The Services We Need

Mental health service users' expectations for the future

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Preface

Central Potential – Te Rito Māia developed *The Services We Need: Mental health service users' expectations for the future* in consultation with its members. It reflects the wishes, needs and aspirations of people with lived experience of mental distress for the services of the future.

Central Potential is a non-government organisation that is run by mental health service users. It holds a contract with the six District Health Boards (DHBs) that cover the central region of the North Island: Hawke's Bay, Wairarapa, Whanganui, MidCentral, Hutt Valley and Capital & Coast.

In brief, Central Potential is contracted to:

- build and strengthen local consumer networks and consumer-run initiatives
- build and maintain links with DHBs as well as district and regional advisory groups
- build and maintain links with alcohol and other drug networks
- provide information, education and training
- facilitate regional support for the development of a national consumer network.

The Services We Need helps to fulfil Central Potential's role in strengthening local consumer networks, maintaining links with DHBs, and providing information, education and training.

The main audiences for this publication are DHB funders and managers as well as people with lived experience of mental distress. It is designed to guide funders and managers when developing services and provide a benchmark against which Central Potential can check DHBs' progress in creating the services we want.

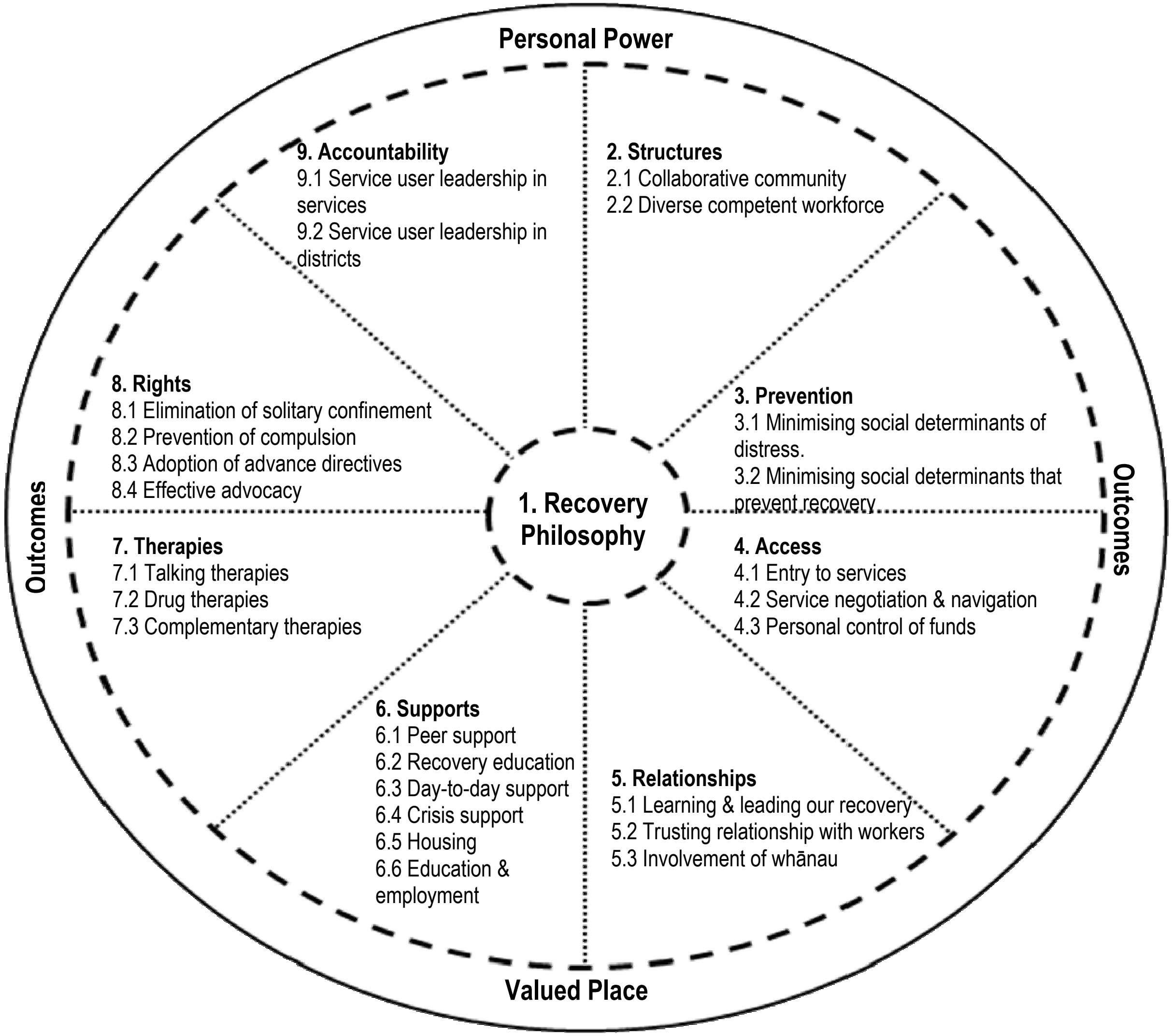
This publication comes with training and presentation guidelines so it can be promoted face-to-face with service users, funders, managers and others, particularly in the central region. Central Potential has also developed systemic advocacy guidelines for central region service users so they are better informed and able to influence the development of the services they want.

Central Potential would like to thank the dozens of members in each DHB area who told us what services they want, the reference group for this publication [names], the writer [name?] and the six central region DHBs that funded it.

The Services We Need will be a catalyst for change.

Introduction

Outline of the services we need



The Wheel

This **wheel** summarises the key points made in this publication.

At the **core** of the services we want is the recovery philosophy.

The **segments** of the wheel represent the aspects of services that need fundamental change.

The **ring** on the outside of the wheel represents the outcomes we want from using services.

1 Recovery philosophy and outcomes

Our Lives in 2014 was written by service users and captures the philosophy and outcomes that need to drive mental health services into the future. It states that the purpose of services and other community responses is to support people to lead their own recovery so they can enjoy the outcomes of regaining personal power and a valued place in their family/whānau and communities. (See (Mental Health Commission (2004) *Our Lives in 2014: A recovery vision from people with experience of mental illness*. Wellington: Mental Health Commission.)

Personal power happens when we have hope, choice in the services we use, self-determination over our lives and a sense of belonging to a community and/or a purpose.

A **valued place** happens when we are an integral part of safe, strong families/whānau have equal access to education, employment, housing, transport and income, as well as goods and services; and participate in the commercial, cultural, political, spiritual and recreational life of our communities.

Leading our own recovery happens when services support us to live the life we choose by:

- viewing mental distress as a challenging but fully human experience
- having zero tolerance of stigma and discrimination
- respecting our self-determination
- recognising the multiple determinants and consequences of mental distress
- providing people with a broad range of responses in our homes and communities
- preventing coercive practices and defensive risk management
- keeping our connections with family/whānau, friends, communities and the wider society
- expecting our recovery rather than lifelong disability
- fostering our leadership in services as both service users and part of the workforce.

2 Structures

2.1 Collaborative community

A broad range of agencies and sectors need to provide services, supports, resources and opportunities to people with mental distress. All the involved sectors must develop many ways to cooperate or integrate their services through, for example, joint planning and pooled funding; moving workforces between teams, services, and sectors; information sharing; or the shared use of communications technologies for online or distance services.

Primary mental health services

The hub of service delivery could be an expanded primary health sector that works closely with a reduced specialist mental health sector as well as social services, iwi and hapū, community resources, and public health and rights agencies.

Most of the work done in community mental health centres and mental health support services should merge into primary health and other settings. Most of the therapeutic and support responses for people with all severities of distress need to be provided in these other settings. These responses need to include service negotiation, navigation, peer support, recovery education, day-to-day support, and most prescribing and talking therapies (detailed in section 6.1).

People with major mental distress will also have improved access to promotion programmes and services for addictions and physical health.

Specialist mental health services

Specialist mental health services should include some, but not always all, acute services, forensic services, early intervention services, child and youth services, older people's services, addictions services and specialist psychotherapies. They will also offer crisis support as well as some therapies and supports to people with severe distress, though many of these people may also use support services from the primary mental health and other sectors.

Social services

Employment, education and housing support need to be delivered collaboratively, using expertise in the employment, education and housing sectors as well as mental health expertise from the primary sector or specialist mental health sector.

Community resources and agencies

Generic community resources must be heavily utilised for the benefit of people with mental distress and loss of well-being. Non-government organisations need to provide a wide array of responses, including clinical responses, often in collaboration with other types of agencies. Many such organisations will be run by communities who are directly affected by mental distress, such as service user, family, Māori, Pacific, and Asian organisations. Iwi and hapū must have control over the development and delivery of kaupapa Māori services.

Public health

The agencies that promote well-being should be structurally aligned and work closely with mental health, primary health, schools, workplaces and community organisations. Their population-based approaches need to dovetail with the individualised responses provided by services.

Human rights agencies

Human rights agencies must provide accessible information, advocacy and rights redress.

2.2 Diverse competent workforce

The workforce needs to change significantly if we are to get the services we want. Emphasis needs to be placed on recruiting or developing:

- peer support workers (for service users and families)
- peer recovery educators (for service users and families)
- peer advocates
- the Asian workforce
- talking therapists
- complementary therapists
- general practitioners
- people in other sectors, especially the housing, education and employment sectors.

The workforce needs to be emotionally competent and skilled in:

- reflective practice and self-care
- all the recovery competencies
- trauma-informed care
- addictions and other problems commonly associated with mental distress
- community development

- working across agencies and sectors.

People outside the health sector who work with people with mental distress also need many of these skills.

The understanding gained from experience of mental distress should be highly valued and seen as a qualification for working with people with mental distress. A large proportion of the mental health workforce needs to have lived experience of mental distress.

No one in the workforce should fear discrimination from openly identifying their own experience of mental distress.

2.3 Broad range of responses

The following responses need to be offered to everyone who needs them:

- service negotiation and navigation
- peer support
- recovery education
- day to day support
- crisis support
- housing support
- education and employment support
- talking therapies
- drug therapies
- complimentary therapies
- advocacy

All these responses need to be as available to people using services, as drug therapies are available currently.

3 Prevention:

3.1 Minimising social determinants of distress

We want to see a whole-of-government approach to the prevention of major mental distress that minimises its social determinants. These determinants include:

- trauma (for example, sexual and physical abuse, severe losses and warfare)
- inequality (for example, homelessness, relative poverty and social hierarchies)
- racism towards indigenous and minority ethnic groups
- deculturation, especially of indigenous peoples
- a lack of social cohesion (for example, transience, fragmented families and communities, and isolated individuals)

These determinants do not just increase people's vulnerability to mental distress but also their vulnerability to physical illness, a shorter lifespan, under-employment, poor relationships and lower psychological resilience. The effects are social and economic as well as personal, and they require coordinated prevention work and responses that go beyond the health sector into other sectors, and communities, as well as social and economic policies. We do not want professionals to continue to explain the causes of mental illness as though they are genetically determined. Although genetics underpin all human experience and behaviour, the latest scientific evidence shows that the environment has a profound impact on the expression of genes. It is no longer nature versus nurture but nature via nurture.

3.2 Minimising social determinants that prevent recovery

We also need to minimise the social determinants that prevent recovery on people who experience mental distress. These include:

- stigma and discrimination
- a lack of understanding of the supports needed for recovery
- a continuation or worsening of the social determinants that led to mental distress in the first place

The determinants that prevent recovery need to be responded with:

- human rights legislation and redress
- anti-discrimination campaigns
- a social inclusion focus in services

4 Access

4.1 Entry to services

Entry into services must be easy with multiple entry points and effective referral.

Before	Changes needed	After
I wanted to throw myself under a truck. My best friend Emma was worried so she took me to the doctor. 'You need a psychiatrist', he said. He got on the phone and I heard him snap, 'No she's not psychotic but she is very depressed and suicidal'. He then told me, 'They can't see you for three weeks but please ring the mental health crisis team if you feel unsafe'. The next day things got bad, so I rang the crisis team and told them I wanted to kill myself. 'Make your self a cup of tea', they said. I took a big overdose instead. Just then Emma came around and rang the crisis team. They said I should go to the emergency department. 'We've got another OD', the nurse sighed to the doctor. 'That was a silly thing to do', the doctor muttered. He asked me lots of questions about the drugs I'd taken and said I needed to stay overnight. Emma came to get me the next morning and asked the nurse if the mental health people had seen me. 'No, you need to go through your general practitioner', the nurse answered. We were going around in circles, getting nowhere.	By the time we try to find services for our mental distress we are usually desperate. We need quick responses, like: • community centres where all kinds of people can go for different issues • crisis teams staffed by peers • 24/7 walk-in emergency mental health services staffed by peers and clinicians • 0800 numbers staffed by service users • online communication through interactive websites • free doctors who have quick access to mental health teams onsite or by phone or email. We want multiple entry points into services. If we go to the wrong place we want to be referred to the right place straight away. We do not want to access services through accident and emergency departments. None of us wants to be told we are not sick enough for some kind of assistance.	I wanted to throw myself under a truck. I'd seen a place advertised on the net where you can go if you're feeling nothing's worth it. So I went online, found rockup.com and answered questions for people who feel like crap. The results said, 'You're really depressed. Your local "Rock Up" would like to contact you to see if they can help'. I selected the 'phone me' option and got a ring 10 minutes later. It was a relief to talk to someone who seemed to understand. The next day I went to an appointment at the local Rock Up with my best friend. You could go there for lots of stuff – not just health information but student loans, job search and info on the best gigs in town. Someone I knew from school was on reception. 'Welcome to Rock Up', she said, and showed me the coffee machine. A young woman came over. 'Hi. My name's Lisa. I'm a peer support worker and you'll be meeting with me and a clinical worker here.' 'What's a peer support worker?', I asked. 'Someone who was sitting right where you were a few years ago.' 'Wow', I thought as we walked into the office.

4.2 Service negotiation and navigation

Service negotiation, unlike an assessment, is a two way discussion of strengths and needs. Service navigation is a must for people who need more than two or three different types of services.

Before	Changes needed	After
I remember the first time I went to hospital, I was homeless, jobless and in a lot of debt. I told the doctor and nurses about my problems. Some of them were sympathetic, but they just said, 'Wait until the medication kicks in – you'll feel better about things then?'. Two weeks later I was discharged with a prescription and an appointment at the community mental health centre. The psychiatrist at the centre asked me a few questions, wrote out a prescription, and said he'd see me in a few weeks. I told him I was looking for a job. 'The Department of Work and Income may be able to help', he said, 'but I think you should stay on the benefit for longer'. 'But I can't afford to stay in my flat if I don't go back to work.' He said he'd get a social worker to contact me but I never heard from one. No one really asked me what was going on in my life or if there were things I needed help to sort out. I didn't know what to do, and I started to feel really down again.	***Service negotiation*** When we start to use services, and at regular times after that, we need to be part of a joint process of identification and negotiation with the service and our family/whānau, if we wish. Through this process, we want to identify our problems, strengths, risks and opportunities, as well as the contributions we, services, our communities, and our whānau can make to our recovery. This information will go into our recovery plan, which will be a living document that can be changed at any time and exists on paper and/or electronically. ***Service navigation*** follows negotiation for those of us who need more than two or three types of services. Using our recovery plan, service navigators will ensure we get access to all the services, resources and opportunities we need in the primary, mental health and social sectors, and in our communities. Service navigators will have an ongoing support role and provide us with some of the responses identified in our recovery plan.	I remember the first time I went into a crisis house. I was homeless, jobless, and in lots of debt. I told the peer support worker about my problems, then she asked me about what made me strong and who were the most supportive people in my life. Over a couple of days we came up with a plan. We decided I would try living without medication. I'd go to a financial management service and a supported employment service that could help me get another IT job. My peer support worker invited me to a recovery education course and a support group. He also helped me find a flat. He kept in regular touch and made sure I got the services I needed, as well as reminding me of what I needed to do for myself. It was incredibly reassuring after getting into such a mess to find a manageable way back, with someone supporting me one hundred percent.

4 Access

4.3 Personal control of funds

We need the option to manage our own individual budgets to purchase what we need to enhance our recovery.

Before	Changes needed	After
When I used services I got pills and pillows – that was about it. I had to go to occupational therapy in hospital, and was able to go to a drop-in centre that was full of old men who were three times my age. I really needed help to rescue my business and to get my confidence and calmness back, but I had no money and there was nothing available for me in the mental health sector. They weren't well informed about other services I could use. Their overriding interest was getting rid of my symptoms and containing me when I was in a crisis. They gave me no choices.	We want the ability to choose the kinds of supports, resources and opportunities that will enhance our recovery. One way of doing this is to put the funding in our hands rather than using it to build and maintain services we don't always find helpful. The funding could be channelled through a service navigator who would advise us on our options and organise payment for the services or opportunities we choose. The recovery funds could be used for paying for our education, fixing a car so we can get to work, joining a gym, hiring a support worker to help out at home or accessing a supported employment service.	When I used services part of my recovery planning process was to identify the services, agencies and community resources I needed to access. My peer support worker said I could apply for my own budget to purchase the services I wanted – especially as a lot of them weren't provided by mental health services and some weren't even publicly funded. A budget was approved for me. I used it to get a therapeutic massage once a week and to upgrade my computer so I could work from home and go on a small business course. It also paid for some mental health services like peer support.

5 Relationships

5.1 Learning and leading our own recovery

We need to learn from our experience in order to lead our own recovery.

Before	Changes needed	After
The staff told me I had a biochemical imbalance and that I couldn't wish my psychosis away. I was told it was a disease. I felt helpless, as though there was nothing I could do to make things better. I felt I had about as much control over my mental state as I had over the weather. All this was reinforced by the staff, who treated me like I was incompetent. I soon learnt to take on the role as a helpless, hopeless person. That was the way I got people to notice me. It took some years for me to realise that I had to put myself in charge of my recovery. No one else could do it for me. It was the turning point, I explored other thing that helped my overall well-being and eventually got me out of the mental health system.	Services must be set up to encourage us to learn from our experiences and to lead our own recovery. We know we are leading our own recovery when: • on a practical level, we make our own decisions, get our lives together, set goals, get up, go to work, eat healthily and so on • on an internal level, we feel good about ourselves and our lives, we feel hope, we feel successful, we can put closure on our problems, and we have a commitment to our recovery • on a relationship level, we can get support from peers and family/whānau, others in our lives believe in us and have hope for us, and we feel loved • on a mental distress or an illness level we can prevent crises, but don't feel guilt or shame when we have to take time out.	The staff kept telling me that I was going through one of the most challenging experiences a human being can have. I would need to call on strengths I didn't even know I had. They said I needed to take responsibility for my recovery. I decided to use a peer support and recovery education service. It was amazing to meet people who had been through similar experiences and had come out the other side and learnt from their psychosis. We shared stories and recovery strategies. After going to the service for a while I noticed I felt much less isolated and much more in charge of my life. I sorted my day-to-day life out, improved my self-esteem, made new friends and learnt how to avoid crises. I became much happier and less dependent on services.

5 Relationships

5.2 Trusting relationships with workers

The key element of a service is the quality of the relationship between service users and providers.

Before	Changes needed	After
The staff looked like they didn't want to work at the hospital. The nurses stayed in the nurses office most of the time and didn't talk much to us. Sometimes they would talk to us in negative ways by calling us 'very unwell' or 'inappropriate'. One night I woke up feeling really paranoid and tapped on the window of the nurses office. 'I'm under attack, I'm going to die', I called out to them. One of the nurses raised her eyes to the ceiling, put down her hand of cards and opened the window. 'Go back to bed', was all she said. She closed the window. Some of the staff were nicer than others but they weren't really interested in how we felt or how we would cope when we got out of hospital.	Our recovery happens at all levels of our being and often involves changes to our self-image, self-agency, relationships, housing, income, work, leisure and spirituality as well as a lessening of our mental distress. We may need assistance with many of these aspects of our lives. We want workers to help us to lead our own recovery by: • giving us practical support, information and advocacy • believing what we say and respecting our decisions • being empathetic and friendly • giving us hope and encouragement • being reliable and available • listening carefully and asking us what we need • motivating us and helping us to set priorities • challenging us win a human way if we are stuck or have addictions.	The staff at the community well-being centre were really helpful and open. After I talked to a few people my support worker, a nurse and I developed my recovery plan. It dealt with all the aspects of my life that had been affected by my mental distress, and they made sure my recovery plan was fully implemented, when I started losing it. The thing I valued most was their unwavering belief in me, their respect for my decisions, and the practical support they gave me. When I felt down or confused they'd help me with my bills or to find a removal van when I was moving flats. They kept me believing things were possible and were practical. They always made me feel better about myself and encouraged me all the way, without taking over. They were always there for me.

5 Relationships

5.3 Involvement of whānau

Our families are sometimes part of the problem but they need support and education to become part of the solution.

Before	Changes needed	After
Whānau often feel mental health professionals blame them for their relative's problems. Whānau frequently feel isolated and don't know how to respond to their relative. Mental health workers won't always talk to whānau or give them information, even when their relative has agreed to it. Mental health workers sometimes don't give any credibility to a whānau's knowledge about their relative's problems. Mental health workers may stop whānau from seeing their relative or aggravate the stress between them. Whānau sometimes see mental health workers neglecting or mistreating their relative.	Services need to be set up to welcome our family/whānau if we want them with us. All our families and whānau should be offered whānau peer support and whānau recovery education when we start to use services. This needs to happen whether or not we decide to have them involved in our supports and therapy. If our whānau members are involved, we still expect to have primary consideration. Our whānau are sometimes part of the problem but they can be part of the solution too. They need to be supported and treated with respect. We want our families to retain hope for us and to have the strength and skills to enhance our individual recovery, as well as the family's recovery from the stresses associated with our mental distress. Services will help us and our whānau to restore the relationships we want.	Whānau are respected and seen as part of the solution. Whānau get support from other whānau and education on how best to support their relative. Mental health workers give as much information to whānau as they can without breaching their relative's wishes. Mental health workers listen carefully to whānau and take their views seriously. Mental health workers help lessen the stress in the relationship between the whānau and their relative. Whānau feel that the mental health service is doing their best for their relative.

6 Supports

6.1 Peer support

Services run by people with lived experience for people with lived experience are the greatest untapped resource in the mental health sector.

Before

When I went to hospital the second time I was scared by how many people were also there who'd been in the first time I was admitted. One of them said she'd been in and out for 15 years. I started to think this was my future.

Some of us used to talk a lot when the nurses weren't around. It was great to be with other people who understood, even if we were all serious head cases.

I found the staff just didn't understand. They saw me as a sick human being, like they were above me in some way. My family and friends felt uncomfortable or angry with me. The only people who really accepted me were the other people in the ward. I used to say we should be running services, but the idea was far-fetched; it was just a throwaway line I used with other patients – just to get a laugh.

That was 15 years ago. How times are changing.

Changes needed

We all want the option to use peer support services, delivered by others who have been through similar experiences.

Peer support services could include:

- peer mentoring
- support networks
- phone lines
- crisis support
- planned respite
- drop-in centres
- information
- advocacy
- recovery education.

Peers can deliver any kind of support services in mainstream or peer-run service settings, but peer services should be managed and governed by peers independently of mainstream services. Peer support specialists need to develop their own methods and practices as well as qualifications.

Peers can work in all kinds of roles in services if they have the right set of skills.

After

When I went to the community wellness centre for the first time I saw was a peer support worker who told me she'd had mental health problems. I was impressed. Maybe there is some hope for me I thought.

My peer support worker took part in my recovery planning. I felt she was on my side and accepted me at my word. I told her I didn't want to be in a support group, so she suggested a peer mentor. I also went along to recovery education classes, when my crisis was over.

I chose my peer mentor online. There was a profile about each one, so I went for the one I thought was most like me. She was wonderful. She gave me hope, supported me when I went to the doctor about reducing my drugs, and gave me a whole lot of information about coping, where to find help and so on. We became quite close, and after she stopped being my mentor we kept in contact as friends.

6 Supports

6.2 Recovery education

Recovery education more than anything, gives people the tools to genuinely lead their own recovery.

Before	Changes needed	After
Losing my mind was a real challenge to me. It stuffed up my job and my relationship. It blew away all my confidence. I also had a drinking problem. The doctors and nurses would give me little pep talks like ‘take your medication’, ‘don’t drink too much’ and ‘avoid stress’. So I sat at home, took my medication, drank too much and avoided stress. I was incredibly miserable and bored. I missed my work and my partner. I couldn’t see there was any way I could get back the things that mattered to me. I stayed in this frame of mind for many months. I felt lonely and useless. I told the mental health team how bad I felt every month when I saw them. They said, take your medication and avoid stress’.	We want access to recovery education to give us the tools to manage our whole lives, not just our mental distress. Recovery education could be delivered to anyone with mental health struggles one on one, online or in a classroom. Recovery education includes: • information on mental health issues • the meaning of our experiences • getting the best out of services • staying well and preventing relapse • sharing stories • dealing with internalised stigma • discrimination and human rights • building social supports • getting organised • physical health and holistic health • parenting and relationships • getting housing, education and employment. Recovery education will be provided mostly by peers who have a lived experience of the process.	Losing my mind was a real challenge to me. It stuffed up my job and my relationship. I also had a drinking problem. When my crisis was over I sat down with a support worker and a nurse and told them I didn’t know how to get my life back together. They suggested I go to some recovery education classes run by a local peer service. They also referred me to a drug and alcohol specialist in their team who gave me counselling and introduced me to alcoholics anonymous. I learnt so much at the course. Firstly, that I could recover and have a good life. Secondly, that there were others in my situation and in even worse situations. The course itself was the distilled wisdom and knowledge of many people who’d gone through the same things as I had. I learnt not to be ashamed, about how to keep myself healthy and how to rebuild my life. I got the confidence to look for a job and go to parties again. I also made some great friends.

6 Supports

6.3 Day-to-day support

The right day-to-day support, even half an hour a week, can keep us from sliding into dependency.

Before	Changes needed	After
I had a terrible struggle with my mental health after my baby was born. I thought I might have to go into hospital. Then the nurse said they had a new support service where someone could come into my home and give me some support. A young man arrived. He was nice enough but he sat down and read the paper. I felt I had to look after him, instead of the other way around. The baby was crying and the house was a mess. I asked him if he could do the dishes. He said, 'I'm not supposed to do things for my clients in case they get dependent'. I nearly cried. It wasn't like I was someone who'd been institutionalised for 20 years and needed to learn to do things for themselves. I was exhausted and depressed. But the support worker didn't have the discernment to know that support means different things to different people.	Some of us need day-to-day support to achieve or sustain our recovery. It may be just someone to talk to or plan routines with. Or we may need someone to support us to get our entitlements at Work and Income, help with the housework or babysit while we go to a support group. Those of us who have an uphill struggle with our day-to-day roles and responsibilities want a trusted support worker who is open and honest with us and prepared to do whatever it takes to provide personal and practical support for our recovery. Support workers also need to be skilled in service navigation.	I had a terrible struggle with my mental health when I was a parent with young children. I don't think I would have survived without my support worker. The medication and the counselling helped but my support worker was there with me at some of my hardest moments. She'd come around and do whatever needed to be done – vacuuming, holding a screaming baby, going to the shop for food or just sitting and talking. The best thing about her was that she was also a mother and had experienced mental health problems. I never felt judged by her and she understood the value of simple practical assistance for someone with all my responsibilities. We also had a few good laughs together. She wasn't afraid to give advice to me but I knew I was free to take or leave it.

6 Supports

6.4 Crisis support

We need to renew the art and skill of providing attentive support to people in crisis.

Before	Changes needed	After
Every time I had a crisis I would end up in the inpatient unit with no one to talk to and nothing to do. I hated the lino corridors and the pokey little rooms, the security guard at the front door and the way the nurses virtually ignored me. I felt really unsafe with men sometimes. I couldn't handle the distress I saw or the insensitive way the staff responded to it.	When we have a crisis we want to stay as near to our ordinary lives as possible. Many of us would prefer to be at home with a team visiting us. If home is not suitable for us or the people we live with, we want to stay in a community setting, ideally a quiet retreat. Very few of us want to go to an inpatient ward; we would be happier that, if inpatient wards had to exist, they were small and home-like.	The last time I had a crisis I was offered home treatment services. At first members of the team (a peer support specialist, psychiatrist and nurse) came around two or three times a day. This eased off over the next three weeks. They worked with me and my family giving us practical help, counselling, advice and medication, and they linked us with other services. They gave us a sense of control and hope.
The last time I went to hospital no one asked me how I was feeling until I saw the psychiatrist. My partner said I needed more human contact from the staff. The nurse assigned to me was sitting in the room and said, 'We're in contact. We do sight her every 15 minutes, you know'. That meant popping his head in the door to make sure I wasn't self-harming, and going away again without talking to me.	During a crisis we want empathetic people with training in crisis support to care for us, spend time with us and listen to what we say. We want them to be sensitive to our cultural and spiritual needs and to respond on a psychological level. They need to ensure that our social connections are maintained and to check our commitments are covered while we are in crisis.	I couldn't believe how responsive they were and how reassuring, especially to my family. They got someone to watch over me the first few nights because I was really suicidal and my family needed sleep. The peer support worker really understood where I was coming from, and the nurse and psychiatrist talked to me in understandable language. I never want to go back to hospital again.
	We want to be safe during a crisis, sometimes from ourselves. Safety should be ensured by having people nearby rather than using locks and keys. Everyone needs to understand that coercion when we are at our most vulnerable, often re-traumatises us.	

6 Supports

6.5 Housing support

It's time to separate the landlord and support roles. Most people want to live in their own homes with the support coming to them.

Before	**Changes needed**	**After**
After my second big crisis I had nowhere to live. The staff said I was too unwell to live on my own and organised for me to live in a house with other people with mental health problems. I had to sign a contract agreeing that I wouldn't drink or take drugs in the house or have sex there. I wasn't even allowed to go to the fridge to get food between meals. A lot of days we just sat around doing nothing. I had nothing in common with the other residents and they really irritated me. The staff were okay but I couldn't see my life going anywhere. When I said to them I wanted to get a flat they always told me I wasn't ready. It was quite depressing.	We want to live in our own homes with people we choose to live with. If we need support from services we would like it to come to us in our own homes or a community of our choosing. We don't want to be forced into staffed accommodation. This should be a temporary option for people who need extra support or who want to work on themselves intensively in a therapeutic group setting. Those of us who are on low incomes need access to affordable housing. Like many New Zealanders a lot of us would like the opportunity to buy our own homes. We would like services to help make affordable housing more accessible for us.	After my second big crisis I had nowhere to live. We discussed this during my recovery planning and my support worker told me the options I had available. I decided to apply for a one-bedroom council flat through the local housing support service. After I moved in my support worker came around at the same time twice a week to help with some day-to-day issues as well as to make progress with my plans to train to be a builder and to get to know some more people. The little flat was just what I wanted. From there I had the strength to rebuild my life with the assistance of my support worker and some friends I made in the same housing complex.

6 Supports

6.6 Education and employment support

Everyone needs support to succeed in education and employment. It’s just that people with lived experience need the kinds of support that often hasn’t been available.

Before	Changes needed	After
I did well at school until I cracked up at the age of 15. I took some time off but when I returned I couldn’t focus on school work and was preoccupied with weird thoughts and voices. The mental health services discharged me quite quickly, and the school counsellor said she wasn’t trained to help people like me. After several months I dropped out of school and got a job washing dishes which I hated. The boss was a bastard to me. My thoughts and voices started to overwhelm me again. I’ve been in and out of crises for the past four years, and I feel utterly useless.	***Supported education*** Many of us start to experience mental distress while we are at school or in tertiary education. We may need additional support from people who understand educational issues as well as mental health issues and accommodation for us to keep up with our study and pass our courses. Support may involve liaison with staff and teachers, being taught better study skills, extensions on assignments or extra tuition. ***Supported employment*** We want support to choose, get and keep employment from someone who understands the labour market, mental health issues and social inclusion principles. They need to work with employers to break down prejudice and educate them about mentally healthy workplaces and workplace adjustments. They need to work with us sometimes to sort out the job we want, to increase our chances of getting it if we apply, and then keeping in touch when we’re in a job. Some of us just want temporary jobs. We want an opportunity to earn money and get beyond a life of financial dependency.	I did well at school until I cracked up at the age of 15. The school counsellor referred me to the local supported education service and a psychiatrist who gave me a small dose of drugs. A mental health specialist from the employment support service saw me twice a week. We worked out techniques for keeping my thoughts and voices at bay when I wanted to focus on school work. He taught me some study skills and negotiated assignment extensions with the school. The supported education worker introduced me to a local support group of high school students with mental health problems. The assistance I got was awesome. I passed all my courses and I’m doing business studies at polytech. It’s hard going with the voices and thoughts sometimes, but there’s a supported education service here to if I need it.

7 Therapies

7.1 Talking therapies

Talking allows us to reframe our stories in a more helpful way so we can get on with our lives.

Before	Changes needed	After
I was sexually abused as a child by a family friend for several years. It did my head in, and by the age of 14 I was referred to mental health services. They asked me a few questions about my life but not the right ones, then they put me on heavy drugs that made me sleepy all of the time. I told my psychiatrist about my sexual abuse. He said there was no evidence that sexual abuse causes psychosis and upped my medication. That was three years ago... The drugs really slow me down, I've put on stacks of weight and can't seem to keep a job. Recently I found out through a friend that I can get sexual abuse counselling through ACC and I've just made an application to them. I hope it helps.	We want talking therapies such as cognitive behavioural therapy, family therapy, interpersonal therapy and others to be available to everyone, when they first enter the service, without long waiting lists. Talking therapies could be provided in several settings, including primary health, community centres and specialist mental health services. They would be free of charge especially for those of us on low to average incomes. Talking therapies must also be available for all people affected by trauma. We want access to therapies such as grounding techniques, desensitisation therapies and behavioural therapies that directly address the impact of our trauma and facilitate our recovery from it. A few of us, in profound intractable distress, may need intensive live-in therapies for weeks or months, if other options haven't worked.	I was sexually abused as a child by a family friend when I was 12. The night it happened I went to my parents and told them. They told the police and took me to a community counselling service for children who have experienced abuse. The counsellor helped me to understand that it wasn't my fault and talked a lot to my parents. As a teenager I started to flip out and I got referred to a mental health service. They asked me if I'd been abused in any way. At the end of the meeting they said the abuse could still be affecting me. They introduced me to a psychologist. We talked about my paranoia, my difficulties with trust and my low self-esteem. We worked on my coping skills. She was incredibly helpful. A year later I was off all the medication, had finished counselling and was making plans to go to polytech.

7 Therapies

7.2 Drug treatments

There needs to be greater acknowledgement that psychiatric medications can do as much harm as they do good.

Before	Changes needed	After
I was medicated to the hilt when I used mental health services. I don't know what medication I was on but I hated it. I was too scared to tell the psychiatrist how awful I felt and I kind of believed he must know what he was doing. After a while I stopped taking the medication. The psychiatrist was annoyed with me and said I could not live without it. I started taking the medication again and then stopped. I decided not to go and see the psychiatrist anymore. He placed me on a community treatment order to force me to take the drugs. Since then I've struggled a lot. If things get really bad again mental health services would be the last place I want to go to.	We want drug therapy to be one of a range of options rather than the backbone of treatment. We will enter into drug therapy in collaboration with the prescriber, with good knowledge of the beneficial and adverse effects and with confidence that any adverse effects will be well managed. Prescribers will never limit information in order to get our compliance. Our drug dosage and side effects will be regularly monitored. The aim of taking psychiatric drugs will be to enhance recovery not just to suppress symptoms. We will be encouraged to experiment with drugs in collaboration with the prescriber so we get the maximum benefits and minimum adverse effects. Choosing not to take drugs will be a valid option that the prescriber will be willing to advise us about. Safer drugs will be on the market that do not interfere with our quality of life or shorten our life expectancy. The government will give high priority to subsidising safer drugs.	When I first went into mental health services the psychiatrist explained that I had experienced psychosis. He said there are many ways of dealing with psychosis and he could help with the drug side of things. He gave me a sheet with all the options on it and explained the pros and cons of each drug with me. He thought the drugs might help me get more out of other services I was using such as cognitive behaviour therapy and recovery education. So I tried Respiridone and it helped to quell my frightening thoughts and voices so I was able to get on with my studies and therapy. I knew what to expect in terms of side effects, though I didn't like them much. Several months later I went back to the psychiatrist and said I wanted to try living without the drugs. He supported my decision and advised me about the best way to withdraw.

7 Therapies

7.3 Complementary therapies

Complimentary therapies can provide relief, tranquillity and meaning, which people with lived experience are often desperately seeking.

Before	Changes needed	After
When I went psychotic I ended up in hospital and my son had to go and stay with my sister. There was definitely something wrong in my life, but no one asked me and I didn't have access to Māori mental health workers. I was sent home on a lot of medication to a small child and no support. A few weeks later I went back to the services and told them I needed to cut down on the medication because I couldn't look after my child – I was falling asleep all the time! I wasn't given any other options. It was awful.	Many of us value complementary treatments highly. We want the State to fund some complementary therapies, often as an adjunct to other supports and therapies. Though many of these treatments lack a conventional evidence base, many of us who use them have found that they provide relief, tranquillity and meaning to our experience. Some of the complementary therapies we value are: • naturopathy • acupuncture • massage • rongoā Māori • aromatherapy • meditation.	When I felt myself starting to go psychotic, I went to see the psychiatrist for some medication. She prescribed some and asked me what was going wrong in my life. She suggested I go home with my little son to my whānau for a while. The key question my whānau asked me was, 'What were you doing when this first happened?'. They guided me through a process of kaupapa Māori healing, reconnecting me with my whenua, my moana, my maunga and my marae and guiding me through tikanga and matters of wairuatanga. Later I went to a kaupapa Māori service. It was very healing. We had waiata, mirimiri, foot massages, kōrero awhi and we collected kaimoana and cooked it for ourselves. I still take a bit of medication at times, but my whānau and the kaupapa Māori service were pivotal to my recovery.

8 Rights

8.1 Elimination of solitary confinement

New Zealand has started its commitment to the reduction and eventual elimination of solitary confinement in the mental health context.

Before	**Changes needed**	**After**
When I was in the ward I couldn’t get any space on my own. One of the other people in there was really taunting me. One day I yelled at this guy, telling him to ‘fuck off’, and then I pushed him against the wall. The nurses put me straight into seclusion. I was terrified. I only had a plastic mattress and a blanket. I screamed to be let out but no one came. I felt so abandoned. Then I needed to pee but there was no toilet or potty. I yelled out again but no one came. I had to pee in the corner. I have never felt so desperate and humiliated. I don’t know how long I was in there. It was a few days I think. After my initial reaction I just curled up and went blank. How else could I deal with the horror of it all.	We want to see an end to solitary confinement (often called seclusion), which is locking people in a small room in a hospital on their own and against their wishes. It is traumatising for us to be forced into isolation and locked up. The environments we go into when we are in crisis will be less crowded, less coercive and more home-like. We will sense calmness and respect from the staff who will have the time to be with us. This will reduce agitation and aggression. If we do act out our frustration, we want staff around who are skilled at calming us. We also want the skills to handle ourselves better when we are in a crisis, if possible. Sometimes we may need a space away from other people because our behaviour is disruptive to them. At these times we want genuine human contact from staff or whānau in a roomy comfortable space.	When I was in the community recovery house one of the other people there really taunted me. One day I yelled at this guy, telling him to ‘fuck off’ and then I pushed him against the wall. One of the staff heard me and took me in to a quiet room. I was really uptight but she stood there calmly while I ranted and kicked the sofa. When I calmed down she showed me a relaxation technique that helped slow my breathing. Then she explained to me that the house needs to be safe for everyone and that it couldn’t happen again. Punching and swearing are unsafe and illegal. She said the staff were working with the other person to stop his taunting. We worked out some strategies for dealing with this guy – ignore him, walk away into the quiet room, unload with a staff member or go up to my room. She said I had to take responsibility for my anger but she would also let the other staff members know how difficult I found this other guy so they could keep an eye on him.

8 Rights

8.2 Prevention of compulsion

Compulsory treatment is not a useful intervention to be invoked as required. It is a last resort intervention that traumatises people, corrupts the therapeutic relationship and is often a result of service failure.

Before

I thought I was an angel. The voices were telling me to put on a see-through gown and walk into the city. I must bless everyone I saw, so they could be saved. It was going well until the police arrived. They threw me to the ground and handcuffed me. They really hurt me and I panicked.

After some time in the hospital I tried to leave but the staff said I couldn’t because I was under the Mental Health Act. I didn’t know what they meant. I was scared. They said I could contact my lawyer, but I didn’t have one and they wouldn’t let me use the phone. I was in there for three weeks feeling frightened and powerless – drugged out and unable to leave the building.

Changes needed

Those who commonly experience compulsory treatment sometimes see it as inhumane. Some of us would like to see an end to compulsory treatment; others think it should happen only occasionally for the duration of a crisis and in the most humane way possible. Virtually all of us want to see an end to compulsory treatment in the community.

Compulsory treatment creates trauma, over-dependency, a loss of trust and additional discrimination. It is frequently used for reasons that were not intended in the legislation. And community treatment orders do not improve outcomes, according to the available evidence.

We want to see more focus on preventing compulsory treatment and using alternatives such as genuinely recovery-based services, a focus on crisis prevention, advance directives, de-escalation, effective advocacy and more choices in a crisis.

After

I thought I was an angel sent to bless everyone so they would be saved. It was going well, then two more people came up to me and asked what I was doing, then said they’d like to help me get my strength back, because having sole responsibility for saving people was very hard work. I agreed and went with them to a house where a woman who called herself a psychiatrist said, “We want you to stay here for a while because we think you need a complete break from saving people, or you will collapse. We also want to give you some drugs to calm you and help you sleep’. It sounded like a good idea to me as I was starting to feel exhausted.

After I’d had a sleep an advocate came to see me and asked me how I was being treated.

On the fourth day the psychiatrist asked me if I wanted to stay a few more days or get a team of people to visit me at home a couple of times a day. I was starting to feel fragile and didn’t want to be alone, so I stayed for a while longer.

In the past I’ve had to be dragged to get help but the people I came across this time were gentle, they entered my world and gave me choices.

8 Rights

8.3 Adoption of advance directives

Advance directives are a brilliant way of responding well to loss of competency, while at the same time maximising choice and minimising coercion.

Before	Changes needed	After
Every time I had a crisis the doctors put me on mega doses of Haloperidol. I got really distressing side effects like lock jaw and an anxious pacey feeling. It nearly drove me up the wall. The side effect pills didn't get rid of the anxious pacey feeling. I would ask the doctor if he could try something different the next time but I always got the same drug. Someone told me about advance directives so I wrote one saying I didn't want any drugs that gave me those side effects. I handed it to the psychiatrist and I could tell he was irritated. The nurse who was with me said later, he screwed it up and put it in the rubbish bin. Several months later I had another crisis and was given a mega dose of Haloperiodal again...	When we are in a crisis we can't always express what we want. Advance directives and crisis planning are crucial to preserving our autonomy at these times. Advance directives and crisis planning will be routinely offered to service users who have experienced a crisis in the past. Clinicians will do what they can to accommodate our preferences, whether we are voluntary patients or under emergency compulsory powers. Advance directives in New Zealand law relate to your consent to or refusal to take treatment if you become incompetent to decide for yourself in the future. They are usually in writing and can be prepared in collaboration with a doctor. They can be incorporated into the crisis planning process. Crisis planning is broader than preparing an advance directive and can include people's instructions for any aspect of their lives that may be affected by a crisis (for example, where they want to go or who will look after the children). They may also name a trusted person to make treatment decisions on their behalf.	After my first crisis I did a recovery plan with my support worker, who involved the psychiatrist and some other people in it. Part of it had to do with crisis planning. We discussed issues like the treatments I wanted, how important touch was to me when in crisis and organising for my support worker to contact my mother as well as my landlord. I'd learnt a few things from my first crisis that I didn't want to happen again. It was a really good discussion and the psychiatrist and support worker were keen to make sure any future crises I had were more manageable for me. Three years later I had another crisis and all our agreements were put into action even though the staff had changed. I was grateful and impressed with their efficiency and willingness to carry out the agreements.

8 Rights

8.4 Effective advocacy

In a democracy, anyone who faces loss of power or removal of rights, must have effective advocacy.

Before	Changes needed	After
I was committed under the Mental Health Act and put into hospital. No one told me I couldn’t leave the hospital or that I had to take medication, but I was a bit out of it. When my head cleared I told the nurse I didn’t need to be under the Act anymore and wanted to see someone about it. It took her three days to give me the name of a lawyer, who took another two days to come and see me. I didn’t really know whose side the lawyer was on. He told me doctors usually put people under the Act for good reason and I could wait until I was scheduled to see the judge in a couple of weeks. He offered to appear for me at the hearing. I agreed but I felt he wasn’t really battling for me. He didn’t say much at the hearing at all and they kept me on the order for another month.	Peer advocates, legal advocates and others will be available to all of us. They will give us the tools and supports to make complaints that services will respond to quickly. Advocates for the small number of people under compulsory treatment will ensure they can match the power of the State. These advocates, whether legal, peer or lay, will listen to what we say, act on our advocacy instructions and show a commitment to our human rights. Human rights redress will be more accessible, effective and speedy for those of us who have experienced discrimination or human rights abuses on the ground of mental distress.	I was committed under an emergency intervention order and put into a community crisis centre. A peer advocate was with me during the assessment process but I was too out of it to know what was happening. I remember the peer advocate was staunch though. When my head cleared a bit a lawyer and the peer advocate came to see me, ‘We’re here to tell you your rights and to see if you have any instructions for us about representing your interests’. I told them I didn’t want to be under the Act anymore. They agreed to talk to my doctor and call the judge if necessary. I was off the Act within two days.

9 Accountability

9.1 Service user leadership in services

All the government in English speaking countries are saying much the same thing. Services need to be accountable to the people who use them.

Before	Changes needed	After
The first time I was asked onto a committee by the service manager I was totally unprepared. So was the committee. Most of the time they talked as though I wasn't there. They seemed so at ease while I was struggling to keep up with their language, and at the same time develop my own thoughts on the issues they discussed. I thought they must all be smarter than me and wondered what I was doing there. It was quite an upsetting experience. Occasionally one of them would turn to me and ask what I thought and I'd just stammer something banal and stupid. I stopped going to the meetings because I couldn't afford to get to them and I hated them. I heard later the committee was angry at me for being unreliable.	Service user leadership will operate at all levels of all services – in governance, in management, as staff, on advisory groups, delivering training and so on. To make this possible we need: • people to have positive attitudes and high expectations towards people with mental distress • intensive service user workforce development programmes, new training and peer mentoring • staff to recognise that they are accountable primarily to service users and to foster their leadership in services to maintain their accountability.	The first time I sat on a joint mental health committee of service users and managers I was just finishing a peer-run systemic advocacy course, which gave me a lot of knowledge about service user values and tools for change. The other service users prepared me well and said I just needed to observe for the first few meetings if I wanted. After every meeting the service users debriefed with me and talked about the dynamics, the tactics they used and the goal they were working towards. I learnt a lot from them and started contributing to the meetings really quickly. Sometimes it was hard to find a consensus with the service managers, which was frustrating, but usually they respected our input and bent over backwards to help improve the service. I gained so much from the experience – self-confidence, skills and a fee for my services. Since then I've become a manager myself and have implemented service user leadership even more strongly.

9 Accountability

9.2 Service user leadership in districts

Service users, families and affected communities can only make services accountable if they have their fair share of human and financial resources.

Before	Changes needed	After
I was appointed to the district advisory group as its service user representative. A representative from our local funder chaired the meetings. All she did was bring the draft plans for us to discuss and tick off. We were given lots of jargon, bits of paper and a crowded agenda, so we didn't have time for broad-ranging discussions about where we wanted to be going with services. We only met when the funder needed us to approve its planning. It was a farce really, and I resented giving up my time for it. I don't think anything we said made any difference. The funder always a found a reason why our ideas couldn't be taken up.	We want to see the establishment of powerful, well-resourced district leadership groups. These groups will be made up of all the stakeholder groups and have a strong service user membership that has a team of staff to work for it. Each district's leadership group needs to: • investigate the needs and strengths of its local communities • oversee community and service development for the district • measure the outcomes for people using services. The district leadership groups will use this information to advise funders and providers from the various sectors that provide for people with mental distress. These people and agencies must be genuinely accountable to the district leadership group. The district leadership group will also oversee the provision of independent information to communities about the availability and quality of local services.	I was appointed to the new district leadership group. There were five of us service users on it and five other people – clinicians, family members and a tangata whenua representative. Firstly, we were given training about the local health and social service systems and our role. We had a small group of staff to do technical and research work for us and to set up and maintain an information database. The group was funded jointly through mental health, primary health and social service budgets. Managers from all these sectors came to our meetings. It made a huge difference when the information started coming through about community resources and gaps and what people wanted from services. The evaluations of various services done by the staff and consultants provided useful information to pass onto the managers and guide service developments. I really began to understand the saying that 'information is power'. The managers couldn't ignore us.

Conclusion

New Zealand has led the world a number of times in social reform. We are recognised as a world leader in deinstitutionalisation and using a recovery approach in mental health. But ‘The Services We Need’ shows us that we still have a long way to go.

New Zealand however is in a much better position than many countries to develop services that genuinely support us to lead our own recovery, as well as regain our personal power and valued place in our families and communities.