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Leadership and innovation in New Zealand's mental health system (B)

Following the November 2008 election of a new National-led government, Janice Wilson, the Ministry of Health's Deputy Director-General, Population Health, looked forward to briefing the incoming Minister on the state of New Zealand's mental health services. A clinical psychiatrist who had headed the Ministry's mental health group since 1993, she had long been committed to developing a world-class mental health system.

But the picture that she would be presenting to the Minister was a mixed one. For the past 15 years, she had led a sector working to overcome the legacy of deinstitutionalisation. A high-profile Ministerial inquiry in 1996 (the Mason Inquiry) had lambasted the system's leadership. Janice Wilson and the Ministry of Health had been directly in the firing line, despite having limited directive powers in the devolved health system. With the resulting political and public furore providing something of a catalyst, the mental health landscape had changed significantly, and was now almost unrecognisable compared with the system thirty years earlier. No longer was it dominated by rundown institutions where mental patients remained indefinitely. Instead, most people with mental illness were cared for in the community, by services focused on recovery, and with the expectation that they would themselves actively participate in their recovery.

This transformation had been supported by a substantial boost in funding. Between 1995 and 2005, the mental health budget had grown from \$390 million to \$866.6 million, an increase

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of 88 percent (taking into account inflation).¹ Spending priorities were guided by the 1998 *Blueprint for Mental Health Services*, produced by the Mental Health Commission (the government's mental health watchdog, created after the Mason Inquiry).

The *Blueprint* detailed the services required to meet the needs of the 3 percent of New Zealanders deemed to have the most severe mental health needs, and of specific sub-groups— Māori, Pacific people, children and youth, the elderly and more.

Janice Wilson was proud of the reforms and innovations achieved to date. By 2004/05, 72 percent of mental health funding was being spent on community services, with the remainder spent on in-patient services.² Through district health boards, public funds were increasingly used to purchase services from non-governmental organisations, many of which were led by service-users and had innovative ways of working. A progressive “recovery” philosophy had become embedded in all policy and planning. A high profile mental health promotion campaign had been developed, and was gradually bringing about some positive shifts in New Zealanders’ attitudes to mental illness and reducing discrimination. New Zealand’s spending on mental health — 10 percent of its total health budget — compared well with other developed nations (in 2001, the World Health Organization said the median spend was less than 1 percent. Australia, the UK and the USA all spent less than 10 percent.)³

For all these satisfactions, Janice Wilson was far from complacent as she prepared to brief the minister. Many of the key targets spelled out in the *Blueprint* had not yet been met, despite the considerable increase in funding. Much of the funding increase, and corresponding improvements in services and access levels, occurred in the first five years after 1996 and had subsequently levelled off.⁴ There were significant gaps in key service areas, especially acute and crisis services. Efforts to strengthen the primary health sector’s capacity to treat mental health disorders before they became severe were still developing, and would require significantly more investment.

How could Janice Wilson highlight the achievements she had helped bring about in the past fifteen years — the development of a recovery approach, the proliferation of differentiated services, the growth in leadership by service-users, the shift in public attitudes to mental illness — while also acknowledging the many issues and gaps that required urgent attention? And how could she convince the Minister that, to address those gaps, the sector’s workforce and funding levels needed to be not just maintained but increased?

The recovery approach

In 1998, New Zealand became the first country in the world to enshrine “recovery” — “the first genuinely post-institutional service philosophy”⁵ — in its approach to mental health.

¹ Mental Health Commission, *Te Haerenga mo te Whakaōranga: The Journey of Recovery for the New Zealand mental health sector*, Wellington: 2007, p14

² *ibid* p 20

³ *ibid* p17

⁴ *ibid*, p16

⁵ Mental Health Advocacy Coalition, *Destination Recovery: Te Ūnga ki Uta: Te Oranga*, Mental Health Foundation of NZ, Auckland, 2008, p19

Driven especially by the growing service-user movement, the concept came to underpin all aspects of mental health policy, planning and services since it was first articulated as national strategy in the *Blueprint*. Working in a recovery-focused way became a core competency for mental health professionals. The second national mental health and addiction plan, *Te Tāhuhu* (2005), said that developing innovative funding mechanisms that supported recovery was one of the leading challenges facing the sector.

The *Blueprint* defined “recovery” as what happens “when people can live well in the presence or absence of mental illness.” Central to the concept was that the mental health service-user must be able to live with dignity, a sense of empowerment and hope. Moreover, it implied a mix of positives and negatives. “Madness is a fully human experience,” said the Mental Health Advocacy Coalition, and stressed that mental distress should not be routinely termed an illness.⁶

Focusing the mental health system on recovery — as distinct from incarceration, cure or even rehabilitation — had some major implications. In particular, it put the experience of people with mental illness at the centre of that system. They led their own journey of recovery. It was the role of the system to provide not only medications and therapies that targeted the symptoms of illness, but also support and resources that enabled individuals to negotiate their passage. Thus, the recovery approach required collaboration between service-users, clinicians and others who provided services, and the wider community whose attitudes and behaviour shaped the experience of people with mental illness.

Māori concepts of health and wellbeing added a distinctive dimension to the recovery concept in New Zealand. For Māori, cultural identity — the ability to understand and express one’s Māoriness — is intrinsic to health and wellbeing. So too is a concept that has come to underlie all Māori health strategies, *whānau ora*. *Whānau* (extended family) is the foundation of society and critical to the wellbeing of Māori, individually and collectively. Health strategies must therefore aim to support Māori families to achieve maximum health and wellbeing. In the mental health context, the idea of *whānau ora* adds another layer to recovery: it is a journey towards collective, as well as individual, autonomy and wellness.

While few in the mental health system would argue that recovery was not a worthy aim, putting it into practice presented challenges for the sector. Its inherent elasticity made measurement and evaluation a challenge, as Janice Wilson acknowledged. Instead of measuring performance in terms of how many hospitals were built, how many people they treated or how effectively symptoms were reduced, a key measure was how successfully services enabled mentally ill people to recover. But when was recovery deemed to take place? What was measured, when and from whose perspective? “For years in mental health we have been more interested in inputs: bricks and mortar or workforce or beds, and in processes: drug treatments, psychotherapies, rehabilitation... [Focusing on recovery] is hard, and by and large uncharted territory,” she said.⁷

⁶ *ibid*, p9, p33

⁷ Ministry of Health, *Mental Health Newsletter*, September 2005.

Some users questioned how successfully the rhetoric of recovery was translated into action. Mary O'Hagan, a former Mental Health Commissioner with lived experience of mental illness, said in 2008 that some services were struggling with the recovery approach and were hanging onto the "control agendas" of the past. "I do still hear some horrific stories. I don't have a huge amount of confidence in mental health services."⁸

The concept of recovery also sat somewhat uneasily with legislative provisions for coercion and compulsory treatment contained in the Mental Health Act 1992.⁹ The views of service-users and clinicians were sometimes polarised on this point. Said the Ministry of Health's Director of Mental Health, Dr David Chaplow: "Some people say that the Mental Health Act is inimical to recovery... But the whole notion of recovery — the sense that people can choose their own destiny — can really only operate in the wellness phase of someone's illness."¹⁰ He believed that when someone was legally and/or clinically mentally ill and unable to make meaningful choices, "there's a need for coercive intervention to promote recovery. It's just like if someone is unconscious and bleeding; most doctors are going to put a bandage on to stop the bleeding even though the patient isn't able to agree to it."

But for some service-users and their advocates, compulsory treatment was an unacceptable intrusion into individual rights and liberty which had no place in a recovery-focused mental health system. Others saw a limited role for it (either in hospital or in the community) but said it was used far too readily, with little evidence that it worked. The Mental Health Advocacy Coalition said in 2008 that transforming traditional thinking about compulsory treatment was essential. In a mental health service truly committed to the recovery approach, it said,

"compulsory treatment is used rarely and briefly. There is no seclusion or compulsory electro-convulsive therapy (ECT). People working in mental health services strive to prevent compulsory interventions. Any use of compulsory powers is done humanely and their use is treated as a critical incident. This is matched by a changed emphasis on professional responsibility; providing the best possible advice and assistance is in the foreground, while containing clinical risk does not dominate."¹¹

The recovery concept, and associated issues around compulsory treatment, sometimes divided service-users and their families. The latter could feel excluded from a system that prioritised the autonomy of the service-user, just as the community at large sometimes feared that the wishes of service-users were given more weight than public safety. So, while it was service-users who had felt marginalised by the system in the past, this changed with the

⁸ Interview with Mary O'Hagan, Radio New Zealand, 3 March 2008

⁹ Under the Mental Health Act, people with serious manifestations of mental illness who are a serious danger to themselves or others, or have seriously reduced capacity for self-care, can be subject to compulsory treatment. They may be detained in hospital or treated in the community. Treatment may include medication, ECT and forced feeding. (See Mental Health Commission, *Te Haerenga mo te Whakaōranga*, p186)

¹⁰ Dr David Chaplow, interview with author 19 Nov 2008. Unless stated otherwise, all comments are from this interview

¹¹ Mental Health Advocacy Coalition, *Destination: Recovery, Future responses to mental distress and loss of well being*, Mental Health Foundation, Auckland: 2008, p37

introduction of the recovery concept. Now, some clinicians, families and communities felt marginalised, along with a number of consumers.

Janice Wilson acknowledged these feelings, and also that the recovery concept needed to be handed carefully when dealing with the acutely sick — especially if they were a risk to themselves or others. But she maintained that a recovery focus could still be reconciled with risk management, sound clinical practice and responsiveness to families. Her views were echoed by psychiatrist Dr Peter McGeorge, appointed Chair of the Mental Health Commission in 2008:

“You will certainly get the ideologues who believe total autonomy is the way to go – that the clinician is part of the problem rather than part of the solution. It is a matter of what is the balance ... between best clinical practice and enabling people to take more responsibility for their lives and managing their own conditions... You do have people who are still major risks to themselves and sometimes others who demand to be released from hospital. Recovery is not a substitute for good clinical care.”¹²

Services and access: minding the gaps

One of the greatest mental health milestones of the past fifteen years, Janice Wilson said in 2008, was the simple fact that most mentally ill people were now cared for away from large, stand-alone, custodial institutions. Having trained at a time when such institutions dominated the mental health landscape, she now considered them outdated.¹³

But she was equally certain that the services that had largely replaced them were far from perfect. Serious shortcomings remained in important areas — acute care, some specialist areas (especially for children and young adults), services for people with high and complex needs, and the coordination of services — and addressing them would continue requiring substantially increased resources..

At the time of the 1996 Mason Inquiry, services were described as “fragmented and under-resourced, both in skills and size. Coordination, in many services, is non-existent.”¹⁴ Ten years later, there had been a huge expansion in the number and range of services, as detailed in a 2007 Mental Health Commission report.¹⁵

- ***Multi-disciplinary community mental health teams working within District Health Boards were the core of the system***, and saw the majority of service-users (in 2003, more than half of the 86,676 people seen in total.) Bringing together nurses, psychiatrists, occupational therapists, social workers and many other professionals, these teams provided assessment, treatment and therapies, and helped connect users with other services. They might see service-users in their own homes, at outpatient clinics or as hospital inpatients. DHBs also provided crisis intervention services, sometimes via the

¹² David Fisher, ‘Did the system kill my child?’, *New Zealand Listener*, Nov 29-Dec 5 2008 Vol 216 No 3577

¹³ Interview with author, 10 Nov 2008. Unless stated otherwise, all comments are from this interview.

¹⁴ Ministerial inquiry under Section 47 of the Health and Disability Services Act 1993 in respect of certain mental health services (the ‘Mason Report’), Wellington: May 1996, p100

¹⁵ Mental Health Commission, *Te Haerenga mo te Whakaōranga*, pp 39-67

community teams or else by standalone units. All DHB services (and those they funded) had to meet national service specifications set by the Ministry.

- **Hospital care for the acutely ill continued.** However, the number of in-patient beds was still declining and, in some areas, there was a constant shortage. As recommended in the *Blueprint*, some home-based or community-based acute services had developed, providing an alternative to hospital admission.
- **Specialist services had proliferated.** Some met the needs of specific population groups — Māori, Pacific people, children, refugees, new mothers, criminal offenders — while others dealt with specific mental health conditions, such as personality disorders, addictions or eating disorders. However, there was still a significant shortfall in the services available to children and young people, and older people.
- **Services provided by NGOs had grown significantly,** especially those providing residential care, employment, training and day centres. In fact, most such support services were now provided by non-governmental organisations (NGOs); some also provided specialist services. In the decade after the Mason Report, the NGO sector's share of mental health funding grew from around 10 to 30 percent.
- **The role of primary health care providers in mental health had expanded.** A national guideline issued by the Ministry in 2008 stated that general practices and other primary providers were “where common mental health problems can and should be managed.”¹⁶ As the *Blueprint* had noted, approximately 17 percent of New Zealanders had mild to moderate mental health problems at any one time, and they did not need to be treated by specialist services.¹⁷ In 2005, the Ministry began funding some primary mental health initiatives out of the budget for primary health (rather than for mental health). Initiatives included training GPs and other primary health workers to recognise the signs of common conditions such as depression, and provision for longer consultation times. Although this funding did not yet extend nationwide by 2008, initial evaluation showed encouraging results.

So, over the decade since the Mason Report, mental health services had proliferated greatly. But were they making a difference to New Zealanders' mental health?

Janice Wilson said that the “very fact that mental health services don't at all resemble what they were when I started to train is very positive. As is the fact that they are much more service-user focused.” For others, the development of more diverse services has been the real gain, as the Ministry of Health's David Chaplow explained: “We have gone from having a rather undifferentiated mass of needy people — children, adolescents, women, men, forensic patients, intellectually disabled people — all lumped into one basket, to a much more differentiated service model. Now we have far more mobile, discrete and smaller units that are held to account for exactly what they do.” Service-user and consumer consultant for the Waitemata District Health Board, Ana Sokratov, agreed:

¹⁶ Ministry of Health, ‘New Guidelines on Identifying Mental Health Problems and Managing Depression’, media release, 17 July 2008, available at www.moh.govt.nz/moh.nsf/indexmh/new-guidelines-on-identifying-mental-health-problems-and-managing-depression (accessed 17 December 2008)

¹⁷ Mental Health Commission, *Blueprint for Mental Health Services: How Things Need to Be*, Wellington: 1998, p7. The 17 percent figure was later adjusted to 20 percent.

“In its true sense, the idea of ‘asylum’ still applies today. Except that how we provide that sanctuary for people, that safe place, has changed. It’s changed from always putting people in large hospitals to providing home-based treatment options, where people in either an acute state or in crisis can receive care in their home. And, in the middle, there’s a continuum of options. There was no continuum in the old days. There was only one choice.

The other shift is that we now know you can’t just treat a mental illness and think people are going to recover. Recovery from a mental illness is broader. It’s about housing, employment, and all those other things that everybody else expects to have in this world. Mental health consumers want those too, and there are services now to help.”¹⁸

But a very different answer to the question of whether the service environment has improved emerges when actual progress is compared against the targets spelled out in the 1998 *Blueprint*. The *Blueprint* said they could be achieved within ten years, assuming adequate funding, and a special funding stream (“*Blueprint* funding”) was made available specifically for that purpose. In fact, ten years on, mental health services were still falling short of the *Blueprint* access targets — well short in some areas. In 2007, the Mental Health Commission estimated that publicly funded mental health services were reaching only around 1.9 percent of the population in any six-month period, or only about 60 percent of the “3 percent” they were meant to be reaching.¹⁹ The discrepancy between actual access levels and the *Blueprint* targets was especially pronounced in newer and specialised service areas. A range of contributing factors was identified by the Commission and others, including:

- Despite the 88 percent funding increase over the past decade, the funding was still not enough to meet needs. This shortfall was more pronounced in some areas than others — in 2004/05, only 11 percent of public funding went to child and youth services, for example, which the *Blueprint* suggested should receive 26 percent.²⁰

As early as 2001, the Mental Health Commission warned that services were unlikely to be able to achieve any more than 70 percent of the *Blueprint* targets with the predicted funding levels,²¹ and that appears to be precisely what happened. One DHB said in 2008 that the boards were receiving only 70 to 90 percent of the funding required to provide *Blueprint* services.²²

- Ring-fencing may not have been enough to prevent some DHBs from spending some of their mental health budgets in other areas. In early 2009, a newspaper revealed that the Auckland District Health Board had “siphoned off” \$2.5 million from its mental health budget to fund other health services and to settle a major pay dispute.²³ Janice Wilson said that the Ministry had commissioned reviews of the way several DHBs planned and funded mental health services, including their use of ring-fenced funding. There were

¹⁸ Ana Sokratov, interview with author, 7 November 2008. Unless stated otherwise, all comments are from this interview.

¹⁹ Mental Health Commission, *Te Haererenga mo te Whakaōranga*, p76

²⁰ *ibid*, p19

²¹ *Annual Report of the Mental Health Commission 2001*, Wellington, 2001, p6

²² David Fisher, ‘Did the system kill my child?’ *New Zealand Listener*, Nov 29-Dec 5 2008 Vol 216 No 3577

²³ ‘Board siphons off millions,’ *New Zealand Herald*, January 18 2009, available at www.nzherald.co.nz/mental-health/news/ (accessed 5 February 2009)

other concerns about DHBs, such as whether they were funding their own provider arms at the expense of developing services within the NGO sector. In particular, there was alarm about the number of DHBs reporting substantial end of year surpluses. According to the Mental Health Commission, this showed that “planning, funding and service development have not kept pace with the funding provided. The year-end funder financial position of all DHBs and the Ministry of Health combined has changed from a deficit of \$4.3 million in 2001/02 (0.6% of revenue) to surpluses of ...\$16.7 million in 2004/05 (1.9% of revenue).”²⁴

- Under-reporting — many NGOs did not report their contacts with service-users, meaning they were not counted when access to services was measured.
- Measuring progress against the access targets did not reflect the growing emphasis on quality, rather than the number of people seen. In some areas, caseloads for mental health practitioners had decreased, allowing individuals to receive more intensive care that addresses a range of inter-related needs. High-quality, “wraparound” services took time to establish and were more expensive to deliver.
- The incidence of mental disorder was increasing worldwide, placing strain on resources everywhere. The World Health Organization said that mental illness now accounted for 15 percent of the total burden of disease in the developed world, and by 2020, depression would be the second leading cause of disability worldwide. In 2008, the United Nations described resources available to tackle the issue as “insufficient, inequitably distributed and inefficiently used,” and said that scaling them up must be a priority in both the developed and developing worlds.²⁵
- The *Blueprint* targets themselves have also come under scrutiny. They were developed using the best epidemiological data available at the time, but it was not New Zealand-specific. According to Janice Wilson, the targets were more appropriate for larger populations than those served by many DHBs today. In fact, New Zealand’s own mental health survey (the Ministry’s *Te Rau Hinengaro*, 2006) indicated that the proportion of New Zealanders with a serious mental disorder was 4.6 percent rather than 3 percent. If so, the mental health system was falling even further short of the *Blueprint* access targets.

There were other troubling aspects of the 2008 service environment beyond the failure to fulfill access targets. Deaths, suicides and violent crimes involving mental health patients continued to hit the headlines in the years since the Mason Report, prompting inquests and regular reviews of services and providers. Many of them highlighted pressures on acute inpatient and crisis units, which were chronically over-crowded. It was found that beds in acute units were sometimes occupied by people who did not need to be there; doctors were loathe to discharge them because there were no other safe options.²⁶ Said Mary O’Hagan:

²⁴ Mental Health Commission, *Report on Progress 2004/05: Towards implementing the Blueprint for Mental Health Services in New Zealand*, p6

²⁵ United Nations, ‘Ban: More Resources Needed for Mental Health Care,’ media release, 13 October 2008, available at www.scoop.co.nz/stories/WO0810/S00253.htm (accessed 15 November 2008)

²⁶ *ibid.*

“When people say they need help, they should get it. We have people ringing the crisis services; the [services] say, you are not sick enough, goodbye. There’s a mentality that we have to keep people out... The gate-closing mentality has got to change.”²⁷

Health professionals had other concerns. In 2008, the Ministry’s Deputy Director of Mental Health, Dr Charles Hornabrook, expressed fears that in-patient units and their staff had become undervalued in a system where inpatient care is regarded as less desirable than community-based care.

“It has been difficult to champion the cause of hospital treatment for mental illness when one reads of ‘exciting and overdue implementation of the community-oriented paradigm’ in mental health service delivery. The prohibitive cost of beds, the long shadow cast by hospital-based services of the past, and the sense that admission to hospital represents ‘failure’ rather than a useful therapeutic choice, all add to the picture.”²⁸

Outside the acute area, services were also over-stretched. For example, an Auckland rehabilitation centre that provided residential care for 40 people who did not need acute care in hospital, but were too ill to be living in the community, reported a waiting list of up to 18 months.²⁹ The chief executive of Schizophrenia Fellowship New Zealand, an organisation supporting families, talked about a “desperate” need for support and resources to cope with the day-to-day challenges of caring for the mentally ill who are not in hospital. Very often, it was family members who struggled with these challenges.³⁰

Empowering service-users

One of the most distinctive features of New Zealand’s mental health system in the twenty-first century was the way it had been so powerfully shaped by service-users, once completely disempowered participants in the mental health system.

Throughout the 1970s and 80s, an increasingly vocal service-user movement developed among former mental hospital patients who saw themselves as survivors of a brutal institutional regime. Mary O’Hagan was one of the founders of Psychiatric Survivors that began, she said, with “rather a separatist agenda. We almost wouldn’t let professionals in the door; we wanted to start our own identity. We learned a lot by forming our own view of the world, within our own enclave, without it being corrupted by what people were thinking in the system.”³¹ The militancy of groups such as Psychiatric Survivors, and their insistence on self-determination, challenged the medical model of mental health and helped shape thinking about recovery. They reclaimed once-shunned terms such as “lunatic” and “madness” (a “National Nutters’ conference” was held in 2006) and said mental illness was not a disability to be eradicated by the medical profession, but a fundamental part of an individual’s identity. They called for better access to treatment options that went beyond medication — talking therapies, social support, recovery education.

²⁷ Interview with Mary O’Hagan, Radio New Zealand, 3 March 2008

²⁸ Ministry of Health, *Mental Health Newsletter*, Issue 22, July 2008, p14

²⁹ David Fisher, ‘Did the system kill my child?’, *New Zealand Listener*, Nov 29-Dec 5 2008, Vol 216 No 3577

³⁰ Schizophrenia Fellowship NZ, ‘Families Meeting the Challenge of Mental Illness,’ media release, 1 September 2008, available at www.scoop.co.nz/stories/GE0809/S00008.htm (accessed 15 November 2008)

³¹ Interview with Mary O’Hagan, Radio New Zealand, 3 March 2008

Over time, groups of former patients began lodging compensation claims for abuse they had suffered in psychiatric institutions. In 2001, 95 former patients at Lake Alice Hospital's child and adolescent unit (near Wanganui) received a \$6.5 million Government payment and an apology for their treatment at the hospital in the 1970s. A further 90 former patients of the unit subsequently received ex gratia payments. By 2004, two Wellington lawyers were representing nearly more than 300 ex-patients who alleged they were abused in various institutions in the 60s and 70s.³² In 2007, a government-appointed confidential forum on historic abuse claims reported back to parliament, calling for a government apology to the many former patients who had "experiences that were deeply humiliating and demeaning, often taking a lifelong toll."³³ More historic claims of abuse continued to be lodged against the government.

At the same time that consumer voices had been growing louder, their perspectives had begun to be acknowledged in the policy process led by Janice Wilson. Her previous experience as medical superintendent at Porirua Hospital in the 1980s had convinced her of the value of service-user involvement:

"During my time there, the first consumers started coming in from the outside and working directly with service-users and patients in the hospital... It could be uncomfortable at times, and it was fairly challenging for some staff."

However, she said, it was critical in changing the hospital's attitudes and approaches. She subsequently applied that experience at the Ministry of Health, ensuring *Moving Forward* contained a national objective of improving responsiveness to consumers and involving them in the planning, design and purchase of services. Consumer participation was part of the National Mental Health Standards first developed in 1997. The advisory group for the national anti-discrimination campaign *Like Minds Like Mine (Exhibit 1)* was made up of service-users. Until recently, the Mental Health Commission's three commissioners always included one person with "lived experience" of mental illness, and the Commission also has a user reference group.

The growth of mental health services established and run by service-users has been called "a particularly innovative area of service development."³⁴ Most services offered support, counselling and advocacy. As at 2005, there were around 40 such services or networks, most of them small and unfunded. In 2006, the Mental Health Commission called for more research into and support for services led and run by service-users, as international evidence indicated they were "an essential ingredient in many people's mental health recovery."³⁵

Meanwhile, other service-users were working in DHBs, NGOs, advisory bodies and lobby groups. They were stakeholders, mental health workers and managers, advocates and leaders. Many worked in consumer advisory or support roles, a new occupation for which formal

³² 'Allegations of Abuse in Institutions, *New Zealand Herald*, 12 June 2004

³³ Nga Hau E Whau, 'Mental Health Sufferers Deserve An Apology Too,' media release, 30 May 2008, available at www.scoop.co.nz/stories/PO0805/S00492.htm (accessed 15 November 2008)

³⁴ Mental Health Commission, *Te Haerenga mo te Whakaōranga*, p131

³⁵ *ibid*, p132

training and a tertiary certificate-level qualification had been available since 1998. By 2004, mental health support workers represented the second largest group in the workforce.³⁶ While it was not essential to have service-user experience to become a support worker, only service-users could become “peer support workers.” This more specialised role enabled service-users to support other people’s recovery by drawing on their own experience and understanding of mental illness: “The personal cost of mental illness can be extremely high, and historically the systems and organisations put into place to help have at times made it even harder. The experiential knowledge ... that I and others bring is a vital element that has long been missing from many of these systems and services,” explained one service user working with a DHB.³⁷

The contribution of user perspectives to the mental health system was enormous, Janice Wilson believed:

“I am in no doubt that attitudes and ways of practice among mental health workers have changed significantly by the very active participation and involvement of consumers. They have challenged the traditional medical paradigm, and mental health professionals have responded and shifted. I’m a very strong advocate for involving service-users. If you want services to improve, you bring in users right to the table and get them working with you on how you change systems to improve service quality... It occurs to me that the rest of the health sector could learn quite a lot from the very active involvement and participation from service-users.”

In light of this, many in the sector found the 2008 decision not to appoint a service-user as one of the three new mental health commissioners both unfortunate and baffling. The decision prompted an outcry. Māori Party leader and health spokesperson, Tariana Turia, said it was not enough to simply consult consumers: they needed to be at the decision-making table. It was incumbent on the Commission “not just to listen to the voices of consumers — it must BE the voice of consumers, and to have integrity, there must be someone on the board of the Commission who has been there, done that.”³⁸ Mary O’Hagan was another of the many to speak out: “There’s been a commissioner with lived experience since the Commission opened. Our presence in such a senior role has had huge symbolic and strategic importance for service-users, the national mental health sector and internationally. This is a backward step and a big blow to innovation and service-user leadership in New Zealand.”³⁹

³⁶ *ibid*, p112

³⁷ Mental Health Commission, *Awhi, tautoko, aroha: Celebrating recovery-focused mental health workers who assist people on their journeys*, Wellington, 2001, p26

³⁸ Māori Party, ‘Commission must be voice of mental health,’ media release, 24 May 2008, available at www.scoop.co.nz/stories/PA0805/S00488.htm (accessed 15 November 2008)

³⁹ Central Potential, ‘Commission Appointment: A Backward Step,’ media release, 21 May 2008, available at www.scoop.co.nz/stories/GE0805/S00105.htm (accessed 15 November 2008)

Turning around stigma and discrimination ⁴⁰

Throughout the early twenty-first century, New Zealand's effort to reduce discrimination against the mentally ill — in the community at large and within mental health services specifically — attracted international attention. It was, according to Janice Wilson, “a stunning success.”

The Mason Report highlighted the many ways in which the mentally ill were stigmatised and socially excluded. Mental illness was constantly associated with violent offending in the media, and this sensational coverage — together with a lack of information — shaped the general public's understanding. Negative attitudes made people reluctant to seek help for mental illnesses. Once the label “mental patient” had been applied, it was hard to shake off: it affected people's relationships, self-esteem, work, housing and educational prospects. The Mason Report recommended an immediate public awareness campaign in the expectation that “a well-informed New Zealand public will then realise that the mentally ill are people whom we should nurture and value.”⁴¹

Over the next twelve years, there were many responses to this recommendation. Chief among them was the ongoing social marketing project, *Like Minds, Like Mine*, which has demonstrably influenced a gradual change in New Zealanders' thinking about mental illness and the social inclusion of people who experience it. Other policy initiatives aimed at combating stigma and discrimination unfolded over the same period. They included the enshrining of anti-discrimination provisions in the Ministry's mental health strategies since 1997; the adoption of Standard 18, a national performance standard applying to all government-funded mental health services; and the publication of the government's New Zealand Disability Strategy in 2001. Statutory bodies such as the Office for Disability Issues, Human Rights Commission, the Human Rights Review Tribunal, the Office of the Ombudsman, and the Office of the Health and Disability Commissioner all undertook monitoring, advisory and/or public education work; some also investigated complaints about discrimination on the basis of mental illness. Non-governmental organisations, both small and large, also initiated anti-discrimination activities — educating, advocating, coordinating, running programmes in workplaces, undertaking research and much more. They included groups set up by service-users, such as Mad Pride.

Efforts to counter discrimination have been criticised for being fragmented. Mary O'Hagan said that work in this area was like “a collection of strands that need to be bound into a strong rope through greater leadership and coordination.”⁴² But overall, there was a sense of progress. Janice Wilson was particularly proud of the Ministry's long-term commitment to *Like Minds Like Mine*, which she said was now paying off. She said its success was not simply that it had encouraged the community to think differently about mental illness: it had empowered service-users, helped engender greater political commitment to the philosophies

⁴⁰ Another case on this subject is available from the ANZSOG case library: (*Like Minds, Like Mine*: the campaign against stigma and discrimination.)

⁴¹ Ministerial inquiry under Section 47 of the Health and Disability Services Act 1993 in respect of certain mental health services (the ‘Mason Report’), Wellington: May 1996, p164

⁴² *ibid*

of recovery and community-based care, and created a climate where innovative and progressive services could flourish:

“It shows that with a social marketing campaign, you have to be consistent, willing to evaluate it and do it for a long time in order to see results... I don’t think we would have got as far as we have with transforming our services if we had not had such a strong programme tackling stigma and discrimination.”

Where to now for mental health?

In 2008, Janice Wilson was well aware of criticisms that efforts to improve the mental health system were flagging. “I have heard people say that mental health reform in New Zealand has lost momentum. We appear to have plateaued — got stuck somehow.”⁴³ By then, Janice Wilson was leading the new Directorate of Population Health, incorporating the Ministry’s Mental Health Directorate. Did that mean mental health was dropping down the health agenda? “I’m sure some people probably saw it like that. But you can also see it as a very positive move to take an integrated approach to mental health alongside other key areas such as environmental health, primary health care and disability,” she said.

With the change of government in 2008, and the global economy in recession, funding arrangements, including annual increases and the guarantee of full *Blueprint* funding until 2015 were less certain. although the new government had signalled health as a priority spending area. Whatever the outcome of future decisions on mental health, Janice Wilson said she was confident that mental health was now in a far better position to “hold its own” than in the past. It could no longer be seen as a separate, isolated and stigmatised part of the health and disability sectors. In fact, mental health could lead the way in some areas — including Māori involvement in services and policy formulation, user participation, innovative workforce development and promoting attitudinal change.

Developments over the past twenty years had also given those in the mental health sector ample experience of working co-operatively — across districts and regions, and across health board and NGO services — to meet the clinical and support needs of users. While acknowledging that funding remained crucial for the future development of the mental health sector, Janice Wilson also considered that it was time for these hard-won strengths to be recognised in wider health debates.

⁴³ Ministry of Health, *Mental Health Newsletter*, October 2008

Exhibit 1: Like Minds, Like Mine

In 1998, the Ministry initiated *Like Minds Like Mine*, a national project to counter stigma and discrimination against people with mental illness. Run out of the Ministry of Health's Public Health Directorate, it was initially conceived of as a five-year, \$12.6 million project. By 2008, the project was in its eleventh year and had cost \$43.8 million in total. Its most public face was a series of television and radio advertisements — some featuring high-profile New Zealanders who had experienced mental illness, others showing the experiences of “ordinary” people through the eyes of friends and family — which won a raft of advertising and social marketing awards. More importantly, the campaign influenced a gradual change in New Zealanders' thinking about mental illness. They were more accepting of people with mental illness as workmates or colleagues, and less likely to associate mental illness with shame or rejection.⁴⁴

Like Minds Like Mine involved much more than high profile advertising. Twenty-six *Like Minds Like Mine* providers were based around New Zealand, addressing discrimination at a local level. They worked with organisations that interacted with people with mental illnesses, such as Police, Work and Income, Housing New Zealand, education providers and the media. Various local providers were contracted to run regional *Like Minds Like Mine* programmes, including NGOs such as the Mental Health Foundation.

⁴⁴ Mental Health Commission, *Journeys Towards Equality: Taking stock of New Zealand's efforts to reduce discrimination against people with experience of mental illness*, Wellington, 2004, p 11.