## Respect Costs Nothing:



A survey of discrimination faced by people with experience of mental illness in Aotearoa New Zealand

### 2004

**Executive Summary** 



Mental Health Foundation of New Zealand



LIKE MINDS, LIKE MINE Whakaitia te Whakawhiu i te Tangata

#### Mental Health Foundation of New Zealand

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## Mihi

E mihi whānui ki a koutou ngā mōrehu o te motu. Ēnei ngā hiahia, mō a rātou tūroro. E rikarika hoki ngā tūroro ki a mātou, nō te mea, Ki te mōhio rātou ngā māwiwi hinengaro, e kino ngā kōrero whakahāwea ki a rātou.

Kō tēnei te kaupapa rangahau i takahia i mua ki a koutou. Ki te pānui, ki te ako, ki te mōhio koutou ngā huarahi whakaruruhau i roto i to koutou whanau, tō koutou hoa i te kura, me tō koutou wāhi mahi.

Te kaupapa whānui i whakakauwhau i runga ki a rātou katoa, e hoa mā, ki te rongo koutou ngā whakahāwea ki ngā tūroro, kauwe e kūare ki te tautoko rātou, a, pā anō, e koi rātou, kō koutou ngā hoariri. Kia kaha, kia māia ki te kaupapa nei.

Tēnā koutou, tēnā koutou, Ki ora huihui mai tātou.

Rawiri Wharemate Kaumatua

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### <u>Preface</u>

In March 2003 an idea was born. It was decided that the Mental Health Foundation of New Zealand, as part of the New Zealand *Like Minds, Like Mine* anti-discrimination campaign, would undertake a survey asking people with experience of mental illness throughout New Zealand about their experiences of discrimination. The survey was funded by the Public Health Directorate of the Ministry of Health (responsible for the *Like Minds* campaign), and the information gathering took place from April to June 2003.

The aim of the research was to find out more about people's experiences of discrimination due to their experience of mental illness. We were not so interested in the numbers of people experiencing discrimination, rather, the nature of the actual discrimination experience. Up until now, there has been a lack of information in New Zealand about peoples' experience of discrimination in this area.

This was the first survey of its kind to be undertaken in New Zealand. The survey was inspired by two pieces of research from the United Kingdom – *Not Just Sticks and Stones* (MIND, 1996) and *Pull Yourself Together!* (The Mental Health Foundation UK, 2000). While such research has been undertaken elsewhere, we developed a completely new questionnaire suitable for New Zealand audiences.

This research shows that discrimination on the basis of mental illness permeates all aspects of the lives of those who experience mental illness – from employment and health services to interactions within communities and with friends and family. Not only is it present in people's lives, it has a major effect on their lives – resulting in job losses, lack of opportunities and social isolation. The challenge, now we have this information, is to work on strategies to reduce the discrimination people face.

Debbie Peterson Senior Policy Analyst/Researcher Mental Health Foundation of New Zealand

## **Foreword**

The Mental Health Commission welcomes this research report. It breaks new ground in New Zealand and makes compelling, but somewhat sobering, reading.

Not everyone with mental illness experiences discrimination. Throughout the report there are stories of hope, where people describe practices and behaviour that supported them in their recovery.

But the overwhelming sense in the report is that far too many people are cut off from participating fully in their communities either because of discrimination or because of loss of confidence arising from fear of discrimination. There are stories of not finding a job, losing a job, being excluded from education and training, having problems accessing financial services, losing flats and not getting government support when entitled to. But, perhaps the most striking finding is that more people reported negative discrimination by friends and families than in any other aspect of their lives. Those who are often the greatest support are also those whose behaviour can hurt the most.

The report suggests changes including better education for everyone about mental illness, training for staff in all government agencies and more support for service users themselves to challenge discriminatory practice.

The Mental Health Commission congratulates the Mental Health Foundation and the *Like Minds* Project for undertaking the survey and the authors for a powerful and very accessible research report. We acknowledge the 785 people who took time to tell of their experiences. Those stories provide a clear signal as to what needs to happen. The report provides an important foundation for action and offers a challenge to us all in both our public and private roles. The challenge is for each of us to radically alter the attitudes and behaviours that exclude so many of our fellow citizens from reaching their full human potential.

Jan Dowland Chair Commissioner Mental Health Commission

## **Executive Summary**

This document presents the key findings from a survey of people with experience of mental illness to obtain their accounts of discrimination. The survey was designed to elicit their experiences of discrimination across a broad spectrum of activities as part of the New Zealand *Like Minds, Like Mine* anti-discrimination campaign. The information gathering for this work took place from April to June 2003.

This document aims to give policy makers, service providers and educators an insight into the discrimination experienced by people with experience of mental illness. For people with experience of mental illness and their supporters this document is intended as an acknowledgement of their experiences.

Survey respondents were asked to comment on their experiences of discrimination across a broad range of situations which included:

- employment
- education and training
- housing
- mental health services and other health services
- government agencies and local government services
- banks, insurance companies and other financial institutions
- sports clubs and other organised activities
- parenting
- friends and family
- community harassment
- fear of discrimination

The main results of the survey showed:

- People report discrimination in all aspects of their lives from employment and housing to discrimination from friends and family and the community. This discrimination results in people feeling excluded from many activities of daily living. Few formal complaints about discrimination are made.
- Discrimination, even when it occurred several years ago, makes a lasting impression and still impacts on people's lives today. Due to past experiences of discrimination, many people seem to attribute any poor service they receive as discrimination due to their experience of mental illness.
- The fear of discrimination (often based on past experience) is as crippling as discrimination itself. Fear of discrimination prevents people from undertaking many activities in their lives such as employment and interacting with others.
- Disclosure is an issue across all the areas of discrimination. When people disclose that they have experience of mental illness they are treated differently (often negatively) from when they do not.
- People tend to believe and act on the common stereotypes of people with experience of mental illness as being incompetent or dangerous.
- We all need (at an individual, community and systemic level) to take responsibility for discrimination and examine our own behaviours and attitudes.

## Background to this document

Since the Human Rights Act was passed in 1993, discrimination on the grounds of mental illness in various areas of daily life such as employment, housing and education has been illegal. With this legislative support, the incidence of discrimination might be expected to be rare. However, informal accounts suggest the incidence is much higher than the number of complaints would indicate.

The *Like Minds, Like Mine* project was established in response to the 1996 Mason Report. Its aim is to counter the stigma and discrimination associated with mental illness. The government has continued to fund the project in recognition that stigma continues to exist and discrimination still occurs and that programmes are required to change this. The purpose of this report is to shed some light on the nature of this discrimination. It is the first national survey about discrimination associated with mental illness in New Zealand.

To do something about discrimination, we need to know more about it – where it occurs and how it affects those discriminated against.

Discrimination occurs when a person is treated differently from another person in the same or similar circumstances:

- it can be direct or indirect; and
- it is not always unlawful.

Discrimination is only unlawful when it occurs on one of the prohibited grounds and in one of the prohibited areas of public life. In the survey, respondents were not limited to the legal definition but could self define discrimination. This led to some individuals considering various actions as discrimination that might not be defined as such by other people.

## How the information in this document was gathered

#### Questionnaire

A questionnaire was used to gather the information for the research. It was a mixture of open and closed questions, so people could record their stories as fully as they wanted to.

#### Distribution

The questionnaire was available on the *Like Minds, Like Mine* website and printed copies were distributed throughout the country. The survey was also distributed through the *Like Minds, Like Mine* campaign newsletter, which has a circulation of over 6000.

#### Response rate

A total of 785 responses were received. The questionnaires were distributed through groups rather than individuals. This probably contributed to the low response rate of 11 percent.

However, because the survey's aim was to explore discrimination, rather than to determine its incidence, the response rate is less significant. The sample was in no way random and the questions were mainly qualitative, so having a high response rate was not vital to the value of the findings.

#### Ensuring participation from different groups

At the end of the questionnaire, respondents were asked about their gender, ethnicity and age. Extra questionnaires were sent to groups which were under represented to ensure a more representative response.

#### Analysis

The full responses were entered onto a computer database using EZ-text. The responses were coded, sorted and analysed using a basic thematic analysis.

Initially all responses were analysed and then Māori and Pacific researchers analysed the Māori and Pacific responses separately. A comparison was then completed to identify the consistent issues and issues that were specific to certain communities.

Throughout the research, a group of researchers and people with experience of mental illness advised the research team and acted as a sounding board as new issues were raised.

#### Ethical issues

The main ethical issue involved the financial incentive to encourage people to answer the questionnaire. The names of people who participated were put into a draw for five \$100 gift vouchers. To ensure respondent anonymity, names and contact details for the draw were separated from the questionnaire before processing.

#### Limitations

The responses to this study cannot be generalised to the entire population of people with experience of mental illness but this was never the aim. The aim of the research was to discover the nature of discrimination or unfair treatment against people with experience of mental illness, rather than measure its incidence. However, from the almost 800 returned questionnaires, we can say that experiences of discrimination seem to be common among people with experience of mental illness.

When people were questioned about their experiences of discrimination (what happened, when it happened and what action was taken) many people answered only part of the question. From the context of the answers most experiences seemed to have taken place recently with a few happening many years ago.

The other main limitation resulted from the method used. A written questionnaire meant we were unable to follow up responses to find out more information. We were also acutely aware that for some people a written questionnaire is not the best method to obtain information. Furthermore, using a written questionnaire assumed a certain level of English language literacy.

#### General comments

In some cases, it was difficult to identify whether the discrimination (or unfair treatment) had been on the basis of the person's experience of mental illness or their ethnicity, gender, or benefit status. Though 'discrimination' has a limited legal definition, in reality it can be a broader, personal experience, so different people will perceive the same action differently. This does not discount the validity of actions described by some people as discrimination, but serves to underline our need to understand our rights, others' rights, and the ways we can reduce discrimination in our own and others' lives.



## Employment

#### Figures

- Of the 785 respondents, 266 (34%) said they had been discriminated against while looking for a job; 354 (45%) said they had not been discriminated against.
- In relation to discrimination within a job, 246 people (31%) said they had been discriminated against; 355 people (45%) said they had not been discriminated against.
- The results were similar across the three ethnic groups.

#### Experiences when looking for a job

Respondents reported a variety of experiences in response to this question from being prevented from gaining employment because of the discrimination they experienced in the application process.

"[I] got along well with the interviewer on the phone, during the start of the interview everything was fine. As soon as I mentioned I was on medication I could tell by their reaction that I was not going to get the job."

To not telling potential employers about their experience of mental illness in case they were discriminated against.

"I have never felt that I could bring it to the attention of potential employers. I am in a senior management role at present, and have been for some time. The question 'do you have any prior conditions that may affect your ability to perform this role' has always been very intimidating to me and implies that the employer believes I would not be able to do a job if I answer honestly."

#### Experiences when in a job

During the course of their employment the majority of the respondents reported having negative experiences, with many people losing their jobs due to their experience of mental illness.

"My boss couldn't deal with the fact that I suffer from major depression. She made my job so difficult to do, and the work environment so hostile that I was forced to quit before the depression got the better of me."

Other people left their jobs because managing their mental illness and work was too hard. Many people did not seem to have adequate support mechanisms.

"I hate this because it makes me feel inadequate, dumb and incapable of doing my job."



There were even reports of abuse.

"Because of my responsibility to ensure that I was making safe decisions, I disclosed my illness to him. Within two weeks he seized this as an opportunity by walking into one of my staff sessions. He accused me of not having done this work before and said in front of my staff 'It's because you're mental, we need a team leader that's sane'. I was humiliated and degraded in front of my own team. I ended up back in hospital with two suicide attempts."

Other people experienced work colleagues being reluctant to have anything to do with them, being judgmental, and treating them differently or not as part of a team.

"I was teaching at the time and although I wasn't being discriminated against because no-one knew I had a mental illness, the staff talked about people with a mental illness in very derogatory terms. I took no action."

People's complaints about their employment situations ranged from talking to the employer to taking their case to employment mediation or the Human Rights Commission.

Though there were many negative experiences, a number of respondents also reported good experiences, including 45 percent who had not experienced any discrimination.

## Education and training



#### Figures

- Of the 785 respondents 161 (21%) said they had been discriminated against while attending an education or training course; 478 (61%) said they had not been discriminated against.
- In terms of ethnicity, 22% of NZ European or Pākehā, 18% of Māori and 19% of Pacific people had experienced discrimination while in an education or training course.

#### Experiences

Education and training are often a precursor to a person gaining employment, increasing opportunities and realising potential. Education and training institutes need to be especially aware of their students' mental health needs and be sensitive so as to not discriminate against them.

Most people reported they had not experienced negative discrimination. Many respondents indicated that providers and/or other students were aware, and that they had received excellent support.

"[My] very supportive training facility went out of their way in ensuring I completed my degree in 1999 while I was an inpatient."

Despite all the positive reports, however, one in five respondents reported that they experienced discrimination in education or training, from other students through to the teachers or tutors.

"Other students discussed me as if I wasn't there."

"Once my teachers etc found out that I had a mental illness they immediately expected my marks to drop and my attendance to go down. They set standards for me that were really different from everyone else. I proved them wrong because my marks stayed high and my attendance mark didn't change significantly."

Several people mentioned that their courses lacked any reasonable arrangements to accommodate their special needs.

"I am currently studying ... and up until recently I found it a real battle to keep up my attendance, not because I was lazy or disinterested, this is a dream career for me, but I was suffering from extreme insomnia ... I don't feel I was given enough understanding and support, and I feel it would be very different if my illness was physical."

When having to withdraw from a course, people found the paperwork and the negotiation required were overwhelming, and there was little allowance made for their illness in terms of course fee refunds.

"I was on my first course of [medication] and found it really hard at times to keep up with tests, meetings and eventually I left the course on my own decision. I have wasted a lot of money on student fees when I have been unwell and not treated properly ... I wish I could get my money refunded, with proof that I was unwell and not making sound decisions."

Respondents also reported instances where they were required to prove that they were able to undertake a course of study whereas other students were not required to prove their ability to participate in the same course of study.

It is reasonable to expect education and training providers to make reasonable accommodation for students with experience of mental illness, as stipulated in the Human Rights Act 1993. Unfortunately, such accommodations were inconsistently provided to different groups.

## Housing

#### Figures

- Of the 785 respondents, 136 (17%) said they had been discriminated against in relation to housing; 468 (60%) said they had not been discriminated against.
- In terms of ethnicity, 17% of NZ European or Pākehā, 18% of Māori, and 17% of Pacific people had experienced discrimination in finding or keeping housing.

#### Experiences

Secure housing is a necessity of life. Most of the experiences mentioned related to unfair treatment in the rental market either when people were looking for or living in a house or flat. A few people mentioned living in their own home as a solution for discrimination, although some also mentioned difficulties in meeting the mortgage payments. Both councils and Housing New Zealand Corporation received some praise for understanding the issues for people with experience of mental illness, as well as some criticism for unfair behaviour towards some respondents.

With regard to renting, prospective landlords attitudes were concerning when they learned of the person's experience of mental illness.

"When we were looking for accommodation in [a town], where I was known to have a mental illness, it was very hard to find somewhere so we moved out of the area and I tell nobody in our community that I have a mental illness."

Many people chose not to disclose their illness to landlords.

"I did not let on to the landlord. I felt that they might question my ability to pay rent, not stopping to consider the fact that I am gainfully employed in a profession, and run my own business. But then, they never asked questions about mental illness."

People were evicted or asked to leave their housing by flatmates or landlords. They believed discrimination was the main factor.

"Landlord terminated lease when he found out I was in [named hospital]."

"Asked to move out of flat ... due to my mental illness. July 1998. Flatmates were professional people."

Respondents also mentioned their dealings with Housing New Zealand. Some reported difficulties with Housing New Zealand as an actual or potential landlord; other experiences were positive.

"Housing New Zealand has told me that I was not able to return to my house after getting out of hospital because I would be a risk to people living around me. So does that mean that all people that have mental breakdowns lose their HNZ house after getting out of hospital?"

"In fact Housing New Zealand has been wonderful and fully knowing of mental health."

They said they would like to sleep on it and the next day they said yes. That was a big morale booster and we had a great year together. One or two other landlords have had a fair idea and have been very supportive."

People also mentioned positive treatment due to their experience of mental illness.

"My best experience was answering an ad in the newspaper and going and meeting the two women and I decided I needed to tell them I had bipolar as I had been extremely unwell the year before and I felt this could impact on us flatting together.

### Mental health services and other health services



#### Figures

- Of the 785 respondents, 267 (34%) said they had been discriminated against when using mental health services; 442 (56%) said that they had not been discriminated against.
- When using general health services, 182 people (23%) said they had been discriminated against; 456 people (58%) said that they had not been discriminated against.
- In terms of ethnicity, 35% of NZ European or Pākehā, 37% of Māori, and 21% of Pacific people had experienced discrimination while using mental health services. Discrimination from other health services was reported as being experienced by 26% of NZ European, 18% of Māori, and 19% of Pacific people.

#### Experiences

For people with experience of mental illness, mental health services often play an important role in their lives. They rely on services to help them recover, so the attitudes of people working in those services are significant. Other types of health services also have an important role. Positive attitudes and active support from people working in the mental health profession are vital to facilitating good health outcomes for people with experience of mental illness.

#### Mental health services

Discrimination from mental health service providers can have a devastating effect on people with experience of mental illness. Discrimination includes failing to provide appropriate services and information, providing disrespectful or inappropriate treatment, failing to respect information from family members, or perpetuating stereotypes. These actions damage people's self esteem and limit their recovery.

Discrimination from mental health services took many forms, for example, disrespect, physical abuse, not being taken seriously, being talked about rather than talked to, being degraded and ill-treated, being put down, ridiculed or discouraged, and being treated as incompetent. Some respondents felt abuse was often subtle and specific to an individual staff member; others reported it as being overt and endemic.

"Respect costs nothing. Kindness costs nothing. Abuse and discrimination from mental health service exacerbated my ill-health."

"If I had to rate the worst discrimination I have been subjected to, I would rate mental health services at the top."

Many people noted poor treatment from hospital services for non-mental health problems, including having all symptoms seen as related to the mental illness, having service providers exhibit fear of the mental illness, and being treated as incompetent or drug-seeking. People consistently reported being treated differently from people without experience of mental illness. When the person was seeking treatment for their mental illness in another part of the hospital (usually the emergency department), reported attitudes varied from fear to annoyance for "wasting their time".

"In the mental health service at [named] hospital outpatients department, I am treated as a condition/illness not a person. In the ward I was badly mistreated on a number of occasions ranging from neglect – that is five weeks and not one of the nurses spoke to me. I had meds changed or discontinued without being informed often ending up back in crisis care. And due to a lack of understanding of my disorder I spent a great deal of time being punished – thrown into IPC and being treated like a criminal. The main hospital has been unbelievably cruel in their treatment of me."

#### Other health services

Other health service providers may know that a person has a mental illness. Mental health services are often provided in the same facilities as other health services and general practitioners (GPs) are provided with patient reports. This knowledge increases the likelihood of discrimination.

"My doctor does not fully understand the effects of my illness on me. He thinks if I act normal in front of him then I am. It is a fairly superficial understanding. He is not comfortable in dealing with it so I just keep him happy."

## Government agencies and local government services

#### Figures

- Of the 785 respondents, 211 (27%) ticked the box saying that they had been discriminated against by government agencies; 451 (57%) said they had not been discriminated against.
- When questioned about local government services, 63 people (8%) said they had been discriminated against (68%) said that they had not been discriminated against.
- In terms of ethnicity, 25% of NZ European or Pākehā, 32% of Māori and 28% of Pacific people experienced discrimination from government agencies. For local government services, 6% of New Zealand European, 9% of Māori, and 16% of Pacific people considered that they had been discriminated against.

#### Experiences

Many people with experience of mental illness are customers of a number of government agencies so their relationships with government agencies are important. People reported their experiences with many different government agencies. Work and Income was the agency that most respondents of the survey mentioned. Other government agencies such as the police, courts, the Inland Revenue Department (IRD), prisons and Accident Compensation Corporation (ACC) are also discussed.

The impact of being treated badly by government agencies can be felt widely. Discrimination can affect someone to the extent that they do not take up the benefits they are entitled to. This may subsequently affect their health, their family's wellbeing, and their self-esteem or confidence.

#### Work and Income

Of all the agencies mentioned, Work and Income, or its predecessors, the Departments of Labour and Social Welfare, was cited most often. The discriminatory actions might have been directed to all beneficiaries, however the respondents considered it was due to their illness.

"Work and Income treat mental health consumers like they are all bludging and are putting on an act. I have had a Work and Income worker say you do not look sick to me, but I am high-functioning and do not always show how unwell I am."

"... I went to WINZ one day to sort out my benefit. They just basically ignored me and sent me off without sorting anything out. I know this was due to me having mental illness."

People used various strategies to deal with these attitudes such as taking along a support person or using humour to lighten the situation.

"I experienced discrimination at WINZ. One staff member was quite rude and asked personal questions in relation to my illness. My dad and the staff member had an argument."

"I found humour really good, always taking a joke or something and staff appreciated it. But then I was a really good budgeter so I never had to go beg for anything. Other consumers aren't so lucky."

Although not specifically asked for, some people reported positive experiences.

"Work and Income NZ have actually been very good to me over the years."

#### Police

Most experiences reported by respondents were negative. In particular, respondents felt that the Police did not take them seriously or believe them when they tried to lay a complaint.

"The Police, just after Xmas 2002, I was a victim of an unprovoked assault from my mother's neighbour ... When Police came (I phoned them) I was seriously concussed and spun-out. The first question they asked about me 'Do you have a mental illness?' I said yes. They decided then that they would not charge the assaulter."

A disproportionate number of Māori women reported being treated badly, including experiencing false accusations of criminal behaviour, and aggressive behaviour by police towards them.

However, some people did report good experiences with police.

"Mostly, the police have been very kind, helpful and patient towards me."

#### Courts

People indicated they had experience with the court system because of the Mental Health (Compulsory Assessment and Treatment) Act 1992, criminal charges or issues surrounding custody and access.

"In the Family Court, much was made of my mental health history when I was applying for access to my daughter. Again too much was made of things in the past that were not relevant and psychologists wanted to review it. It is as if they didn't believe me."

A few respondents commented about their experiences with the Inland Revenue Department, the Accident Compensation Service and Prisons. The majority of these comments were negative and related to poor child support and government policy and/or bad customer service.

#### Local Government Services

Few comments were received from people about local government services. This may reflect people not using these services or that they are easy to use without having to disclose experience of mental illness.

"I have never encountered discrimination with government agencies or local government agencies. Then again I have never disclosed my illness in this situation."

Discrimination in these services does not appear common, but this may be because people tend not to disclose their experience of mental illness when using these types of services.



#### Banks, insurance companies and other financial institutions

#### Figures

- Of the 785 respondents 159 (20%) said they had been discriminated against by financial institutions; 491 people (63%) said they had not.
- In terms of ethnicity, 23% of NZ European or Pākehā, 15% of Māori and 14% of Pacific people had experienced discrimination in this area.

#### Experiences

Almost all of us have relationships with banks, insurance companies or other financial institutions. Having a bank account is essential to daily life.

If a person with experience of mental illness runs into difficulties with banks or insurance companies, the entire foundation of their lives can be affected. Financial institutions need to minimise their risk but this does not justify treating people with experience of mental illness poorly.

#### Banks

Bad experiences with banks were most commonly related to poor service (which may or may not have been given to other customers) rather than overt discrimination.

Mortgages were declined because of people's experience with mental illness.

"When purchasing a house I had met all the written requirements of the Bank (personalised for me and my mortgage) and whilst I was at my lawyers finalising documents the lawyer said that the Bank had declined my mortgage (I was not given a reason for this). I can only guess that it was because I was a mental health consumer and had disclosed this in a life insurance application which the Bank requested, or, that I was a beneficiary through WINZ. The lawyer said at the time this could be a case for the Banking Ombudsman. Finally, the Bank agreed to approve."

#### Insurance companies

People may need insurance if they have dependents, are buying a house, are travelling overseas or wanting to insure their income, health or possessions. The consequences of not having insurance can be severe.

The survey shows that many people with experience of mental illness find it hard to obtain insurance, and if they do obtain it, there may be special conditions or higher premiums.

"Insurance companies will not insure me as I have a mental illness and they see me as being a liability."

"Insurance company increased my premium and added clause of no payout if suicide."

"With the insurance company I had a two year stand down period. They intimated that I was a suicidal candidate.'

#### Good experiences

Many people reported good experiences with banks and insurance companies. Some people stated they thought their good experiences were because the bank did not know that they had experience of mental illness.

"Banks are excellent and the Insurance Company was very good as they paid for my new bed and gave me some money to replace what I had lost in the fire."

One in five people with experience of mental illness said they had experienced discrimination in their dealings with banks, insurance companies and other financial institutions. However, few respondents reported taking action when they experienced discrimination from banks or insurance companies or other financial institutions. Respondents considered that the behaviour of staff in these institutions could be improved by training.

## Sports clubs and other organised activities

#### Figures

- Of the 785 respondents, 86 (11%) said they had been discriminated against in sports clubs and other organised activities; 517 (66%) said they had not been discriminated against.
- In terms of ethnicity, 12% of New Zealand European or Pākehā, 6% of Māori and 16% of Pacific people had experienced discrimination in sports clubs or other organised activities.

#### Experiences

Sports clubs and other organised activities provide an opportunity for people to socialise and participate in society. They require the person to make an effort to go along to the activity and join in. When this effort is met with discrimination or hostility a person may be put off from participating.

The effects of mental illness and the side effects of medication were issues for some respondents. Certain medications can reduce the coordination required for physical activity.

"People frowned and shunned me because I suffered from a mental illness."

"Some members of the sports club openly showed discrimination and refused to play me because I am mentally ill."

"With such activities as sports and dancing, my co-ordination problems (part of having Asperger's Syndrome) meant I could not learn the activity as quickly as others. In dancing classes, the teacher became impatient and annoyed with my ineptitude ... causing me stress, and in my finally quitting the activity."

Some people reported good experiences and no discrimination.

"Being able to play with others was cool. We didn't really talk about it, just did it."

"I'm in a gym club - with other people and we get on."

All these activities play a major role in people's lives. When people face discrimination in these areas it can have a major impact. Some respondents who answered this question were clearly devastated by the treatment they had received, and felt that they could no longer participate in their chosen activity.



## Parenting

#### Figures

- Of the 785 respondents, 186 (24%) said they had been discriminated against in their experience as parents; 274 (34%) said they had not been discriminated against.
- In terms of ethnicity, 24% of New Zealand European or Pākehā, 25% of Māori and 25% of Pacific people had experienced discrimination as parents.

#### Experiences

Raising children is an important role in society, and people with experience of mental illness have as much a right to be parents as any other group. Parenting is never easy, but it is made harder when you are experiencing discrimination. All parents face judgments about their decisions and parenting styles from others in the community. Parents with experience of mental illness face added judgments including that they are a danger to children or are inadequate parents, or that their children would be better brought up by others.

The parents in this survey described losing custody of or access to their children, being judged, and not receiving needed support. Fear of other people's judgments meant parents avoided disclosing their illness in case they were automatically perceived as incapable of giving their children appropriate care. They also worried about how their children might perceive them, and were concerned that they did not receive adequate support during periods of illness to allow them to keep and care for their children.

Many parents said their children had been taken away from them by Child, Youth and Family (CYF) or they had been denied custody or access. This had occurred after allegations of child abuse or a perceived inability to care for their children.

"My ex-husband tried to use the fact that I have a mental illness as proof that I was an unfit mother in one of his custody claims."

For other people it was the reactions from children to their parent's mental illness that concerned them. Children often did not understand the issues and judged parents harshly.

"My ex-wife told my children to be careful around me as I might be dangerous. There is nothing I can do except show my children I am not violent which they knew anyway and show them I still love them."

Some respondents reported positive experiences with their children. Education about their parent's mental illness seemed to be the key.

"My two children are wonderful. They are thoughtful, listen when I explain what is wrong, and they are helpful when I need it. Adults could learn a lot."

From this survey, it appears that many people have had their children removed from them after concerns were expressed over care and protection issues, or due to disputes over custody and access where the parent's experience of mental illness has been a primary factor.

## Friends and family



#### Figures

- Of the 785 respondents, 460 (59%) said they had been discriminated against by families or friends; 259 people (33%) said they had not.
- In terms of ethnicity, 61% of New Zealand European or Pākehā, 57% of Māori and 49% of Pacific people had experienced discrimination from friends and family.

#### Experiences

Friends and families are the people with whom we have the most intimate relationships. It is important, however, to remember that people can gain their greatest support and understanding from their friends and family and incur the greatest pain and discouragement from them too.

Rejection by friends or family members was the most often reported form of discrimination.

"All the time, left out of activities. They think it is too shameful to be seen with me, uncool, lack of understanding, hurtful words, actions."

"[It is] just that they [my whānau and friends] do not understand what is going on in my walk with mental illness."

People also mentioned that people avoided them.

"I became mentally ill while I was at high school. The school was really good but my friends (most of them) were too scared to visit me and didn't want to hang out anymore. So I got new friends who were also mentally ill."

People mentioned that sometimes others tried to take control of their lives, not allowing them to make their own decisions or take responsibility for themselves.

"Sometimes they do treat me differently and do not take me seriously. As a result I don't share my problems with them because they won't believe or understand my situation."

None of those surveyed reported taking any direct action against the way they were treated. The most common action reported can be summed up in one statement.

"The action I took was I gave them love and respect with the hope of having it returned."

Out of all 12 areas, discrimination by friends and family was reported most often. Because friends and family are often the closest relationships people have, there is a greater potential for discrimination to occur. Moreover, people tend to expect more understanding attitudes from their friends and family and therefore may be more affected by discrimination by them.

## Community harassment



#### Figures

- Of the 785 respondents, 251 (32%) said they had been subject to hostility or harassment in the community; 455 (58%) said they had not.
- In terms of ethnicity, 32% of New Zealand European or Pākehā, 36% of Māori, and 26% of Pacific people had been subjected to hostility or harassment in the community.

#### Experiences

Harassment in the community and other public discrimination is important because it can make people afraid of being in public, thus severely limiting their lives.

Discrimination in the community was reported in all aspects of public life - by neighbours, passers-by, children and local business people. Some people reported continual harassment and hostility from their community. People reported that the harassment generally appeared unprovoked, although some commented that their appearance might have provoked it.

"Because my first episode of psychosis being in public I've been teased at social events and other things."

"Children have teased me in the street and occasionally in public places."

Physical violence was also mentioned.

"Walking down the street and being harassed and yelled at and hit in the back to wind me up."

A common response to the harassment was to ignore it or modify behaviours to avoid it but not to challenge it.

"I am too afraid to go anywhere by myself because I am afraid of the harassment from people."

An interesting phenomenon was that sometimes the perpetrators of the discrimination were also other people with experience of mental illness.

One aspect that stood out from respondents' accounts was the experience that people had with their neighbours who were often hostile and discriminatory.

Community harassment appeared commonplace. It took place in public, and was sometimes continuous. Rather than people with experiences of mental illness posing a danger to the community, it seemed the community posed a danger to them.

# Fear of discrimination



#### Figures

- Of the 785 respondents, 360 (46%) said they had not done something for fear of discrimination; 323 (41%) said that they had not experienced this.
- In terms of ethnicity, 47% of New Zealand European or Pākehā, 45% of Māori and 42% of Pacific people had not done something because they were afraid of being discriminated against.

#### Experiences

The fear of being discriminated against can have just as powerful an effect as discrimination. This fear can be paralysing, interfering with all aspects of people's lives.

Responses to this question give a picture of the debilitating effects of such fear across all areas. It prevents people from leading full lives.

"I felt I would not be in with any fair chance as I was disadvantaged from the beginning with a mental illness."

People feared discrimination in many aspects of their lives, from employment, to education, in social situations, sports clubs and churches.

"I entered the sex industry because I thought I would find it easier than competing out there with the normal folk."

"I have actually wanted to do courses and get an education but from previous experience and the media discrimination about mental illness really put me off like for example I wanted to look after or teach children but from the media and discrimination of society stop me from doing it."

"Sometimes its fear of not being accepted. I also find it very difficult when people I have just met almost invariably ask "what do you do?" If I don't give a satisfactory answer they press the point and I feel I am being cross-examined without a crime."

"I have stayed away from joining a club for fear my illness will be seen. I am sick of being seen as an illness and not the courageous, intelligent, creative, wise, healthy thinking and skilled person that I am. I am so much more than my illness and I want to be seen."

Many people had not disclosed their experience of mental illness, remained isolated, or had not drawn attention to themselves to avoid discrimination.

"I seldom divulge my experience of mental illness because I fear discrimination. This means I don't feel who I am is entirely okay. I feel ashamed because I don't feel I can be completely open in many situations."

People felt they would have recovered more quickly with other people's support, but the need to watch out for the negative reactions of other people held them back.

"I lead a quiet, mostly unsociable life because I feel so segregated and unaccepted in so many places. I am getting better, but know that because of people's reactions I would have got better a lot faster if I had had support and understanding. It is my biggest hurdle now. I have learnt a lot about myself and others and will continue to grow and learn. I just hope I can bring about a change for the better where other people are concerned."

People were afraid of using mental health services in case others found out they had experience of mental illness. This fear included avoiding general health services.

"Mainly not gone to doctor or phoned nurse/receptionist when wanting to ask something about the children for 'fear' of them misinterpreting scenario and being biased or condescending in their response."

People wanted to complain about discrimination, but were scared of the repercussions of doing so.

"For some time I was scared to speak out about the discrimination that was happening to myself and others due to a fear of being discriminated against. When I did speak up I was subjected to harassment by co-workers."

Some people mentioned that they had overcome their fear of discrimination even when they recognised discrimination was present.

"For years I did not branch out from mental health services circles, jobs and friends. The Like Minds campaign has given me confidence to branch out from mental health services but not enough confidence to put a name to this statement. I am very thankful for what the campaign has done."

"Those who are likely to be discriminatory are nine tenths of the time ignorant of mental health issues, and I feel confident in my abilities to deal with them. That is at the moment though, when I am well."

The stigma that people feel, reflected in this fear of discrimination, is probably the most challenging type of discrimination. Direct discrimination may be dealt with by education and enforcing of anti-discrimination legislation. Helping people overcome the fear of discrimination, however, means also working with people with experience of mental illness so they are no longer afraid. The most effective way of addressing this fear is to reduce the incidence of discrimination so people feel safe.

## Other comments



#### Figures

Of the 785 respondents, 369 (47%) responded to this section. These responses ranged from thanks for being given the opportunity to be part of the survey to more experiences of discrimination.

#### Experiences

Although some people reported good experiences the majority of survey respondents reported negative experiences.

"Discrimination is a fear reaction that can rub off from society and cultural attitudes of those around you and get into your own psyche so that you kind of do it to yourself. Like a critical parent sitting on your shoulders."

The comments included clear messages about what can reduce discrimination with education being the main tool. The Like Minds, Like Mine project received a lot of positive comments.

"The discrimination I have been aware of is not direct not at anyone in particular but comments about mental illness in general made from ignorance due to lack of education."

"I think internalised stigma is a significant thing for me (and probably others). It is something I work on all the time. The Like Minds Campaign has had a big impact on me with regard to this - it has helped me to be proud of who I am and what I have lived through and it is great having role models such as Mahinarangi Tocker and John Kirwan."

The responsibility of the media and health professionals to get their ideas and messages right was emphasised.

"I really wish media would not describe a person by their diagnosis i.e. he was a paranoid schizophrenic."

"It [discrimination] is as bad in mental health services as anywhere else. It is insidious and reveals its ugly head in little comments, oversights and actions."

Discrimination was perceived as being common and occurred in response to widely held beliefs about people with experience of mental illness. Addressing these stereotypes with education was seen as important.

### Analysis of issues reported by Māori

#### Discrimination by whānau

Māori respondents report experiencing discrimination in all areas, but most commonly from whānau and friends. Over a third of tāngata whai ora also report experiencing discrimination, due to their experience of mental illness, from health services (37%), people in the community (36%), and in employment (35%). In order to cope with hurt from the judgements made about them, some tāngata whai ora limited their contact with their whānau and friends. This disassociation was not always a decision willingly chosen by the tāngata whai ora though.

"Parents and siblings do not want to know me or what happened. They are scared of me harming my nieces and nephews. They avoid any kind of communication around mental health. This happened over eight years. I now do not have much contact with them."

The lack of support shown by whānau and friends may be a result of a lack of understanding about how to deal with mental illness. Conversely, being too supportive and over-protective may be equally counterproductive. An example of this is a person being unable to provide for their whānau because of the experience of mental illness and subsequently having financial decisions made on their behalf without their consent or adequate explanation.

#### Other forms of discrimination

Nearly two out of five Māori respondents indicated they had experienced discrimination in health services, including mental health services. This included enforcing heavy measures to make tangata whai ora comply with their medication regimes and threatening tangata whai ora with punitive action for being "non-compliant".

Over a third of Māori respondents reported they had experienced discrimination in the community, and a similar number in employment. This included being discriminated against due to their altered physical appearance as a result of the side-effects of psychiatric medication, such as weight gain.

Many Māori respondents did not feel able or allowed to express emotion like any other member of society, lest it be misconstrued as being due to their experience of mental illness. For example, some tāngata whai ora tried hard to keep their anger at bay, for fear that they may be discriminated against if they portrayed it.

Some tangata what ora chose not to disclose their experience of mental illness to prospective employers because of the discrimination they had experienced in the past when either they had done so, or when others had done so without their consent.

#### Summary statistics

A quarter of all Māori respondents (25%) reported they had experienced discrimination as parents including losing custody of, or access to, their children.

Almost one in five Māori respondents (18%) indicated they had experienced discrimination from government services, particularly Work and Income and the Police.

Almost one in five Māori respondents (18%) reported experiencing discrimination in education. Discrimination may make some tāngata whai ora even more determined to succeed in education, but more commonly they felt disempowered by the discrimination they experienced. Very few tāngata whai ora actively sought assistance to deal with the discrimination they faced in education.

Almost one in five Māori respondents (18%) indicated they had experienced discrimination in finding or keeping housing.

The majority of Māori respondents (85%) reported they had not experienced discrimination from financial institutions.

The majority of Māori respondents (94%) reported they had not experienced any discrimination in sports clubs or other organised activities.

#### Tāngata whai ora aspirations

Many tangata what or a expressed the belief that there needs to be more understanding amongst the community about mental illness. They suggest that the greater the level of understanding about mental illness and its effects, the less discrimination there will be. In particular, it is important for whanau to understand about mental illness.

Many Māori respondents carried hope for a better future, and reported taking positive steps and actions to improve their lives.

A number of Māori respondents made comment about the need for personal acceptance of mental illness. Once there is acceptance, tāngata whai ora can learn to manage it, and in doing so learn to manage the discrimination that society levels at them.

Other Māori respondents refer to time being a great healer.

"You can not help me directly – only indirectly by bringing the community around to thinking and believing that change is both possible, necessary and beneficial to all."

## Analysis of issues reported by Pacific Peoples

#### Context

Pacific people's worldviews need to be considered in any analysis of responses from Pacific respondents. Amongst these are general expectations for structured co-operation and belonging that hold the extended family unit together. The social structures hold strong the norms of internal cohesion, favourable consideration, recognition and accorded prestige in return for blessings for conformity. To opt out is to not contribute to or be part of a family, a community. To bring shame for one's actions or because of one's condition can bring shame to the family unit. For Pacific consumers of mental health services, having one's family unit understand and be supportive can be critical to maintaining their illness management strategies and ensuring successful outcomes in the long-term.

#### Discrimination by family and friends

The most reported area of discrimination was from family and friends (49%). The examples of discrimination ranged from feelings of being avoided by family and friends to openly hostile and abusive behaviour. The examples also showed that discrimination can be localised, coming from certain individuals within the family or friends' network, rather than a common attitude.

Pacific respondents related examples of behaviour from families and friends that appeared supportive on the surface, but could be debilitating in the long term. Not being taken seriously and being treated as incapable of making decisions implies a person has little or no contribution to make to the family group; it diminishes their sense of value and self-worth.

For elderly people, whose 'mana' comes with age and experience (and even a family title) and should be at its highest, discrimination can be doubly hurtful.

#### Discrimination in other areas of life

Discrimination also existed in employment (31%). It ranged from abusive name calling to being ostracised within the workplace. For some, the fear of being discriminated against was enough to prevent them from moving past the application phase. This reduced or eliminated their opportunities to participate in the job market.

Hostility or harassment by people in the community was reported by 26% of Pacific respondents. Examples included a sense of awkwardness from members of the wider community and being "kicked out" of a congregation.

Discrimination from government agencies was reported by 28% of Pacific respondents. Some commented that the discriminatory behaviour could have been influenced by race or physical-impairment as well.

Discrimination in their role as a parent was reported by 25% of Pacific respondents. Issues included the need to hide episodes of illness to protect the children in their care from other discrimination, and that the responsibilities of being a parent and a provider were always tempered by a need to look after themselves.

Discrimination by mental health services was reported by 21% of respondents, while 19% of Pacific respondents experienced discrimination with other health services.

Two Pacific respondents described an increased sense of emotional and cultural safety when information was provided for them in their own language by mental health workers of their own ethnicity.

Pacific respondents noted they had experienced discrimination while they were on an education or training course (19% of respondents), and 17% had experienced discrimination in finding or keeping housing.

Discrimination by banks or insurance or other financial institutions was reported by 14% of Pacific respondents.

The area that rated higher for Pacific than for either Māori (6%) or NZ European or Pākehā (12%) was Sports Clubs and other activities, with 16% reporting discrimination.

#### Pacific Peoples' aspirations

Several Pacific respondents commented on activities organised through Pacific providers that were enjoyable, but that do not seem to be available any more. The sense of routine that regular activities provides for consumers of mental health services also brings with it a sense of comfort and time and opportunity to concentrate on other things other than themselves. Connecting in a supportive environment, especially with same-island groups, gives Pacific peoples a sense of home or nostalgia, an opportunity to make and have reinforced tribal and familial connections, and to provide a sense of place.

There is a paucity of research into Pacific mental health issues, and respondents took the opportunity to advocate on behalf of other Pacific consumers of mental health services. Not all experiences with Pacific providers were positive, however, reflecting the need for continued monitoring and support for these services.

"People in the community need to be educated about mental illness. And people with mental illness should be able to not feel ashamed of themselves, and people in the community should accept people with mental illness with open arms."



## Conclusion

The purpose of this survey was to better understand people's experiences of discrimination. It has achieved this aim. Discrimination, in legal and general senses, against people with experience of mental illness occurs in New Zealand.

Discrimination was reported in a wide range of settings. From organisations with discriminatory policies to the many examples of discrimination by employees of those organisations, members of the public, public officials, health service employees, and family and friends.

The responses described people who were prevented from contributing or had lost their confidence to contribute as a result of discrimination. They described people who could not find a job, had lost their job, were unable to gain the education needed to get the best possible job, or had difficulty obtaining government income support. Some could not contribute to and/or were not supported by their family. Some were prevented from taking part in recreational or leisure activities; others were reluctant to seek or did not receive necessary health services because of health professionals' attitudes.

#### Discrimination by family and friends

The most concerning finding was that more people reported negative discrimination by their friends or family than in any other aspect of their lives. Despite these being the people from whom those who experience mental illness could gain the most support, they were also the ones whose behaviour could hurt the most. This demonstrates the need for education for everyone about mental illness. Education, alone, however, is not the answer. We also need to find more creative solutions to combating discrimination.

#### Discrimination in other areas

One of the issues that permeated every area of life respondents were asked to comment on was whether or not they should disclose their experience of mental illness. There were numerous examples of where disclosure had led to discrimination and non-disclosure by the same person in a similar situation had not. It appears that it is still not safe to be open about experience of mental illness in many circumstances.

Fear of discrimination was another big issue. People reported being afraid to apply for jobs, undertake education or training, or engage in social interactions. Fear held people back from fully participating in society.

A note of hope prevailed in the accounts. In almost every area of daily life people described practices that supported them, or behaviours that made them feel not discriminated against, even though they were not specifically asked for such examples.

#### Discrimination across different groups

The types of discrimination reported by male and female respondents varied. Women were more likely to report discrimination as parents, from health services, and from friends and family. They were also more likely to report fear of discrimination.

The responses of Pacific people and Māori were analysed separately as well as with the other responses. Pacific people were less likely than other respondents to report discrimination by mental health services or to report harassment from the community, but more likely to report discrimination from government agencies. NZ European or Pākehā were more likely to report discrimination from other health services, and banks and insurance companies. Māori were less likely to report discrimination from sports clubs or being in a job, but also more likely to report discrimination from government agencies than other respondents.

The issues reflected in NZ European or Pākehā, Māori and Pacific responses were similar in all but three areas. Although discrimination from friends and family featured as the largest source of discrimination for all respondents, the proportion of accounts of hurt experienced when discriminated against by family was much higher for Pacific people.

One of the issues that stood out for NZ European or Pākehā respondents was the high incidence of "you could get over it if you tried" comments from some people who discriminated against them.

#### Education to reduce discrimination

The nature of the experiences reported suggests that education is still a key factor in reducing discrimination. Many people reported that education did help when faced with discrimination from friends and family.

The accounts of discriminatory practices or at least unfair treatment and derogatory attitudes within government agencies also suggest that the human rights legislation is not applied consistently within the public sector. Front-line staff may require more training or education about working with different people. It is not surprising that those agencies with which more people with experience of mental illness might come into contact were the ones in which most discriminatory practice was noted. Local government was mentioned only in relation to housing, where experiences were mixed.

#### Complaint procedures

Many people could have complained to the Human Rights Commission about the experiences they reported. The few accounts of people taking constructive action against discrimination suggests that more information needs to be provided to people who are discriminated against, so that they are supported in responding to discrimination.

Organisations such as *Like Minds* providers, Citizens Advice Bureaux and community law centres need to be familiar with the legal and other practical actions a person can take if they experience discrimination. As long as few examples of discrimination against people are formally reported, organisations and individuals have little incentive to change their behaviours. In some areas there are no legal remedies if people are discriminated against. In these situations, education, rather than complaints will need to be the way forward.

The findings of this survey do not reflect well on the effectiveness of the human rights legislation. New Zealand society, through its law, has said discrimination is unacceptable, that we respect diversity and that it is okay to be different. The challenge is to find ways to enable us all to live up to these expectations. Utilising the formal complaint procedures and providing support and education would be good starting points.



Working to improve the mental health of all people and communities in New Zealand

#### www.mentalhealth.org.nz

The Mental Health Foundation leads mental health promotion, and works to eliminate stigma and discrimination through the work it provides for the *Like Minds, Like Mine* project.

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For copies of the *Executive Summary* or *Full Report*, contact the Mental Health Foundation's Auckland or Wellington offices. The reports can also be downloaded from <u>www.mentalhealth.org.nz</u> or <u>www.likeminds.govt.nz</u>



*Like Minds, Like Mine* is New Zealand's project to counter stigma and discrimination associated with mental illness and is an initiative funded by the Ministry of Health. For further information about Like Minds project visit <u>www.likeminds.govt.nz</u> and for copies of the *Like Minds National Plan* contact <u>moh@wickliffe.co.nz</u>





Mental Health Foundation of New Zealand



LIKE MINDS, LIKE MINE Whakaitia te Whakawhiu i te Tangata