulties accessing services, lack of understanding from some professionals, lack of information and lack of opportunities for real participation (Mental Health Commission October 2000).

Forensic services and services for people who are under a compulsory assessment or treatment order place more constraints on service users than most other
services. These constraints should be clearly identified and any decisions that lie outside them should be made in a participatory way. Forensic services are often residential services, and service user participation processes should acknowledge peoples' right to make decisions about their living arrangements in the same way as any other residential service should.

Alcohol and drug services

In general, alcohol and drug services have made little progress in developing and supporting opportunities for service user participation. Some providers in alcohol and drug services assume that because many staff are former service users, they will wholeheartedly support the views of service users. In many instances policies and procedures around service user participation in decision-making have not been written. Confusion also needs to be addressed about service user roles, position titles and tasks.

Current service users have voiced concerns that staff members who are former service users are not necessarily able to advocate for service users, unless that person is employed in a consumer advisor or similar role. The process of involving service users is as important as the outcome.

Dual diagnosis services

There are no specific dual diagnosis service user groups. People who have been diagnosed as having both a mental health and a drug or alcohol problem sometimes belong to mental health or alcohol and drug service user groups and have input into mental health services through those groups. But people with dual diagnosis are not formally recognised as a distinct constituency, probably because coordination between alcohol and drug services and other mental health services is often poor.

In fact, there are very few dual diagnosis services. Most people with a dual diagnosis use different services for their drug and alcohol problem and other mental illness, and may therefore experience a kind of split participation, and in varying degrees. It is of utmost importance that people with a dual diagnosis are consulted as dual diagnosis services are developed.

Services for children and young people

Services for children and young people sometimes have a special challenge when it comes to involving service users. The younger the service users are, the more providers will rely on the opinion of their family/whanau. However, it is important to acknowledge that family/whanau do not invariably act in the interests of the service users. Children know what they like and do not like; they should be assisted to express their needs and choices. Services for children need ways of reducing barriers to participation. Services for youth must take their views into account as they would with adults.
Services for older people

Older people have tended to accept authoritarian services more than younger people do, and they may be slower to get involved. Older people often experience a loss of respect and of self-confidence, which can impact on their participation.

These factors do not detract from the value of service user participation but, to achieve acceptable levels of service user participation with older people, services will need to make special effort.

Services for people with physical, sensory, or intellectual/neurological disabilities

Providers need to find ways of involving these groups. They need the same means of access to participate in mental health services as they do in the rest of society. Such means include physical access for people with physical disabilities and access to sign language and Braille or large print for people with sensory disabilities. Deaf people may want separate services or require the opportunity to participate in deaf languages. People with intellectual disabilities will need to have ideas presented to them in a clear and concrete way and, if they have trouble communicating, their family/whanau may need to assist or step in.

Encouraging all service users' participation

Efforts need to ensure that quiet service users or those who lack confidence can have their say. Often people find it easier to communicate with someone who is or has been a service user, or to participate in a small group of service users. Another way to involve service users who are quiet or lack self-confidence is through questionnaires or semi-structured interviews. Some service users, who will not volunteer themselves for high-profile participatory roles, may be open to other ways of participating if there is active support to do so.
Types of service user participation

Organisations actively working with service users are aware that service users can participate in decision-making in various ways and fulfil various roles. Service users can be involved in decision-making as:

- an individual user of services
- an influencer through personal opinion
- an influencer through work-related expertise
- a representative of service users.

Some service users may participate in more than one of these roles at any one time or over a period of time.

Participating as an individual user of services

Service user participation at an individual level is most likely to happen with frontline workers. As a recipient of services, a service user can expect to participate in decisions about her or his own treatment and support. Individual service users also have the right to complain about the service they have received.

A service user should participate with their mental health worker on:

- applying a recovery approach to the individual's circumstances
- putting the Code of Health and Disability Services Consumers' Rights into action
- collaborative contribution to file notes and exchange of personal health information
- assessing strengths and goals, as well as needs
- decisions about treatment and support
- crisis planning.

Participating as an influencer through personal experience

It is important that individual service users give their views in evaluations or consumer satisfaction exercises. Providers can use the views and experiences of service users to help improve their services. A variety of research, evaluation and consultation methods may be used to gather information including:

- surveys
- focus groups
- hui
- fono
- questionnaires
- one-to-one interviews.

Service user participation in evaluation is most likely to happen through frontline workers, service managers and, in some cases, independent researchers or evaluators.
Participating as an influencer through work-related expertise

Some people with mental illness possess professional qualifications and work-related expertise (for example as consumer advisors, consultants, trainers, clinicians, managers or researchers), as well as their experience of using services. Their expertise can provide valuable input into organisational decisions at all levels.

These influencers are likely to work mainly with service managers and staff in funding, policy and monitoring roles. They may be involved in the following activities:

- membership on boards and committees
- advice to management
- provider training
- provider selection
- service planning
- service evaluation
- policy development
- legislation development.

Participating as an influencer through representation

Service users can participate and represent collective service user interests. They need to be mandated by a group of service users and should have an understanding of collective service user issues and links with other service users.

Service user representation can be used in a wide range of decisions, from governance and management, to service delivery. Opportunities for participation will arise at all stages of activity, from planning and design, to implementation and evaluation. Service users participating as representatives can be involved in activities such as:

- policy development
- input into the development of legislation
- input into decisions regarding funding and contracting within mental health services
- service design
- quality improvement processes
- advisory groups
- service evaluation
- training programme design.

Service users in multiple roles

Often people who have not used a particular mental health service (but have used other mental health services) assume an influencer role. Similarly, some service users in an influencer role no longer use mental health services. This should not be a problem if current service users are happy with their
involvement, and if these influencers maintain regular contact with service users and base their work on service user perspectives.

Organisations should not become over-reliant on a few paid service user participants. There is a danger that these people will become a service user clique and that the current service recipients will be overlooked.

Organisations and service users should be clear about whether service users are participating as formally mandated representatives of a group of service users or as individuals with expertise, or as individuals with personal experience.
Critical competencies

Service users and mental health workers need to be competent at effective and inclusive service user participation.

The following sections set out participation roles, activities and competencies of service users and mental health workers.

Individual service users

Participation competencies for mental health workers
For service users to participate in decisions about their treatment and support, they need:

• understanding of their mental illness and treatment/support options
• understanding of personal processes in recovery
• knowledge and understanding of their rights
• communication skills
• skills to get the most out of services, treatments, and communities.

Participation competencies for service providers
To help service users participate effectively in decisions about their treatment and support, service providers need to ensure that staff understand and apply all 10 recovery competencies, which are:

• understand recovery principles and experiences in the Aotearoa/New Zealand and international contexts
• acknowledge the different cultures of Aotearoa/New Zealand and know how to provide a service in partnership with them
• understand and accommodate the diverse views on mental illness, treatments, services, and recovery
• have the self-awareness and skills to communicate respectfully and develop good relationships with service users
• understand and actively protect service users’ rights
• understand discrimination and social exclusion, its impact on service users, and how to reduce it
• know about the service user movement and be able to support their participation in services
• know about family/whanau perspectives and be able to support their participation in services
• recognise and support the personal resourcefulness of people with mental illness
• have comprehensive knowledge of community services and resources and actively support service users to use them.
Service users as influencers through personal experience

Participation competencies for service users
Service users who are relating their experience of mental illness and using services should have:
• knowledge of what to expect from services (and life in general)
• skills to articulate their personal experience and preferences.

Participation competencies for mental health workers
Mental health workers, in seeking the participation of service users as influencers through their personal experience should:
• demonstrate knowledge of inclusive information gathering and research methodologies
• relate to a broad range of service users including those who are quiet or in other ways need support to participate
• know when a service user is speaking only for themselves, and when they are speaking from a broader consumer perspective
• understand service user views in a non-discriminatory way.

Service users as influencers through work-related expertise

Participation competencies for service users
Because of both their work-related expertise and service user experience, service users in an influencer role need:
• demonstrated knowledge of:
  – relevant mental health structures and issues
  – the range of service user opinion
  – the service user movement
• communication skills
• skills in dealing with complex information
• skills in persuasion
• skills to articulate a service user perspective
• skills in minimising internalised discrimination.

Participation competencies for mental health workers
Mental health workers involved in policy, funding and delivery should involve service users with work-related expertise. The people working in mental health services need:
• demonstrated knowledge of:
  – the range of service user opinion
  – the service user movement
  – understanding of processes that support service user participation
• skills in obtaining both the personal views of service users, and the broader consumer perspective, and knowing how to distinguish between them
• non-discriminatory understanding of service user views.
Service users as influencers through representation

Participation competencies for service users
Service users who participate as representatives of service user interests in a collective sense need:
• demonstrated knowledge of:
  – relevant mental health structures and issues
  – the range of service user opinion
  – the service user movement
• communication skills
• skills in dealing with complex information
• skills in persuasion
• skills to articulate a service user perspective
• skills in minimising internalised discrimination.

Participation competencies for mental health workers
Mental health workers involved in policy, funding and delivery should involve service users as representatives. These workers need:
• demonstrated knowledge of:
  – the range of service user opinion
  – the service user movement
  – understanding of accommodations that need to be made to support service user participation
• skills in obtaining both the personal views of service users and consumer perspectives and knowing how to distinguish between them
• understanding of service user views in a non-discriminatory way.
What service users need to participate

Mental health organisations should assist service users to understand participation processes and requirements. Service users may need a variety of support resources to develop the confidence to participate. Organisations can help by addressing any internal practices that result in paternalism, tokenism, stigma or discrimination.

Training and preparation

"If, as consumers, we don’t do a good job, or are not adequately supported by the service to do a good job, there’s a cost to us as individuals and to the whole consumer movement. The individual cost is stress, the cost to the movement is people saying ‘I told you so – consumers don’t make good workers.’"

(Consumer participation in hospital and health services Pupu Whakaaro, No. 1 Mental Health Commission 1998b)

When service users are asked to participate but are not given adequate training and preparation, their participation will be compromised.

A person needs information and support to participate in decisions about care and recovery. Service users should receive information on their rights. Service users whose first language is not English should have access to interpretation services. Māori service users should be able to communicate in te reo Māori if they wish.

Organisations need to have fair expectations of the service users they involve. Having experience of mental illness does not necessarily qualify a service user to contribute as an expert or representative. No service user knows it all, and it is unfair to expect this. Service user participation should be based on a personal experience of mental illness and use of the mental health services. It must also be acknowledged that some service users do have specific expertise.

Organisations can assist participation by ensuring the language they use is clearly understood and inclusive. An organisation’s language can act as a barrier to effective service user participation e.g. the use of health and medical terms, government policy jargon, acronyms, and management and quality management phrases. It’s not uncommon for service users to feel inadequate or excluded because they don’t understand the terms that are being used.

Service users participating as influencers need clarity about their roles and responsibilities, meeting procedures, consultation processes and so on. They may need special supports. Providers should ask service users whether they have particular needs to assist them to participate. It may be as simple as receiving the meeting agenda well in advance of the meeting date so they can prepare. They may need administrative support or access to reference materials on a particular issue.
Service providers who employ consumer advisors should make sure that the terms and conditions of employment are clear, and the employee is well supported, including access to supervision so any issues and concerns can be discussed in confidence.

**Adequate and appropriate resources**

“You have to have a lot of support ... I think you need more support than just friends and family. You need good professional support.”

(Health Funding Authority 1998:1)

Service users sometimes don’t participate because of a lack of appropriate clothing, lack of transport, difficulties in finding childcare to attend meetings, or the financial ability to contribute to activities like a shared lunch. Service users often survive on meagre resources. This situation is often exacerbated because of a person’s illness, they may be unemployed, or be struggling financially to find their feet.

Organisations need to be aware of any resource constraints that affect service user participants and find ways of overcoming such barriers. Remuneration, in-kind support, or arranging meetings in venues and at times accessible for service users might be required.

**Building self-confidence and trust**

“I think it is time consumers started interviewing health professionals as to whether they are in fact the person they want to deliver to them the sort of services they want ... I think it is time for the consumer to sit back, stop baring their soul, whilst the other party doesn’t take their overcoat off ... the sorts of questions that they ask us. They are just as valid in reverse. They are just as valid so that we know who they are because we are trusting those people with our lives.”

(Health Funding Authority 1998:45)

Service users need confidence and trust in an organisation with which they are going to participate, whether as an individual recipient of a service or as an influencer. Many service users have a deep sense of distrust of health professionals and of providers, formed through their experiences of being on the receiving end of services. Distrust may be expressed in service users’ cynicism about both the purpose and outcome of participation.

“Consumer employment changes the culture of mental health services. We cannot under-estimate the positive effect resulting from merely ‘being there’. Presence, being present is an ever constantreminder to the service about consumer focus. And as we learn to work together, we challenge and start to change the traditional role from consumers as sick people receiving services to a role where consumers are empowered people of equal value participating in an ongoing dialogue about service development and delivery.”

(Consumer participation in hospital and health services Pupu Whakaaro, No. 1

(Mental Health Commission 1998b)
It can be very difficult for a service user in an influencer role to confidently interact with managers and staff who have known the person as a recipient of services. Similarly, many service users who work within mental health settings experience an internal tension when one is known as an employee with a service user background. Managers and staff may also find it difficult to adjust their perceptions and expectations when interacting with a service user in an influencer role.

It can be very difficult for a service user in an influencer role to confidently interact with managers and staff who have known the person as a recipient of services. Similarly, many service users who work within mental health settings experience an internal tension when one is known as an employee with a service user background. Managers and staff may also find it difficult to adjust their perceptions and expectations when interacting with a service user in an influencer role.

**Inclusive structures and processes**

“I have never been asked for feedback on a service, in hospital or anywhere.”

(Health Funding Authority 1998, 205)

Service user participation cannot grow in a hierarchical structure where people in authority habitually make decisions behind closed doors or where there are long, unwieldy processes of reporting and decision-making. This kind of system does not invite people to make complaints, question decision-making or suggest new ideas.

Organisations serious about service user participation foster a culture where decision-making processes are clear, negotiated, and transparent; where there is no fear of reprisal for dissenting voices; and where everyone feels they have a right to contribute and the safety to take risks and learn from their mistakes. This approach fits well with most contemporary management practices, which emphasise flexibility, empowerment, and customer responsiveness.

Service providers should acknowledge a need for management commitment to service user involvement at all levels, and this commitment should be clearly communicated to staff. Staff need an understanding of working with service users as colleagues in influencer roles. Policies and structures for service user participation should convey to staff what the requirements and expectations are.

**Eliminating stigma and discrimination**

“I found a lot of mental health professionals thought they had some sort of monopoly on insight and knowledge. That’s a kind of discrimination and it used to really annoy me”.


Stigma and discrimination may be evident in mental health workers’ attitudes and behaviours. Given the prevalence of stigma and discrimination, service users
have experienced stigma and a general mistrust from staff members, and
behaviours towards service users that are negative, fearful, exclusionary, guarded
and distant. Because of such attitudes, service users may internalise those
messages, believe they have nothing to contribute, and be discouraged from
participation.

Service user participation is part of removing discrimination. This requires
positive attitudes and behaviour towards service users that acknowledges their
right to participate. It also requires providers develop flexible and inclusive
service user participation processes that value and respect service users.
Conclusion

This discussion paper has outlined some key ingredients that mental health sector organisations need to provide so service user participation can work well for both service users and mental health workers. Some competencies for organisations and service users are also outlined. Achievement of these competencies will strengthen and enhance service user participation.

However, this paper is only a first step. There needs to be greater acknowledgement by frontline workers, managers, funders and policy developers that service user participation is integral to an individual's recovery from mental illness. More effort needs to be invested in developing effective processes for service user participation at all levels – as recipients of services, and as influencers.

Service user participation is not fully incorporated into the mental health system. In some instances organisations perceive service user participation as too difficult to achieve and consequently decide to dispense with it. There are several reasons for this. Organisations may not acknowledge the fundamental right of service users to participate. They may not understand the role and importance of participation in recovery. They may lack the skills and knowledge to develop and implement effective service user participation processes. There may be problems in finding service user representatives with the appropriate skills, or time and resources. Service user participation has also been hampered by lack of support and resource.

Although these may be real barriers to involving service users, they are not reasons for organisations to put aside their responsibilities to ensure opportunities for participation as part of basic service user rights and a recovery focus.

As a way forward in strengthening and enhancing service user participation, the Commission recommends that organisations in the mental health sector work on four areas:

• the first area is to demonstrate a commitment to service user participation at all levels, and to express that commitment in relevant policies and procedures

• the second area is to develop participation competencies for staff and to convey clear expectations that those competencies are developed

• the third area is to support the development of the participation competencies of service users

• the fourth area is to develop mechanisms and processes that provide practical support for service user participation.
Glossary

**Service user**
A person who experiences or has experienced mental illness, and who uses or has used mental health services. Also refers to consumer, survivor, patient, resident, client, and turoro (Māori person who engages with mental health service).

See also **tangata whai ora**.

**Fono**
A meeting held with Pacific protocols.

**Kaupapa Māori services**
Māori centred services that are offered within a Māori cultural context. They are used by Māori in particular, but are available to, and used by, people of other ethnicities.

**Taha hinengaro**
The intellectual (thought) dimension; mental wellbeing.

**Taha tinana**
Physical health; physical wellbeing.

**Taha wairua**
The spiritual dimension; spiritual wellbeing.

**Taha whanau**
The familial dimension; family wellbeing.

**Tangata whai ora**
A term for service users or consumers that is preferred by many service users. It loosely translates as “people who pursue wellness”, which reinforces hope and promotes the view that recovery from mental illness is possible.

**Whare tapa wha**
A Māori health model that suggests that good health is described in relation to the four walls of a strong house: te taha wairua, te taha hinengaro, te taha tinana and te taha whanau. A person is considered unwell if any of these foundations are weak. For a person to be healthy, all four walls need to be strong.
Appendix

What The Blueprint has to say regarding service user participation

“Recovery happens when mental health services protect service users’ rights and treat them with respect and equality. This means mental health services offer the most possible independence and choice to service users in their treatment and the support they need in their recovery. They involve service users as equals in all decisions made within the services that affect users’ lives. Mental health services should provide the least restrictive setting and use the least possible coercion and restraint. When service users are unhappy with a service, they must have a fair and easy process for making complaints.” (pg17)

“Recovery happens when mental health services enable people with mental illness to take on competent roles. This means people with experience of mental illness are given every opportunity to use their competence in the mental health sector. As individuals, they take an active part in their assessments and in decisions about their treatment and support. As a collective, they are involved in the planning and evaluation of services at all levels. People with experience of mental illness, with the right aptitude and skills, should be encouraged to seek employment in mental health services, and the mental health sector should support the service user movement to develop support networks and service user-run services. When service users take up these kinds of competent roles, they assist their own recovery – and through the role models they offer, they also assist the recovery of others.” (pg 17-18)

“It is widely acknowledged that discrimination generated by the mental health sector against people using services is a major issue. At the policy and funding levels, discrimination has historically contributed to services that exclude people from society and to the chronic under-funding of mental health services. 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.” (pg 20)

“Consumer advice and input into the planning, development, and monitoring of services, and into the recruitment and training of staff. These services can also provide peer support, education and training services, and employment initiatives, and are run by consumers for consumers, with a focus on recovery.” (pg 39)

“No one should leave a service (or transfer between services) without a plan that outlines treatment, and recovery strategies, which include information on how to reduce risk of harm. A discharge plan includes clear relapse prevention and crisis management strategies that have been prepared in partnership between the individual and the service. Family/whanau and others should be involved where appropriate.” (pg 54)
“Active Māori participation ensuring Māori (including tangata whai ora) have the opportunity to make the decisions for, manage, and implement mental health services for Māori.” (pg 59)

“The following active measures are seen as the most effective means of addressing the problem [Workforce development]:
- genuine commitment to training Pacific people with experience of mental illness for meaningful jobs in the sector.” (pg 69)

“There needs to be an expansion of opportunities for people with experience of mental illness to take up roles in the mental health workforce. Training programmes and recruitment strategies need to explicitly encourage people with experience of mental illness to apply for training or positions. They can be employed as consumer advisors, in clinical roles, or support roles.” (pg 80)
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