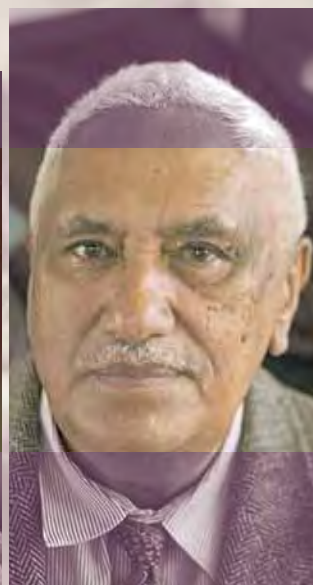


Respect Costs Nothing:



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

2004

Full Report



Mental Health
Foundation
of New Zealand



LIKE MINDS, LIKE MINE
Whakaitia te Whakawhiri i te Tangata

Mental Health Foundation of New Zealand

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Respect Costs Nothing:
A survey of discrimination faced by people
with experience of mental illness
in Aotearoa New Zealand

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Full Report

Written for the Mental Health Foundation of New Zealand by
Debbie Peterson, Lynne Pere, Nancy Sheehan and Gael Surgenor



Working to improve the mental health of
all people and communities in New Zealand
www.mentalhealth.org.nz

The logo features a stylized, overlapping circular shape in shades of purple and grey, resembling a traditional Maori koru or a modern 'M' shape. The word 'Mihi' is written in a bold, black, sans-serif font to the right of the graphic.

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

Acknowledgements

There are many people to thank for their efforts during the course of this research, but most of all we would like to thank all those people who completed the questionnaire. Without them this research would not exist. We acknowledge the time and effort involved and the trust placed in us to do justice to their stories.

The many *Like Minds* providers, consumer groups and individuals who helped distribute the survey, without whom this would not be such a success. The Ministry of Health for the funding and support provided. Belinda Hill for her editing efforts. Fiona North for her extensive contribution to the final report. The survey reference group who provided extensive guidance in the development and the write up of the research. The staff of the Mental Health Foundation for their support and contribution to the research.

Thank you.

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Preface

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.



Introduction

Discrimination prevents people from contributing and participating fully in society. The anecdotal evidence gathered in this report suggests that discrimination is still a major problem for people with experience of mental illness.

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. By identifying where and in what form discrimination occurs, we can better assess what is needed to eliminate it. It is an introduction to the issues for policy makers, service providers and educators. For people with experience of mental illness and their supporters it is an acknowledgement of their experiences.

The specific findings for Māori (tāngata whai ora) and Pacific people are covered in separate chapters at the end of this report.

Background

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. In 2001 this law was extended to cover the government sector. With this legislative support, the incidence of discrimination might be expected to be rare and, indeed, there are few complaints to the Human Rights Commission reporting this. Nevertheless, 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 (Inquiry under section 47 of the *Health and Disability Services Act 1993* in respect of certain mental health services). Its aim is to counter the stigma and discrimination associated with mental illness. Initially funded for five years, to 2001, 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. There has, however, been little research on the nature of this discrimination. The purpose of this report is to shed some light on this area.

The impact of discrimination on people's lives is enormous. It can affect the ability to find somewhere to live, get a job and interact with friends and families. Discrimination can lead to social exclusion, so people cannot participate fully in society. Discrimination on other grounds, such as gender or ethnicity, may exacerbate the situation.



To do something about discrimination, we need to know more about it – where it occurs and how it affects those being discriminated against. This was the purpose of this survey, which was part of the 2003–2005 *Like Minds, Like Mine* National Plan. It is the first national survey about discrimination associated with mental illness in New Zealand.

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

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

Discrimination covers past, present and assumed circumstances. The legal definition of unlawful discrimination occurs in the *Human Rights Act 1993*. Discrimination is only unlawful when it occurs on one of the prohibited grounds (stated in the Act) and in one of the prohibited areas of public life. Other forms of discrimination are also unlawful, including racial disharmony, racial harassment, sexual harassment and victimisation.

Discrimination is defined in the dictionary as unfavourable treatment based on prejudice – an unjust distinction. A person may feel discriminated against even though the offending action does not fit the legal definition of discrimination. In the survey, respondents were not limited to the legal definition but could self define discrimination. This led to some individuals considering something as discrimination that might not be defined as such by other people. Nevertheless, the feeling of being discriminated against existed for that individual, with all the consequent adverse effects on their life.

The survey did not place any time limits on people's experiences, so some people referred to incidents that took place many years ago. This does not lessen the value of these experiences but demonstrates the long term impact they have obviously had on people for them to be recalled so vividly.

Although the survey was designed to collect experiences of discrimination, many people gave examples of positive experiences. For the most part, the accounts collected through the survey establish that discrimination against people with experience of mental illness still occurs. Each area about which respondents were surveyed is discussed in a following chapter. Quotations from respondents capture the nature and effect of the discrimination on people's lives.



Method

Questionnaire

A questionnaire was used to gather the information for the research. It could be completed online or on paper and is reproduced in the appendix. We chose to use a mixture of open and closed questions, so people could reflect on their contribution and 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 by *Like Minds* providers, consumer groups and other people involved in mental health networks. The aim was to get questionnaires to as many groups as possible. Groups and individuals were mailed several copies of the questionnaire and asked to distribute them through their networks. A large non-government organisation sent the questionnaire to everyone on its mailing list who had experience of mental illness. We know some people received several copies through different sources. The questionnaire was printed onto four colours of paper so the distribution and return of forms could be roughly tracked. The survey was also distributed through the newsletter of the *Like Minds, Like Mine* campaign, which had a circulation of over 6000. Approximately 11,000 questionnaires were in circulation.

Response rate

A total of 785 responses were received. Because the questionnaires were distributed through groups rather than individuals, the overall response rate of 11% was low. Half the questionnaires were distributed through the *Like Minds* newsletter with a response rate of only 2%. On the other hand, questionnaires distributed through the non-government organisation had a response rate of 22%.

The low response rate for the forms in the newsletter was because the newsletter's distribution was wider than people with experience of mental illness and some recipients received and used a form from another source. However, the 2% may represent people not easily contacted by other methods.

The response rate from those who chose to reply using the form from the website cannot be calculated, as there is no way to tell who visited the site and then decided to fill out the survey.



However, because the survey's aim was to explore discrimination and obtain more qualitative information, rather than to determine its incidence, the response rate has less significance. 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, three demographic questions were asked – about gender, ethnicity and age. As forms were returned and answers collated, it became apparent that there was low participation from people of Pacific descent. We then targeted individuals with contacts in the Pacific communities and through them increased the response rate from Pacific people. The overall response from Māori and Pacific people was high – with 21% of responses coming from Māori, and 10% from Pacific people.

The question on ethnicity was based on that used in the New Zealand census. Responses were then grouped into four categories according to the ethnicity of the respondent – New Zealand European or Pākehā, Māori, Pacific (including Samoan, Cook Island Māori, Tongan and Nuiean), and Other (all other respondents). The survey instructions asked people to prioritise their choices when they chose more than one ethnic group. Many did not do this, however, so if a person chose more than one category and no preference was stated, priority was given in accordance with the New Zealand census protocol. For example, if a person indicated they were both Pacific and Māori they were classified as Māori for the purposes of this research.

In terms of gender, 57% of those answering the survey were female, and 39% male. There was a reasonable age spread, with 13% aged under 25 and 7% over 60.

Analysis

The survey responses were collated and numbered for future reference. The full responses were entered onto a computer database using EZ-text. This software is designed to handle semi-structured data, such as the information in this survey. The responses were coded, sorted and analysed using a basic thematic analysis.

The responses from all respondents were analysed initially. Māori and Pacific researchers then analysed the Māori and Pacific responses separately. The three analyses were compared to find 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 issues were raised.

Ethical issues

There was a financial incentive of five \$100 gift vouchers offered to encourage people to answer the questionnaire. To ensure respondent anonymity, names and contact details for the draw were separated from the questionnaire before processing. It is possible that some respondents sent in incomplete forms to be in with a chance to win a voucher rather than to contribute to the research.

In a postal survey the researcher can do little to help people if they become upset when filling out the questionnaire. Based on some of the comments received, a few respondents did become upset. Two telephone calls were received from people who had received their questionnaire from the non-government agency. They were concerned about how they had got the questionnaire and whether the researchers had their name or address (which they did not). Those concerns were responded to directly.

Limitations

The responses to this study cannot be generalised to the entire population of people with experience of mental illness. However, this was never the aim. We were more interested in discovering the nature of discrimination or unfair treatment against people with experience of mental illness, than we were 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 we asked people to tell us more about their experiences of discrimination (what happened, when it happened and what action was taken) many people answered only part of the question, often leaving out when the experience took place. From the context of the answers, however, most experiences seemed to take place in the near past, with a few happening many years ago. The fact that they still feel strongly enough about it to recount it years later illustrates the power an experience can have on people's lives.

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. Often we were left wanting to ask more questions after reading a response, but were



unable to do so. We were also acutely aware that for some people a written questionnaire is not the best method to obtain information. We are especially interested in follow-up research with Māori and Pacific people to gain more detail about their stories.

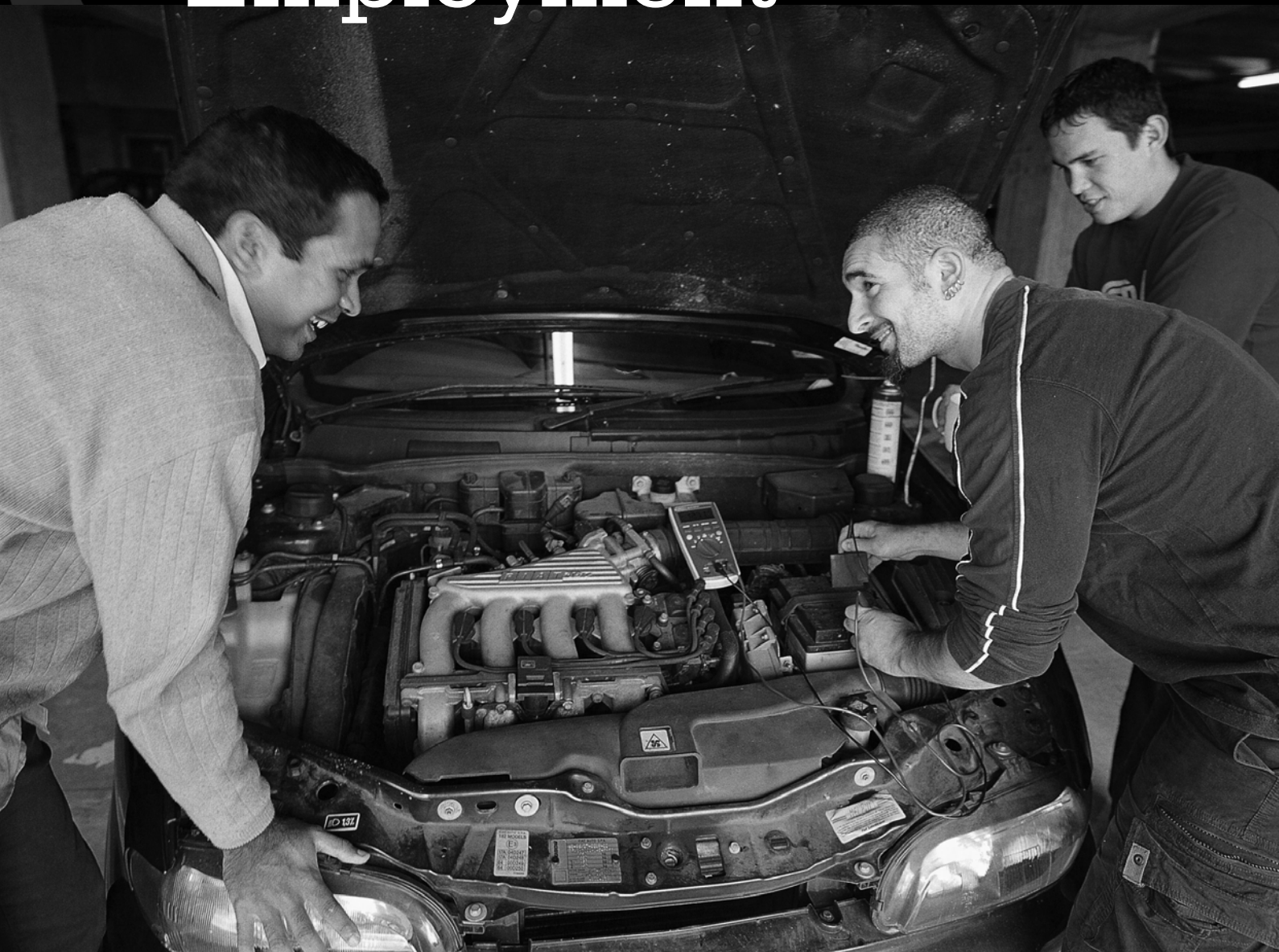
Another aspect, related to using a written questionnaire, was that it is biased towards people with a certain level of English language literacy. Many of the comments received from Pacific people indicated that this may have been an issue.

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. Many of the accounts were about poor service, but poor service, if experienced only by certain groups, is discrimination.

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, however, 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



Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness:

- a) while you were looking for a job?
- b) while you were in a job?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 266 (34%) said they had been discriminated against while looking for a job (33% of female and 34% of male respondents); 354 (45%) said they had not been discriminated against. The question was not applicable for 148 people (19%) and 17 (2%) did not answer it.

- In relation to discrimination within a job, 246 people (31%) said they had been discriminated against (30% of female and 34% of male respondents); 355 people (45%) said they had not been discriminated against. The question was not applicable for 137 people (17%) and 47 (6%) did not answer it.

- The results were similar across the three ethnic groups, with 33% of NZ European or Pākehā, 35% of Māori and 33% of Pacific people who completed the survey having experienced discrimination when looking for a job. There was a greater difference in the results by ethnicity while in a job; 33% of NZ European, 26% of Māori, and 31% of Pacific experienced discrimination when in a job.

Experiences

Employment allows us to gain an income and helps us contribute to society. Most people, including people with experience of mental illness, want to work and will work if given a chance.

The *Employment Relations Act 2000* and the *Human Rights Act 1993*, make it illegal to discriminate against someone on the basis of disability (which includes mental illness) in employment (which includes looking for a job). The survey indicates, however, that many people with experience of mental illness have been subject to discrimination.

Experiences when looking for a job

Some respondents reported that they were prevented from gaining employment because of the discrimination they experienced in the application process after disclosing their experience of mental illness. They had revealed their experience of mental illness in a job interview or on an application form that asked whether they had health problems or a history of mental illness. Some found the questions about experiences of mental illness inappropriate; others found them difficult to answer. The result of a truthful answer was that often the person did not get the job they were applying for.

"[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."



Some people compared their experiences of going for a job when they disclosed their experience of mental illness with their experiences when they did not. Some did not disclose they had a mental illness because of the response they had experienced in the past when they had done so.

"Once I applied for a job – asked me how I handle stress. I revealed a little bit about my past and I didn't get the job. Next day similar job – same question – I answered stress – I go shopping and eat chocolate and I got the job so I rest my case. It is very unwise to tell people you have had a mental illness. I do not let it be known."

Some people wondered whether a question about disability was relevant or necessary.

"I was rapidly dropped midway through interview with large [named] company when I mentioned I had had mental illness, but had okay from psychiatrist to return to work ... two months later I applied to same company for a higher level job and did not mention my mental health history and was subsequently offered the job – the only difference between the two times was their knowledge of my mental health status. Ultimately I turned the job offer down as I did not want to work with a company with such a poor attitude to mental health problems."

Many people felt they had to disclose their experience of mental illness because they were asked a direct question about their health or about gaps in their work history. Some people decided to lie to explain the 'gaps' in their employment record, even though dishonesty could be a ground for dismissal if the truth were revealed. Others found ways to provide the information more discreetly.

"Whilst signing declaration forms for company sponsored medical forms [I] was required to state if you had ever suffered from mental illness. This in itself is reasonable however forms were collected by the company and may well have been exposed to perusal by executive and staff members. I felt this situation gave rise to the possibility of breach of privacy. I resolved the problem by stating NO to previous experience of mental illness on the declaration form, then subsequently contacted the medical insurance company with a confidential amended declaration along with my reasons for having to do so. Am pleased to say this was received in a very understanding way."

Several people decided not to tell 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."

The reactions of potential employers to being told the person being interviewed had experience of mental illness were commented on.

"Job interviewer asked if I had a disability, if yes, what? I told him. He almost ran out the door as if I had some catchy disease. Approximately 45 mins past nearly an hour later a lady came in and said the job was taken."

Inappropriate comments were made by some interviewers; others found excuses not to hire the person.

"I applied for a job and disclosed my illness to the person interviewing me, who promptly told me a story of someone else who had worked for them, with the same illness, who had slacked off. I felt like he was saying he slacked off because of his illness."

Some potential employers asked for medical certificates, even when the person was not seeing a doctor.

"When I was applying and put in CV I was questioned about gaps in employment. When I said why they asked for a doctor's certificate to say I was mentally well. I told them I hadn't seen anyone for mental health for 3 years."

Some potential employers were specific about why they declined a person for employment.

"Applying for a job got application straight back declared mental illness. I did nothing about it thought 'their loss'."

Some people felt that disclosing their experience of mental illness had led to their being offered different employment terms than if they had not disclosed.

"I applied for a teaching job as I am a trained teacher. A few months ago the Head Teacher wrote me a very nice letter but said I would have to go back as a volunteer. I am not willing to go without pay."



Two people had their experience of mental illness disclosed to their potential employer by others, and felt they missed out on jobs because of that disclosure.

"Someone I put down as a referee decided to tell prospective employer that my mental health was too fragile for the stress of the job I was applying for. I didn't get it."

"I was looking for a job as a mechanic – the service manager said I would be okay then the owner of the garage walked up. He knew that I was an ex-patient ... A letter arrived a week later saying the job had been taken."

Two people referred to being unsuccessful in their attempts to take up jobs they had temporarily left because of an episode of mental illness.

"Worked for this firm before becoming unwell then I had the breakdown (bipolar). Left the job temporarily on treatment. Went back to get the job – They said there was none, thus now I am unemployed. My friends were happy to see me back but the bosses weren't."

Experiences when in a job

Many people lost jobs due to their experience of mental illness. If they became unwell when working, some employers told them not to come back. Other people left their jobs voluntarily due to the reactions of their employers or workmates.

"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 cannot say I was turned down from a job or fired from a job because of mental illness, but I have had to quit several jobs because I felt there was no way to work around my illness and stay at work."

One person resigned because their mental illness was not improving despite the efforts of the employer, who had provided sick pay for a prolonged period. The person noted that their employer had a standard process for dealing with sickness including having counselling available.



Some employers saw people with mental illness as potentially dangerous. Two respondents gave this as the reason for losing their jobs.

"I have always come across discrimination while applying for jobs as people do not think I can do it. One job I had ... I was hounded by the charge hand until I left. He told me afterwards that he had a brother who was a paranoid schizophrenic that was considered a risk to the community and he did not want a nut case running around his factory with a knife ... I left and did not seek work again for five years."

At least one employer associated mental illness with a lower level of intellectual ability.

"When someone I worked with said that I would not be able to do a particular computer task, it would be too much for me, and that I was lower functioning compared to other people. A person at work thought that I could not do alphabetical order when filing."

Respondents described the patronising way in which they were treated by some mental health professionals and prospective employers who knew of their experience of mental illness. They were treated as if they needed protection from the pressure, stress and social problems of work.

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

People's complaints about their employment situations ranged from talking to the employer and taking a case to employment mediation or the Human Rights Commission. Reports of complaints about discrimination in employment were few compared with the number of people who indicated experiencing discrimination in the workplace.

"I needed a week's leave due to a breakdown, my boss said 'sort it out and be back on Monday or I will have to let you go'. I could not be back on Monday so I lost my job. I took it to mediation with an Employment lawyer and got a compensation pay out – a small one. I worked there and was their best employee for three and a half years until then."

Employers' attitudes to people with experience of mental illness made some people's working life difficult. People reported employers' lack of understanding or trust and their being considered unreliable or incapable.



"In one job, which caused a recurrence of clinical depression, I decided to 'spill my guts' to my boss to explain how I was feeling etc. He responded with something like 'just pick yourself up and keep going' which is like a red flag to someone suffering from depression. It was difficult for me to speak to an employer about it, so to hear that made me feel very misunderstood."

One of the most abusive experiences noted was by a manager within a mental health provider.

"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 became unwell when I was working at the ... freezing works. The people there did not understand about my illness and they used to give me a hard time about it. I could not do anything about it because there were too many people there. I think the only thing that got me through was the medication I was on."

"Somehow other staff (other than the bosses) found out and wouldn't work with me or even sit with me at morning tea time. When you're honest they will not give you a job and they do not want to know you."

Sometimes a colleague's, an employer's or a customer's attitudes escalated to harassment or disparagement. Respondents indicated that teasing was common.

"I had daily wind-ups, abuse, you name it. I realised I should have left but I tried to be tough. This abuse caused me to become unwell."

Respondents reported feeling hurt or disempowered by this treatment and by their employer's failure to take action when the behaviour was reported to them.

"Verbally abused at work – discussions with managers but no suitable outcome."



One person described feeling hurt when colleagues made derogatory remarks about people who had experience of mental illness, although they did not know a person with such experience was among them.

"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."

Others mentioned receiving unfair or different treatment because of their experience of mental illness.

"When I first developed agoraphobia I had to take time off work – I was told after a very short time that unless I returned to work full-time within a week, my resignation was required. Another staff member who had had a hysterectomy was given more time off and option of part-time work on her return."

In some cases the actions taken by employers to ensure the person with experience of mental illness undertook their work commitments were considered discriminatory.

"They were watching for any mistake I made, and made me sit a practical test (that only students have to do)."

Some people found it difficult to manage their medication while working. Some experienced difficulties due to the side-effects of medication, and some employers made little accommodation. One person did not tell their employer about the effects of their medication because they *"wanted to be like everyone else"*. In one case, changing medication made all the difference – before the change *"people could see that I had a mental illness and would not give me a job"*. After the change, *"they can't tell I have a mental illness and I don't tell them"*. The person reported that they now have held their part-time job for three years.

Sometimes mental health professionals have become involved in people's employment decisions – influencing the person to not attempt a certain type of job or encouraging them when they were less ill. These examples were reported as discrimination, but it was difficult to tell from the brief information given whether the health professional was using their influence to steer the person away from positions that would put their health at risk, or perpetuating a view that a particular job was not suitable for someone with experience of mental illness. In either case, the respondent felt it was discrimination.



One person mentioned that they thought they were unemployable. This seemed to relate to the discrimination they felt from being seen as 'different'.

"I suppose my looks intimidated people when I went for the interview in my first job about 25 years ago. I never went again. I hate the humiliation of being stared at – You wonder what's going on in their heads – I'm now permanently unemployable."

Some people mentioned their experiences undertaking voluntary work.

"In the late 90's when I was working as a volunteer, I was offered a paid position. I then confided in the Manager that I had a bipolar disorder. The next day she told me she was interviewing someone else for the job."

A few Pacific respondents felt they were not being paid equitably or for the work that they had completed – that they were *"expected to work for nothing"* or were misled.

"I was lied to about how long I will be employed for. They did not pay me a set wage".

For some people, discrimination was even an issue in roles set up to combat such discrimination, such as the consumer advisors in mental health services. Most referred to the attitude of other mental health professionals who appeared to struggle with the role of consumer advisor.

"As Consumer Advisor I was left out of clinical meetings in which issues with my colleagues were discussed, with much disrespect for my mates."

Good experiences

Many good experiences were reported. Some people found work they enjoyed and, for some, having experience of mental illness was seen as an asset or a requirement for their job.

"I went to the suggested mental health service provider and applied for a job there – and got it. I have worked there for three years and learned a great deal about discrimination and stigma assigned to mental illness in my position as an employment consultant, both within and without the mental health sector. Conversely I have also met and learned a great deal from those people who do not discriminate (positively and/or negatively) and have had positive experiences from employers and service providers."



Other people described their employer as being kind, as if good employer behaviour was out of the ordinary and unexpected.

Many respondents (45%) indicated that they had not experienced any discrimination while employed, and some specifically commented on this. One obtained a job with a mental health service provider and noted their positive experiences; another noted their employers have made suitable accommodations to the workload.

Discussion

If people with experience of mental illness disclose their experience, potential employers may turn them down for a job. Of the people who reported that they had not experienced discrimination, many may have disclosed their experience of mental illness to employers or colleagues without consequence. From the few positive experiences reported, however, this does not appear to be common. On the other hand people may have avoided discrimination by not disclosing their experience of mental illness.

People reported being asked questions about disability, their mental health history, or medication. However, it is illegal to ask such questions for the purpose of discriminating against someone because of their experience of mental illness.

Many people reported having lost jobs due to their experience of mental illness and employers' attitudes to that experience. Some people had become unwell while working, had taken time off to recover, and then found themselves without a job when their employer found out. Others had left work because of employers' or work colleagues' attitudes. They had been unable to put up with a work environment they felt was discriminatory. Lack of support mechanisms and the nature of mental illness meant some people had to give up their employment. Some people raised the difficulty of working while experiencing the side-effects of medication.

Few people reported lodging official complaints. More needs to be done to ensure people are aware of their rights and the complaints process under the *Human Rights Act 1993* and the *Employment Relations Act 2000*, and have support when lodging complaints. High profile complaints may discourage employers from discriminating against people with experience of mental illness.

Attitudes of employers and work colleagues were also a concern. The reported experiences ranged from people not being trusted, being considered unreliable



or incapable, having difficulties with work colleagues and not fitting in. Sometimes these attitudes escalated to harassment or abuse, leaving the person concerned feeling hurt or unwell.

People also reported problems when undertaking voluntary work. Many people undertake voluntary work for pleasure or as a stepping stone to paid employment. Discriminatory attitudes experienced in this area may put people off applying for paid work.

The attitudes of mental health staff were also important. A person may feel discouraged and inadequate if they want to undertake paid employment, but are told not to by mental health staff. Encouraging people to work may make all the difference in their employment experience. Mental health staff could also play a role in helping people deal with discriminatory experiences and by encouraging people to lay complaints where appropriate.

The experiences reported indicate that people with experience of mental illness may not get the same reasonable accommodations as others in the workforce. Moreover, to gain such accommodations, people need to disclose their history and make arrangements with employers for any special needs. However, disclosing their needs may leave people with experience of mental illness open to discrimination.

The people who participated in this survey reported working in all sorts of paid and voluntary occupations including manual and professional employment. Their experiences show that discrimination occurs across the employment spectrum.

Education and training



Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness while you were in an education or training course?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents 161 (21%) said they had been discriminated against while attending an education or training course (22% of female and 18% of male respondents); 478 (61%) said they had not been discriminated against. This question was not applicable for 130 (17%) people and 16 (2%) did not answer it.
- In terms of ethnicity, 22% of NZ European or Pākehā, 18% of Māori and 19% of Pacific people who completed the survey had experienced discrimination while in an education or training course.

Experiences

Education and training are often a precursor to a person gaining employment, increasing their opportunities and realising their potential.

Most people undertake further education and training once they leave school. This is at an age when people are more likely to develop a mental illness. Education and training institutions need to be especially aware of their students' mental health needs and be sensitive so as to not discriminate against them.

Two factors come into play, discrimination and support. An education provider should consider the support and reasonable accommodations needed by a student with experience of mental illness to allow them to manage both education and illness.

Most people reported they had not experienced negative discrimination. Although some noted that this may have been because they did not disclose their illness to anyone, many respondents indicated that providers and/or other students were aware, and that they had received excellent support from the educational institutions they attended. Support was reported from both the staff and classmates, and included support in the form of not disclosing the person's illness to others. Some people experienced support to complete their education in the mental health field, and others noted that their mental health service provider had supported them during their studies.

"[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. This included discrimination by the tutors and by other students on the course and institutional discrimination. The behaviour of tutors included their treating people with experience of mental illness differently from other students by ignoring or making disparaging comments about



them, or treating them as if they were of lower intelligence. Some reported that this behaviour also affected the behaviour of other students.

Most examples were from tertiary education or after the person had left high school.

"She [the tutor] knows about my mental illness and avoids me. When I speak at the course my words fall on deaf ears. It is as though I don't exist and the others in the group also notice and treat me accordingly."

Other students' behaviour towards them included their being patronised, talked about, teased and left out of activities or discussions. There were specific accounts of sexual and verbal harassment.

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

"When I sat National Certificate in mental health support I didn't tell my class I had experience but someone else did during one of our assignments and I felt my class friends attitudes changed towards me."

One person said the discrimination made them more determined to succeed.

Some people mentioned discrimination by teachers and students that took place at school. Others felt that to stop the harassment teachers were told too much private information. Some people left school due to the harassment, and one person noted that they experienced less discrimination once they were in tertiary education.

"When I was at school and first got ill, my friends completely ostracized me. I was called crazy and a nutter and nobody would talk to me. I tried to resolve this with teachers but I ended up leaving the school."

Some people were refused entry to courses because of their experience of mental illness. Such institutional discrimination was a result of the education provider's policies. The courses mentioned most were those that enabled people to study for a career in a 'helping profession' like counselling or social work.

"Have been told by Polytechnic that [I am] unable to study for Social Work qualifications due to being diagnosed with a mental health problem."

In other cases students who had completed many of the prerequisite requirements for a course were declined entry because of their experience of mental illness. One person felt that if they had not mentioned their illness, they would have been accepted.



Disclosure, and the consequence of this, was an issue for some people trying to undertake education and training.

"I have just started a course but they do not know I have a mental illness because I have not told them. I haven't as yet experienced any discrimination."

People mentioned their illness affecting their performance in class. Illness made them less able to manage, but support during the illness would have made a difference.

"Again, I have had to quit training programs because I became ill. Is it discrimination that there were no services to support me so that I could stay in school?"

Several people mentioned that their courses lacked any reasonable arrangements to accommodate their special needs as a person with a disability. Little support was available for people with experience of mental illness.

"Doing a University Masterate, I was not given access to reasonable accommodations that others with physical disabilities were given."

"When I was at university and had many periods of instability there was no additional support or accommodations available to me – or any staff designated to assist people with disabilities."

Several people became unwell while they were on their courses and mentioned a lack of support available to them to complete their courses.

"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."

One student acknowledged, however, that the presence of a support person could exacerbate an already discriminatory environment – highlighting their "different-ness".

Several people had to stop studying because of their mental illness or others' attitudes towards their mental illness. They found dealing with other people's attitudes too difficult, with little support. Few people mentioned seeking such help.

When having to withdraw from a course, people found the paperwork and the negotiation required were overwhelming, particularly if the person was unwell. One



person "simply gave up on the forms ... I will have 'fails' which will then have to be explained to future employers." Others noted there was little allowance made for their illness in terms of course fee refunds. They were left with a student loan but no qualification if they had to withdraw.

"I was studying at [a tertiary institute] ... They had a 7 day refund policy. I ended up in hospital 'couldn't be in two places at once'. I was withdrawn. Anyway, I am left with a student loan, no education due to being unwell. They wouldn't compromise with a discount or provide me with what I enrolled for."

Some education and training providers' application forms linked mental illness and criminal behaviour. Other providers excluded students from activities that were a required part of their course because of their experience of mental illness.

"I am currently in my third year of nursing and have just been refused a placement (from a mental health provider) because of my illness."

Steps that other students did not have to take were required of some people with experience of mental illness to be accepted on or complete their courses, for example, additional interviews. While the provider may have thought these interviews would help make sure the person did not fail, they were seen by some as inappropriate.

"Initially I was told that I would require psych evaluations prior to re-enrolment"

"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."



Discussion

People undertake education and training to improve their qualifications and enhance their career. It can be hard to balance undertaking a course with dealing with the effects of mental illness, and this is made more complicated when other students and the course administrators treat people unfairly because of their experience of mental illness.

Many people talked about leaving their course as a result of being patronised, put down, treated differently and excluded from parts of a course. Others left because they could not do the course and deal with their mental illness at the same time. Forfeiting their course also meant forfeiting their future career plans.

Some discrimination appeared to be sanctioned by the institutions, such as refusing entry to some courses and denying places on certain required placements to people with experience of mental illness. People seemed to experience these difficulties more with courses such as social work or nursing. People also reported overwhelming paperwork when they had to withdraw. Many students were left with a substantial debt, but no qualification.

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

Housing



Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness in finding or keeping housing?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 136 (17%) said they had been discriminated against in relation to housing, (17% of female and 18% of male respondents); 468 (60%) said they had not been discriminated against. The question was not applicable for 163 people (20%), and 18 (2%) did not answer it.
- In terms of ethnicity, 17% of NZ European or Pākehā, 18% of Māori, and 17% of Pacific people who completed the survey had experienced discrimination in finding or keeping housing.

Experiences

Secure housing is a necessity of life. Most of the experiences mentioned by people in the survey 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. Discrimination that occurred when people first bought their own home is covered in the chapter discussing banks and other financial organisations.

Few responses came from people living in supported accommodation, and none mentioned their being discriminated against in respect of housing (they possibly saw supported accommodation as a health, rather than housing service), although one mentioned the resistance of neighbours to supported housing being established in their neighbourhood.

Both local bodies 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.

Some respondents found it difficult to find housing. Prospective landlords had overt changes in attitude when they learned of the person's experience of mental illness. At other times the discrimination could have been attributed to having a low income or being on a benefit.

"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.



"Why would anyone tell their landlord their health issues? It's just not necessary so it has never applied to me."

"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."

Some people attributed difficulties finding accommodation to being on a benefit, rather than because of experiencing mental illness.

"Our landlord gave us notice to vacate premises so we registered ourselves with [rental agents], but in the forms we fill up there is a clause where do you get your main income from?, we were honest enough to write – sickness benefit but our forms were never ever forwarded by the rental managers to the landlords concerned despite having a good credit history, goods references, timely payments etc ... The Real Estate Rental Managers have not even called back."

Landlords attitudes, once they knew the person had experience of mental illness, were concerning. Some people were disparaging; others outrightly discriminating – they *"didn't want someone with a mental illness living in their flats"*. One person was accused of having a mental illness.

"One landlord said to me 'what have you got to be depressed about? You need to go out and find a good man.'"

Some people mentioned having to go through steps to gain accommodation that they believed people without experience of mental illness would not have had to undergo.

"[City council] housing – applicants with mental illness are required to provide an extra reference saying what supports they have."

"The [city council] insisted on the medical certificate for any psychiatric disabilities had to be done. They told me it was for risk management and nobody but the psychiatric nurse they employ would see it."

Some people considered it harder for people with experience of mental illness to live independently, maintain the upkeep on a house or keep flatmates.



"The goal is live independently but due to circumstances with having a [mental illness] I am living with other people until such time I am able to move on."

For some the issue was not finding accommodation, but keeping it. Paying the rent or mortgage was a struggle, especially for those on benefits.

"I have found accommodation without any problems. The issue for me is the fact I have to rely on a benefit and the accommodation supplement to afford to pay my rent."

People were evicted or asked to leave their housing by flatmates or landlords. Although, the reasons given for this differed, people stated they believed discrimination because of mental illness was a 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.

"Housing New Zealand have 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."

Some experiences with Housing New Zealand were positive.

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

Many people owned their own home, although this was the case mainly for those that identified as NZ European or Pākehā. Often the home had been left to them by a deceased parent. Many people also lived with their parents or in their parent's house.

"Still live with my sister and family. The children have grown up but I used to look after them when young – now they look after me."



The other main difficulty people mentioned was their ability to maintain the property. Some people had lost their accommodation because they were not able to keep it in good condition. While this may not have been as a result of discrimination, it may have occurred because they did not receive sufficient support when they were unwell. Such support is not unreasonable, since it is provided to some people with physical disabilities.

Flatmates' attitudes were also concerning. Some could not cope with living with a person with experience of mental illness.

"Mainly flatmates in flatting situations when mental illness first appeared. Had to leave several situations as flatmates could not cope (or did not want to) with symptoms of my mental illness."

Some neighbours harassed people when they learned they had experienced mental illness, but one person reported that their landlord had supported them against this behaviour. Some situations were nearly intolerable, with harassment occurring at all hours – a relentless pressure on people to move.

"Neighbours were friendly at first contact. After discovering our experience of mental illness we were ignored, talked about and sometimes complained about indirectly. If we made noises we would be reported to noise control. If other neighbours did the same nothing was done. Some complaints were made to the Council saying they were not safe or feeling safe because of the nutty neighbours."

One person had a positive experience when moving into a new house, being told by a neighbour that the people next door were *"ex-psychiatric patients but not to worry because they were nice and not at all dangerous"*.

Another person recounted attending a public meeting organised in objection to supported housing. The meeting was *"vicious, nasty and frightening for anyone who might have the slightest hint of mental illness"*.

People also mentioned positive treatment due to their experience of mental illness, for example being moved further up waiting lists for certain types of housing, and obtaining extra support.

"Because I am a psychiatric patient I am able to have a house cheaply and a lot of support."

"For the majority of time I have lived in supported accommodation, however when I left I was moved up the list for flats, my illness working for me."



People recounted positive stories about landlords being aware of their experience of mental illness and supporting them.

"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. 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."

Discussion

It is important people have secure and affordable accommodation. Without it, people find it harder to cope with other tasks such as finding a job. It is disturbing to read accounts of people being evicted or asked to leave their accommodation due to their experience of mental illness. Discrimination on the basis of experience of mental illness when renting a house is unlawful under the *Human Rights Act 1993*. People reported being required to prove they were "well" or "supported" which is also questionable under the *Human Rights Act*.

Attitudes of neighbours and landlords were also concerning. When people disclosed their experiences of mental illness they were often treated negatively and seriously harassed.

Some people owned their home. They saw ownership as preferable to dealing with landlords, but mentioned responsibility for maintenance and upkeep as sometimes being a problem, along with difficulty paying the mortgage.

Some people experienced positive discrimination by being moved up housing waiting lists. But others faced extra difficulties when it came to council housing, having to prove they were well enough before they could take advantage of the services.

Mental health services and other health services



Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness:

- a) with mental health services?
- b) with other health services?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 267 (34%) said they had been discriminated against when using mental health services (36% of female and 34% of male respondents); 442 (56%) said that they had not been discriminated against. This question was not applicable for 48 people (6%), and 17 (2%) did not answer it.
- For the second question, 182 people (23%) said they had been discriminated against by other health services (27% of female and 18% of male respondents); 456 people (58%) said that they had not been discriminated against. This question was not applicable for 71 people (9%) and 76 (10%) did not answer it.
- In terms of ethnicity, 35% of NZ European or Pākehā, 37% of Māori, and 21% of Pacific people who completed the survey had experienced discrimination while using mental health services. For the question on discrimination from other health services, 26% of NZ European, 18% of Māori, and 19% of Pacific people had experienced discrimination.

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 by people working in the services encourage people with experience of mental illness to use these services and have their physical health needs met.

People need to be able to trust the health services with which they have contact and be treated with respect. If people with experience of mental illness are not considered credible and their health complaints are disbelieved, their overall health is put in jeopardy.

Mental health services

Discrimination from mental health service providers can have a devastating effect on people with experience of mental illness. They may be reluctant to access services even when they really need them. Reported discrimination included failing to provide appropriate services and information, providing disrespectful or inappropriate treatment, failing to respect information from family members, or perpetuating stereotypes (such as the view that people with experience of mental illness cannot recover). These actions damage people's self esteem and limit their recovery.



"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."

Discrimination from mental health services was described as taking 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.

"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."

One person noted.

"I was too unwell to respond appropriately at the time. But I realise I should have laid a complaint through appropriate channels."

Insensitivity of some staff to cultural differences, like the need to attend tangi or involve family, was noted.

People complained that they did not receive appropriate help for their mental illness. Examples provided by respondents include a succession of new staff unfamiliar with their details, service provider preference for using medication rather than counselling, no access to Pacific staff for Pacific people with experience of mental illness and compulsory day programmes.

"I have been told on a few different occasions that I was not sick enough to receive help."

One person said that laying a complaint against mental health staff made things worse.



"When I made a complaint to [a provider] about a psychiatrist they took three months to investigate, never asked me for my input, then sent me a standard letter stating that due to the fact I was an inpatient at the time, that I probably misinterpreted what had happened. I have seen almost identical letters sent to other consumers. I was insulted but gave up trying."

Two respondents noted that services specifically responsive to individuals with personality disorders were required.

"Mental health services are the worst discriminators of all against people like me. No wonder so many of us are in jail."

The lack of family involvement in treatment was an issue for some respondents. They were concerned that the family members' knowledge of the person was discounted in favour of the health professional's view.

"My family were not listened to or consulted during the course of my treatment in acute services."

One person had (albeit years ago), received a poor prognosis, which had a major effect on their life, leaving them with little hope for the future.

"They said that I could not have the dreams I had when I was 20, and there would be some things that I would not be able to do, this really hurt me."

Several people implied that medical decisions they did not agree with were discriminatory – perhaps because the decisions had not been well explained to them or that they were not involved in making them. Although some referred to trying to address these decisions through channels such as the Mental Health Review Tribunal or by laying complaints with the service, no-one reported positive outcomes. This may have been because no outcome had yet been reached or that the outcome had not been favourable, but the inference was that no action had been taken in response to their complaints.

Some people did mention that they had had good experiences when using mental health services including that they had received good service, the service quality had improved, or that access to culturally appropriate services were available.

"In the past I found staff in hospital lacking knowledge and understanding of my illness therefore I was badly treated. I am glad to say that this has changed over the years and most staff are a lot more understanding."



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 and was reflected in the responses.

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".

People cited difficulties in dealing with GPs, especially about mental health issues. This included poor attitudes, a tendency to attribute all problems to the mental illness, and a lack of skill to treat people with experience of mental illness. The poor attitudes of chemists, dentists and physiotherapists were also mentioned. Another mentioned the difficulties of having an experience of mental illness in prison, and receiving unfair treatment from the prison health professional.

"I sometimes feel explanations I am given are over simplified and when I question further am 'brushed off'. My problems are with my mind not intellect. I have recently changed GP. The first one was great while I was unstable however I feel he puts all of my problems in the mental health box so I have since changed."

Some people said they were seen by health professionals as people with experience of mental illness, and only then in terms of the medical condition for which they were seeking treatment.

"When you go to A & E or to your GP about a medical problem they invariably ask if you want the crisis team involved, or put it down to your mental illness. I have changed to a better GP and prepare myself when using other services. If you require medical treatment they tend not to put you in an open ward. You are either separated from the other patients or put in the psychiatric ward and treated from there."

The poor attitudes of some health professionals led to inappropriate medical treatment for some respondents when they were treated for their mental illness instead of their physical illness.



"Because I had a history of mental illness, the doctors didn't believe me when I had an ectopic pregnancy. They thought it was all in my mind. I needed surgery once I got MYSELF into hospital. Similar treatment when my baby got gastroenteritis."

Other people reported being treated like children or as if they had lower intellectual ability.

"They look at you differently because I have schizophrenia and speak to me like an intellectually handicapped person. Spoke to me roughly because they have to repeat often. They do not understand I have other voices happening in my head and collating information can be sometimes frustrating so they get stroppy when repeating conversations. But you don't tell them there are voices because they don't understand."

Respondents reported dealing with poor treatment in various ways. Some did nothing.

"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."

Others laid complaints. Many of the people who laid complaints were dissatisfied with the complaints process.

The failure to act on complaints and the consequences were reported.

"I complained about my experiences and was not listened to. I was subjected to further abuse. I don't believe that the complaint process works for mental health consumers. We are not believed because we are mental health consumers. This causes a lack of accountability which stops services getting better."



Discussion

Many respondents reported inappropriate attitudes, unfair treatment and abuse from mental and other health services. These attitudes and behaviours were described as discrimination and in some cases, the results of such experiences were life threatening.

It could be expected that mental health professionals would be the most sensitive in terms of their attitudes and behaviour, because they have better information about and greater experience with people with experience of mental illness. However, the survey responses suggest this is not always the case.

Compulsory mental health treatment gives mental health professionals power over people with experience of mental illness. If this power is misused people will feel they have been treated unfairly and report discrimination. One option to reduce the feeling might be to give people sufficient information, when well again, about the reasons for treatment actions taken when they were acutely ill.

In other health services, some discrimination took the form of people being treated as if their mental illness, not physical illness, was the cause of their problem, as if they were children, or as if they were unable to understand the issues involved in their treatment. These attitudes were reported from people using hospital and general practice services.

Government agencies and local government services



Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness:

- a) with government agencies (eg. Work and Income, the Police, Courts)?
- b) with local government services (eg. libraries, swimming pools)?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 211 (27%) ticked the box saying that they had been discriminated against by government agencies (26% of female and 29% of male respondents); 451 (57%) said they had not been discriminated against. This question was not applicable for 91 people (12%), and 32 people (4%) did not answer.

- For the question about local government services, 63 people (8%) said they had been discriminated against (6% of female and 10% of male respondents); 536 (68%) said that they had not been discriminated against. This question was not applicable for 107 people (14%) and 79 (10%) did not answer.

- In terms of ethnicity, 25% of NZ European or Pākehā, 32% of Māori and 28% of Pacific people who completed the survey had experienced discrimination from government agencies. For local government services, 6% of New Zealand European, 9% of Māori, and 16% of Pacific people 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. For those who depend on a social welfare benefit, a level of trust must be formed with Work and Income. The police are a necessary societal safeguard. If they are needed, it is important for people to be able to have some credibility with them and that they are treated with respect. The same is true with other government agencies such as the courts, the Inland Revenue Department (IRD), prisons and Accident Compensation Corporation (ACC).

As a result of the questionnaire identifying three specific organisations, respondents tended to focus their replies on them. Therefore, results should be interpreted carefully. These organisations may treat people with experience of mental illness no worse than other organisations.

People have a right to equal access and treatment when using local government services such as swimming pools, libraries and public transport.

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. Such experiences can lead to an expectation that all government agencies will treat people with experience of mental illness badly.



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. However, this may be as a result of it being specified in the questionnaire, so results should be interpreted with care. Although the discriminatory actions witnessed from Work and Income staff might not have been directed at people with experience of mental illness specifically but to all beneficiaries, most respondents thought that it was due to their illness.

"... I went to WINZ one day to try and 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."

"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."

People used various strategies to deal with these attitudes.

"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."

Sometimes taking a support person proved effective.

"I had to take [a] clinical nurse [with me] to make sure I had received all my entitlements because when I went by myself it was frustrating, because I could not understand where they were coming from, and I could not relate or understand them either."

But not always.

"The girl who dealt with me addressed all her conversation to my supporter, ignoring me. I made an official complaint."

A requirement for the client to take a support person to meetings was seen as discriminatory.



"... a stand-in case manager came down heavy on me when I turned up by myself for an appointment. She blew me up and said I should have gone there with a support person. That was news to me as I had never gone there before with a support person. I had always done my own business and am quite capable."

One person referred to downplaying her experience of mental illness to avoid discrimination when interacting with Work and Income staff. She implied this coping mechanism had become almost second nature to her now.

Although the relationship between client and case manager was seen as particularly important, some people had difficulties with their case managers so took action against them or enlisted help.

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

Intervention or complaint sometimes resulted in a change of case manager.

"I was unemployed and had told WINZ advisor that I needed a low stress job due to my suffering from anxiety in high pressure situations. She called me in one day for an ideal job she had found for me on her database – DEBT COLLECTOR. I ditched the case manager and found another one."

Several respondents referred to being inappropriately treated by Work and Income staff who did not understand the effects of mental illness or medication. For some, the result was to become unwell.

"In the beginning [they] were not tolerant of my behaviour. I was asked to wait [and] others [were] served before me [so] I up and left. When I returned they told me to make another appointment. This going backwards and forward stressed me out real bad. I got sick again."

People expected the agency to help them find work. However, sometimes they were actively prevented from applying for jobs or directed towards unsuitable jobs.

"... WINZ seem to find reasons why I should not apply for jobs ... I have physical problems ... and they continually push me to apply for bushmen and stone-mason positions. I look for work through other means, not involving WINZ."



"Work and Income refused several times to let me apply for job vacancies as I wasn't on the unemployment benefit."

On the other hand, some people were encouraged to find jobs when they felt they could not hold one down because of their experience of mental illness. One person felt their case manager should have checked with their doctor or counsellor about their emotional state before reducing their benefit. Another said the effect of their illness was not properly taken into account.

"Work and Income are the worst especially if you are agoraphobic and you can't make it to an appointment. I've also about a year ago been pressured to go to job interviews I know I couldn't handle – when you tell them you have a mental illness they think you are lying or they start talking to me like I am a baby. I felt like I couldn't do anything about it because who are people going to believe – the govt agency or the nutcase?"

Some people's mental health deteriorated as a result of the treatment they received.

"My normal case worker was on holiday and the case worker I saw was quite abrupt and rude to me, making me feel worthless and suicidal. I was severely depressed at the time. It happened in 2001."

Some staff made damaging assumptions.

"When looking at enrolling for full-time study ... I spoke to a local ... case-worker (not mine though) about staying on the invalids benefit or going on a student allowance. I was asked if I had spoken to my doctor about studying and the lady from WINZ stated 'I know people like you have times when you seem OK but ...' It was said in a very derogatory way. When I got off the phone I was starting to doubt my own ability to manage."

Benefit abatements and other rules caused difficulty for some, especially for those who wanted to work. One person mentioned special benefit money being directed to an accommodation provider, rather than paid to them.

"... the 15 hour per week policy makes it difficult to move from the Invalids Benefit to full time work ... I was not sure about how I would perform and if I could handle full-time work."

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

A number of respondents felt that police did not take them seriously or did not 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."

Other people reported police ridiculing or verbally abusing them.

Police are often called in to take people with experience of mental illness to hospital in accordance with the *Mental Health (Compulsory Assessment and Treatment) Act 1992*. How police fulfil their role can leave a lasting impression.

"The Police took me to hospital in the police car while I was dressed in my pyjamas. They did not let me have a lawyer before taking me to hospital. No sympathy. They make me feel like a criminal with a police escort. No rights."

A disproportionate number of Māori women reported being treated badly, including experiencing false accusations of criminal behaviour, and aggressive behaviour by police towards them. Some people described being physically handled or having the effects of their mental illness and their need for medication misinterpreted.

"Police used unnecessary force and comments when I was unwell and hearing voices."

"I have had involvements with the police because of my illness and I have been treated like a criminal more than a person who is sick. Laughed at me and were physically harsh with me."

Some people approached by the police about criminal matters implied police processes were not well explained or understood. If people with experience of mental illness are not given the information to which they are legally entitled, because of their experience of mental illness, this is discrimination.

I was charged with a minor offence – not drug related, and I have never taken illegal drugs and told them I had a mental illness when I was being held in custody and needed my prescribed medication. I was then stripped searched by the Police."



To be effective, some medication must be taken regularly. A failure by police to understand this can impact badly on a person's health.

"I was once in trouble with police and spent a night in the cell, I was not given my meds."

Some people did report good experiences with police.

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

"According to doctors when admitted or readmitted they said that the Police had given me a hard time. This to me was not true and the doctors were giving me more of a hard time than the Police were. I had by then been once or twice at the Police Station."

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.

One person thought they had been discriminated against because of being held under a compulsory treatment order.

People described having their history of mental illness brought up and being discredited in the Family Court. Discrimination was reported in relation to access and custody of children.

"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."

In relation to criminal proceedings, people mentioned having their crime attributed to their medication, being required to have a psychiatric assessment, and their view of events having no credibility due to their experience of mental illness. Credibility was also mentioned as an issue in civil actions.

"The court system allows at the depositions for defence lawyers to question victims about their psychiatric history in great detail in an attempt to discredit the victim/witness. In my case it continued for one and a quarter hours and included medications, total number of admissions if compulsory treated or not. At present I am looking at going to the Law Society."



Sometimes the courts took into account the person's experience of mental illness when making decisions.

"In the court the judge said in likes of my condition that I might not have understood the question. This was after I was over my experience."

One person felt their court appearance could have been avoided if they had received appropriate help earlier.

Prisons

Only two people mentioned their experience of being in prison. One noted there was no support through their internment in prison, and little psychiatric input from the medical prison staff who did not have the required knowledge. The other reported more open discrimination.

"... some prison staff were openly abusive and treated taking medication as a joke or threatened to have me locked up in isolation if I was feeling a little down as what happened when the medication was changed. I could not think straight and became completely confused. To some I was good for a laugh by making fun of my confusion. I could do nothing and complaints were often dealt by the person I complained about with veiled threats."

Inland Revenue Department

Respondents who mentioned the Inland Revenue Department noted issues around child support and government policy rather than individual staff behaviours.

Accident Compensation Corporation

Complaints about the Accident Compensation Corporation (ACC) mainly related to bad service. One person specifically said that they had been discriminated against due to their experience of mental illness; another felt pressured to get back to work early; others had problems with assessments.

One person however, reported good service from the ACC.

"During the time that I was on [accident compensation] I found my case managers to be exceptionally kind and supportive. They were certainly not pushing me to a quick recovery as I have heard stories about ACC."



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 at swimming pools was reported, including "funny looks" from staff members, and feeling unwanted.

"Thought [Like Minds, Like Mine] article on [discrimination at] swimming pools was tame to what I experienced Oct 2001. Never been back. Rivers are free (but cold)."

Few examples of discrimination in libraries were received. One person noted that staff need to be more patient and another said they had been refused service, so would not go back. One person mentioned they had difficulty accessing mental health resources from a library because they were in a small rural community and were afraid of the reaction they would receive. Positive comments were made about how supportive libraries were and how people had not experienced any problems.

One person mentioned their experience with buses.

"Bus drivers can be a real pain if I am slow and have to take time over stating my destination and calculating the appropriate fare."

One person mentioned the difficulties of living in a small community and the problems that arise accessing local government services.

"Often because I live in a small community everyone knows I am a mental health consumer, local government department eg. district councils often treat me like I'm stupid and can't grasp concepts or understand things."



Discussion

Most comments about government agencies were about Work and Income, although this is not surprising because it was specifically identified in the questionnaire and it is the government agency (outside of health services) that people with experience of mental illness come into contact with the most. There are changes happening however. Work and Income is currently developing a strategy which places an emphasis on improving the way their staff work with people on Invalids or Sickness benefits. This would include a large number of people with experience of mental illness.

Apart from poor service, there were two other main issues mentioned in the survey: not being taken seriously because of having experience of a mental illness, and not receiving service tailored to the individual (for example, by being told to look for work when the person did not feel able or wanting to look for work but the agency discouraging this).

A few people reported that they had not been discriminated against but implied that this may have been because the government agencies were unaware they had experience of mental illness. The tone of the comments suggested that the non-disclosure was intentional.

One Pacific person reported being too overwhelmed by the number of people at government agencies, to visit their premises. The particularly Pacific concept of shame, or losing face was also reported. The feeling of cultural and emotional unease felt by Pacific respondents underlies this sense of shame and is a reminder to agencies to provide emotionally and culturally safe environments for Pacific people, so they can make best use of their agency's services.

Few people reported discrimination by local government services. When they did, the discrimination occurred in swimming pools and libraries (probably because these were the examples given in the question), and public transport.

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

Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness with banks or insurance companies or other financial institutions?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents 159 (20%) said they had been discriminated against by financial institutions (20% of female and 21% of male respondents); 491 people (63%) said they had not. This question was not applicable for 111 people (14%) and 24 (3%) did not answer it.
- In terms of ethnicity, 23% of NZ European or Pākehā, 15% of Māori and 14% of Pacific people who completed the survey 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 if people are to participate fully in society. Without a bank, a person cannot invest their income, buy a house or receive welfare payments. Without access to finance it is impossible to participate in education or employment. Insurance companies help people to manage the risks in their lives.

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. It is possible to lay complaints with the Banking Ombudsman or the Insurance and Savings Ombudsman but there was no evidence from the survey that people actually did this.

Banks

Bad experiences with banks were most commonly reported within the financial sector, with most of the comments related to poor service (which may or may not have been given to other customers) rather than overt discrimination. However, those experiences may have felt like discrimination to the person experiencing them or affected their ability to access financial services. Because people's experience of mental illness may lead to unemployment and/or low incomes, poor treatment of people on social welfare benefits or low incomes may impact disproportionately on people with experience of mental illness.

Staff attitudes caused problems for many people, including "extreme prejudice", suggesting staff need more training for dealing with people with experience of mental illness.

In other cases, people felt the bank's policy of, for example, asking about a person's health was discriminatory.



"My husband and I had business at the bank and one of the forms asked whether or not we had received psychotherapy. I felt this was irrelevant to our business and I also felt it was an invasion of our privacy."

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."

Being a long-time customer of the bank did not always help.

"They wouldn't give me a mortgage even though I'd banked with them for over 20 years ... I did get one from the [named bank] with the help of a mortgage broker."

Two people described their experiences with banks that resulted in mortgagee sales.

"When I was invalided out of work due to mental illness the bank refused to make allowances for the mortgage and effectively made it necessary to sell the house. I acknowledge that this was not specifically due to mental illness but illness in general."

"I fell behind on mortgage payments while waiting for an income insurance policy to 'kick in'. It was obvious that once the insurance money was available I would be able to keep up with the payments. The [named bank] insisted the house be sold by a deadline. My life savings were wiped out as I had no choice but to sell the house at a huge loss."

One person reported a negative experience after disclosing their experience of mental illness.

"Refused a cheque account with a bank when I said I was mentally ill."

But another reported a positive experience.

"Applied for a \$5000 graduate loan (2000). Disclosed my illness and was still accepted, bank officer was supportive, did not phase him."



Several people thought their experiences with banks had been influenced by their receiving a benefit rather than their experience of mental illness.

"Manager was surprised how nice and normal I was when applying for a mortgage on an Invalids Benefit."

One solution to difficulties with banks was to change branches or go to another bank.

"I went to one bank, they told me one thing then I approached another branch which helped me solve my problem."

Some people mentioned that others (for example, family members or mental health service staff) helped them with their finances. One person's experience with being helped was not positive as the helper revealed information about the person's health, resulting in the bank employee being discriminatory.

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. Insurance companies spread the risk of any one claim over several customers, thus reducing the cost to all. Without insurance, the person carries the risk and the cost of a major incident. And if a mortgage company refuses to lend money, a person's family home may not be safe if the person dies.

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.

Several people reported being declined life or mortgage insurance.

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

People are often asked in insurance applications whether they have been previously denied insurance. If they have it may affect their future ability to gain insurance. If the insurance had been declined without good grounds, they could be repeatedly affected by that decision.

Without mortgage protection insurance, banks may decline to offer a mortgage, threatening a person's ability to own their home.



"I applied for mortgage insurance. On filling out the questionnaire I stupidly admitted to have some problems with depression, and so was denied mortgage insurance, or pay heavy premiums or so up front. I explained my excellent work record with minimum time off with depression, and the fact I had two school children to provide a home, but to no avail. Even the agent was disgusted. I had a good record of handling difficult positions and managed 24 hour calls with midwifery."

Even when applying for insurance for which there was no medical check, one person still had difficulty getting insurance:

"Banks and insurance company would not give me cover even when it was being offered with no medical needed. Said that if on invalids benefit it must be life threatening. Even when I pointed out suicide exclusions clause and that I did not smoke it was still declined."

People resorted to having others intervene with insurance companies on their behalf to try to get cover. One person had their doctor write a letter to the insurance company; another asked their parents to intervene. Both were successful.

It was not unusual for people to be turned down more than once by different insurance companies. Often insurance was approved, but people found themselves paying higher premiums. One person mentioned that their premiums for health insurance were as high as those for a family of five.

"I applied to all of them for life insurance and except for one they turned me down. The one who didn't said they would look at accepting me in two years – if all went well. But there would be a loading of twice the premiums of others."

"Not sure whether this could be accurately described as discrimination because insurance companies are in the business of making money by judging risks but I have a higher life insurance premium because of my mental health issues."

Exclusion clauses were added to policies.

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

Extra conditions were attached to policies.

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



Another difficulty that people with experience of mental illness had with insurance companies was covering a mortgage or other loan with an insurance policy. The difficulty and expense in gaining insurance threatened their obtaining a mortgage.

"One thing they [the bank] did was to insist that a small mortgage was covered by life insurance. Of course, I could not get life insurance so [the banks] own insurance company covered me. However, they charge twice the premiums."

Other types of insurance were also refused, including house, mortgage protection, income protection and medical insurance.

"A few years ago I applied to [named insurance company] for income protection insurance when I was self-employed. Despite a letter from my GP saying I had not had any disability or significant mental health problems for 12 years, I was refused the insurance because I had a psychiatric diagnosis and was taking treatment."

One person reported that not all companies' acceptance policies were the same.

"I have recently got my first job and was declined life and medical insurance by two out of three companies due to mental health problems."

People reported negative experiences with health, travel and income protection insurance. These types of insurance generally provided no cover for mental illness.

"If you have travel insurance and experience an episode of illness while away, you are not covered. You are only covered for a broken leg, heart attack or pretty much everything other than mental illness. How discriminatory is that?"

One person joined a group scheme as a way around the exclusions for health insurance. Their existing conditions were covered, when usually they would not be.

"I had an opportunity to join when we had a group scheme at work joining with all conditions. This was luck as I had no other access to health insurance."

It is important to disclose experience of mental illness to insurance companies if they ask; not to do so puts future claims at risk. Several people, however, reported that they did not disclose their experiences.



"An insurance company asked me whether I have ever had a mental illness. I answered no as I think it may have affected me being able to be insured. So now, I always think maybe because I lied, they might not cover me."

One person reported

"An insurance agent told me not to reveal my psychiatric history when applying for insurance."

No one reported laying a complaint against an insurance company with the Human Rights Commission or the Insurance and Savings Ombudsman.

Good experiences

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

"Had a good experience with bank manager. When she knew where I worked in mental health she said 'is schizophrenia a split personality?' So I gave her some up-to-date information there and then verbally."

"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."

"I find, being well prepared, confident, and again good attitude, I come away not feeling discriminated against, but successful."

Discussion

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. Much was related to behaviours that could be improved by staff training.

Few people reported taking action when they experienced discrimination from banks or insurance companies. Those that did changed banks or approached other insurance companies. No one laid a complaint with the Human Rights Commission or the Banking or Insurance and Savings Ombudsman. For Māori this was one of the least reported areas for discrimination.

Sports clubs and other organised activities



Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness in sports clubs or other organised activities?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 86 (11%) said they had been discriminated against in sports clubs and other organised activities (11% of female and 12% of male respondents); 517 (66%) said they had not been discriminated against. This question was not applicable for 154 people (20%) and 28 (4%) did not answer it.
- In terms of ethnicity, 12% of New Zealand European or Pākehā, 6% of Māori and 16% of Pacific people who completed the survey 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.

People reported ill-treatment that resulted in their feeling left out or treated as different.

"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."

"In clubs often the reaction is to treat me as though I am mentally impaired. You spend much of your time on the outside looking in. It is incredibly easy to be lonely and isolated in a crowd. I am sick not stupid. I wish people could see me not my illness."

This treatment extended to people being bullied or harassed by others involved in the activity.

"In my home (what used to be my home before I came unwell) the town I lived in at that time, while watching a local rugby game, several players and afterwards in the clubrooms I had spectators hassling and calling out while I drove away."

"I had lots of problems with peer group bullying when I was a member of one of the medieval groups ... I have no social contacts anymore other than my children and a neighbour now for well over a year."



Some people felt they had to stop being involved in sport altogether.

"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 were extremely upset that they could no longer participate.

"People don't talk because they know you have been in hospital. And because you get mixed up with quick firing instructions they leave you out. Too much stimulation is not good but I want to participate like everyone else. I am good at sports. Before I became unwell I was doing representative sport. Now I cry because I can't do what I was doing. It makes me sad and when I get like that because I can't do my sports it is hard to live."

Side-effects from medication sometimes interfered with people's activities and limited their involvement.

"I was sailing and heavily on an anti-depressant. I never told the captain or other crew. I was never a danger but was a bit dopey. It angered some of the crew, I wasn't as alert but I just enjoyed being out on the water."

Some people mentioned problems faced when attending church.

"Sometimes at church if they know you have a mental health problem, they act like hypocrites. The church I go to now the people are very nice to me as they know me. They invite me for breakfast, dinner and I get on well with them and the kids."

"The church I go to sweeps mental illness under the carpet and puts it in the too hard basket. I have been excluded from friendships and activities on a number of occasions."

People mentioned other reasons for avoiding participating.

"Mainly my own apprehensions and fears about other people's attitudes (for many years)."



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."

Discussion

Although not as many people reported discrimination in sports clubs and other organised activities as they did in other areas of their lives, for those who did it was clearly significant.

The discrimination faced in sports often consisted of rejection, which was extremely painful for people. Some people then chose to avoid any situation where it might reoccur.

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.

The benefits of participating in sports and in other activities are great and include getting fit and socialising. However, the effects of discrimination in these activities can be severe, with many people being put off their chosen activity, limiting the options for making friends and belonging in the community.

For many people, having a spiritual dimension to their lives is important. Attending church and being involved in church activities can be a major part of their life. Experiencing discrimination in this forum can be devastating, especially if it is less expected than in other areas.

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 people 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

Questions

People were asked:

Have you experienced discrimination due to your experience of mental illness in your role as a parent?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)

A few people interpreted this question as asking about discrimination by their parents or ex-partners towards them. These responses have been included in the section on friends and family.



Figures

- Of the 785 respondents, 186 (24%) said they had been discriminated against in their experience as parents, (28% of female and 17% of male respondents); 274 (34%) said they had not been discriminated against. This question was not applicable for 300 people (38%), and 25 (3%) did not answer it.

- If the people who ticked "not applicable" are excluded, then 38% of parents say they have been discriminated against.

- In terms of ethnicity, 24% of New Zealand European or Pākehā, 25% of Māori and 25% of Pacific people who completed the survey 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 in society. 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, all because of their experience of mental illness. Fear of other people's judgments meant parents with experience of mental illness avoided disclosing their illness in case they were automatically perceived as incapable of giving their children appropriate care. They 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. They saw the stereotypes, rather than the realities, of their mental illness working against them in custody disputes.

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.

"CYPS took my now 5-year-old baby off us when it was three months old because I was on medication and could not function properly. They just took it out of my arms and made my husband sign the forms.

"They took my two babies."

Many people were concerned that custody or access was not later restored or that the person looking after their children was not suitable.



"After the birth of my daughter it was organised that I would be discharged from National Women's after three weeks there to go to Bethany. After a few nights there, I didn't take my medication for one night. The next morning my child was taken off me and I would never be able to have custody of her again because of this one mistake."

"Yes my younger son ... partly because I have been under the mental health, he was taken away from me by the Social Welfare when he was only three years ... I have had very limited access to him all these years. First it was only once a fortnight ..."

One person reported being unable to defend allegations against them because they were in hospital.

Several people felt CYF had a bad attitude towards them.

"I have supervised visits with my children and CYFS act like I'm a criminal. This is really a big stress as all I want to do is spend time with my children."

One person reported that CYF were not responsive to their child's needs.

"I was breastfeeding when my daughter was uplifted. [Her] foster mother would bring her to me for feeding. We did not tell CYFS."

People talked about trying to gain custody of their children from their partners. Mental illness was often given as the reason why they were not awarded custody.

"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."

The role of the Family Court was also mentioned by some people, especially in terms of custody disputes. They reported their illness being given as a reason for restricted access, having access removed or having joint custody declined. In one instance a woman who sought help from her ex-husband to care for her daughter while she was unwell, believed that the Family Court and Counsel for the Child demonstrated a lack of understanding of mental illness by not viewing her as responsible for seeking help in caring for her daughter when she was ill. Excessive caution by the court was another complaint.

"Past mental illness was given as the reason for an Auckland Court judge removing access to my children even though all allegations against me had been rejected by the Counsel for the Child and the Court. This was on the



grounds that judges were required to err on the side of caution if there was even a suggestion of risk to the child. This was after years of fighting for just access to my children through the Courts. The result? I had a breakdown."

People were also withheld access to their children because of their experience of mental illness. One person, a grandparent, was denied access to their grandson because the mother thought they were not capable of looking after him. Sometimes there was interference from the person's extended family. They would refuse access or threaten to have the child or children removed from the person's care.

Some people reported comments and judgements from others about their ability to competently parent due to their experience of mental illness. Some of these seem to suggest that other people felt that they had a right to judge a person's parenting ability if that person had experience of mental illness.

"Neighbours are judging my ability to be a parent while I know I am a better parent than some of these NORMAL people."

"By a student ... who commented 'How could you!' when I disclosed I was a mother and had experience of mental illness."

Some people thought others assumed they were violent or dangerous due to their experience of mental illness. These assumptions even came from some health professionals.

"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."

"I concealed the fact that I had mental health problems as much as possible for fear I would lose my children. On one occasion when I had been hospitalised against my will and separated from my children, one of whom was a baby I was breastfeeding, the staff would not tell me where my children were and who was looking after them. I was worried sick. My baby did not know how to drink from a bottle or a cup. I assumed there was some peculiar association between mental illness and violence in the people's mind. I have never been violent."

People noted that children also felt the effects of discrimination against their parents. One father reported that his son had got into fights with other children because they had referred to the father as "mad". 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 their parents harshly.



"Yes, my children did not understand the illness and dismissed any efforts on my part to explain it to them. They were in denial and constantly criticised me for not having a job, no money etc. Every time I was unwell they would get angry with me and put me down even further. After a year of asking mental health professionals to explain my illness to my children (seeing they were not going to listen to mum) they have finally come to the party and extended their support to my family. I am very grateful to them for this as my relationship with my children has changed very much for the better."

When the issues were explained or the children grew older, attitudes tended to change. This seems to indicate an important role that mental health services can play in educating children about their parent's mental illness.

"I was put down many times by my own children. It took many years to gain any respect, but now I just think to hell with them, and get on with my own life. Now that they are older and understand my illness better, we do get along as a family."

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

"I had to reassure them it was my responsibility not theirs. A simple 'I do not feel very good today' left them to carry on as usual without guilt. They (four children) in all responded very helpfully – 'I'll cook tea Mum', 'I will make you coffee' or disappear upstairs to do their own thing on the computer. Their co-operation inspired me to get better quicker."

"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."

Parents mentioned that it was difficult raising children when dealing with the effects of a mental illness, and that discipline was more difficult to maintain. People had received support from other family members. Some mentioned being badly treated by their children's school.

"Because I was a solo mother, a Māori, and a psych patient I was patronised by the school my son attended. When he was bullied they ignored my call for help and neglected to make the school environment a safe place to be."

Some people commented on how their role as a parent had been restricted because of their experience of mental illness. They would have liked to have spent more time with their children and to have played a fuller role in raising them, but were



prevented because of custody or access problems or because there were insufficient supports during their periods of illness. People also experienced poor responses from people in their role as a parent. This included other parents refusing to let their children stay with their children, and generally not being able to do things that other parents did. Sometimes the wider family was not supportive.

"I was discriminated against by my own parents as they believed that because I had had a breakdown that I did not know what I was doing with my children ... I stopped my parents from seeing my children for a year until they realised that I was not going to accept the abuse or negativity for myself or my children."

One person described her sister's attitude.

"My sister said she does not agree with my pregnancy because CYP's asked her if she could look after my new baby and she feels that psychiatric patients should not have babies."

One person reported a positive experience when their family looked after the child until they recovered, but wondered what might have happened if family was not available and non-family support services had been needed.



Discussion

Parents with experience of mental illness are often judged harshly, with their greatest critics often being members of their family, including their children. Mental health services could play a greater role in helping to educate family members about mental illness.

Support should be available for parents with mental illness, just as it is for other groups who face difficulties when parenting. Helping people who are experiencing mental illness, rather than removing their children, may be a positive approach. None of the survey respondents mentioned receiving positive help when it came to parenting, other than occasionally from family members. While the survey did not especially ask for positive experiences, these were freely given in sections of the questionnaire relating to other issues. If support is needed and is not provided there is a risk that the children will lose one of their most important connections – with their family.

The issues for parents with experience of mental illness are not just support issues. Discriminatory attitudes, particularly based on stereotypes of danger to children or bad parenting, may be influencing professional decision-making. As a result, the interventions used may be inappropriate and have a profound negative impact on parents with experience of mental illness and on their children.

Child, Youth and Family may be intervening on some occasions because they see people with experience of mental illness as risks to their children, instead of looking at each situation on its merits. While we are unable to judge from the survey data whether this is widespread, if the fluctuating nature of mental illness is not taken into account and a judgement is made at a certain point in time but not revisited when the parent is well, then unfair treatment based on incorrect stereotypes is occurring.

Friends and family



Questions

People were asked:

Have you experienced discrimination from families and friends because of your experience of mental illness?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 460 (59%) said they had been discriminated against by families or friends (65% of female and 52% of male respondents); 259 people (33%) said they had not. This question was not applicable for 38 people (5%), and 28 (4%) did not answer it.
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- In terms of ethnicity, 61% of New Zealand European or Pākehā, 57% of Māori and 49% of Pacific people who completed the survey 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 while people can gain their greatest support and understanding from their friends and family, they can also be the cause of the greatest pain and discouragement too.

Rejection by friends or family members was the most often reported form of discrimination, and the pain this caused was clearly reflected in the language people used to describe their experiences. The person who said *"friends who discriminate are not friends at all and it is their problem"* was probably correct, but the discrimination clearly hurt.

"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."

Sometimes this rejection happened as soon as a person disclosed or the family found out about their experience of mental illness. It also happened over time when contact with friends and family diminished.

"I don't get help or support (contact is very limited). I miss them. My brother has almost cut me out of his life. Old friends cut me off completely – cross the road – too busy to talk or visit, neighbours stopped all communication (we had, I thought, been very good friends)."

Friends and family misunderstood the issues surrounding mental illness. Some people commented that family and friends did not try to understand.



"Family are clueless about mental health issues. Are very anti-me ... They are not interested in learning anything about it ... My friends who are registered nurses are some of the worst offenders in not understanding anything about mental illness."

Some respondents seemed to believe the problem was with them, not with the person treating them unfairly. People also mentioned how they tried to educate their friends and family.

"Family and friends don't understand my illness and don't know how to cope but some of them are slowly learning."

Many reported that their friends and family were not very accepting of their experience of mental illness. Friends and family found it hard to deal with, were ashamed or wanted to hide it, or did not believe it existed.

"My family do not want to know. They put their heads in the sand, and ignore it. I feel isolated and am working on not feeling bitter towards them. I have also experienced this with friends and have lost most of them. However, I am aware that lack of experience and understanding on their part plays a vital role. The only people that can identify with what I am going through are those with similar experiences. I lead a life with few people in it."

Being called names such as "psycho" and "nutter" was common, and hurt.

"My brother called me a mad psychiatric bitch."

"Absolutely. I am a 'loony' I went to the 'funny farm' and all other usual phrases. From family, though not so much from friends."

One Pacific respondent told of family making abusive comments in their first language. This was more hurtful than if the words had been spoken in English, perhaps because of the context in which the name was used or the disdain with which it was delivered.

"Only my family know about my mental illness and health professionals – my family are ok but my mother when she's angry with me she teases and put me down by saying 'leaga le ulu' or 'ka le ulu' and it hurts me."

In some cases families' and friends' comments suggested there were easy solutions to people's problems if only they would "pull themselves together". These comments were reported only by the NZ European or Pākehā respondents.



"They think I should just 'pull myself together' say they just want to see me off my meds, but never mention my severe asthma and wanting me to be off those meds. They say it is all spiritual and if I got myself sorted spiritually I would be okay."

"Friends and family who do not understand mental illness only see a 'symptom' and say 'get over it', 'lots of people have problems and they move on', 'What is the matter with you'. There is not a lot of understanding."

"If I hear 'just think positive', 'its all in your mind', or 'buck up your ideas' one more time ..."

Some people thought their friends and family treated them differently than they treated other people. This meant being treated as unintelligent, not being taken seriously, or not being trusted to look after children or make important decisions.

"Family and friends tend to think that you are unable to lead a normal life because of your illness and also that they should take over instead of supporting me to lead a normal life."

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. 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 self-worth. It also fails to acknowledge the person's right to make decisions or that an illness does not necessarily deprive a person of competence.

"They don't let me make the choices that I want whether it is good or bad."

One person's comments demonstrated the result of being treated as incompetent. Their family's over-protectiveness isolated them from the support the family was probably trying to provide.

"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."

People also mentioned encountering fear from their family or friends and not being allowed near their children.

"One family member will not allow me into their house because of my illness, they fear that I may do something."



"Parents and siblings don't 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 ... I now do not have much contact with them."

They 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."

Friends or family members were reported as placing pressure on people to be hospitalised or using the *Mental Health (Compulsory Assessment and Treatment) Act 1992* to have people treated against their will.

"I had a couple of girls who I thought were friends threaten to put me in hospital. [They] always use hospital as a threat towards me."

Some people worried about the possible reaction of friends and family if their experience of mental illness was disclosed. When the illness was disclosed, it was not always the person with experience of mental illness that did the disclosing.

"I still have not told my sister or brothers for fear of discrimination."

"To me, he had no right to share that information without asking me first. After that, his friend started to treat me differently."

Although some people suggested their family was more supportive than friends, others experienced the opposite.

People stated that they lost friends because of their experience of mental illness, but also made new friends.

"I lost a lot of friends, but gained two very close ones. My new friends accept me for who I am so I am happy with that."

"Friends disappeared as they didn't understand and I was too ill to explain. Mental illness has introduced me to a whole new world and I have new friends."

Others mentioned having social difficulties. It was difficult to deal with occasions involving large groups of people and where there were social expectations.



"To a point, I can be quite afraid of leaving my home environment: often I will accept an invitation to go somewhere with friends, but usually have a panic attack before leaving. My friends, though I am sure they care for me, simply do not ask me to join them anymore."

"Tend not to get invited to social functions or parties. I suffer depression for extended periods and have not worked for several years. This can make socializing difficult if you are not working."

For some Pacific respondents not being asked to join in family activities was particularly hurtful. This was felt severely by older family members who were denied the "mana" that usually comes with age and experience (and even a family title). For elderly people with experience of mental illness the sense of isolation can be made more acute by family members' actions that essentially result in their abandonment.

"My children and grandchildren seems to ignore my advice, taking for granted that I do not have the ability to make good decisions. Lack of communication, and updating me of what is happening in the family"

"Most friends expect someone well to walk and go out with. Families expect title and family position to be filled in."

None of those surveyed reported taking any direct action to halt 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."

Several tāngata whai ora referred to the practical ways in which whānau and friends can support them, as opposed to discriminate against them. One of those ways was simply by visiting. One person implied he would just like someone to lend him a hand with transport so he could visit the urupā (cemetery).

Positive stories of people gaining support and understanding from their friends and family also featured.

"Lost some friends, they do not talk about the taboo subject and do not want to listen. Other friends have been absolutely marvellous. You soon find out who your true friends are."

"My family I have found to be very supportive in my darkest times."



Discussion

Out of all twelve areas mentioned in this survey, discrimination by friends and family occurred most often. Friends and family can and do support people with experience of mental illness when they become unwell. However, this can potentially place a strain on people's relationships. 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.

Friends and family, as with other people, are often influenced by the stereotypes of people with experience of mental illness. This includes people being regarded as always incompetent or dangerous. Changing these stereotypes is important if we are to reduce discrimination. This means that it is important that any anti-discrimination work includes working with friends and family and the wider society. The challenge in any anti-discrimination campaign is to not only educate this group about the effects of mental illness but also to reinforce the importance of maintaining the family connection and support to a person with experience of mental illness.

Community harassment



Questions

People were asked:

Have you ever experienced any hostility or harassment by people in the community because of your experience of mental illness?

Please tell us about your experience (eg. What happened? When did it happen? What action did you take?)



Figures

- Of the 785 respondents, 251 (32%) said they had been subject to hostility or harassment in the community (32% of female and 33% of male respondents); 455 (58%) said they had not. The question was not applicable for 45 people (6%) and 34 (4%) did not answer it.
- In terms of ethnicity, 32% of New Zealand European or Pākehā, 36% of Māori, and 26% of Pacific people who completed the survey had been subjected to hostility or harassment in the community.

Experiences

Harassment in the community and other public discrimination are important issues because they can make people afraid of being in public, thus severely limiting their lives. People may not feel safe walking down the street and have the extra stress of trying to keep their experiences secret to avoid maltreatment.

Harassment is extremely difficult to do anything about until it becomes so serious that the police are called to intervene.

Discrimination in the form of harassment and hostility is often based on stereotypes of people with experience of mental illness as "strange" or "dangerous". People believe (and fear) these stereotypes so anyone who is perceived as "strange" becomes a target. This harassment is based on perceptions not reality, so it is hard to combat.

Many people interpreted this question to mean discrimination in general, so areas that have already been canvassed such as friends and family and employment were also mentioned.

Discrimination in the community occurred 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."

Others met discrimination from people who had seen them when they were unwell or knew they had spent time in mental health institutions.



The discriminatory actions included general put downs and behaviour that left the person feeling rejected or being talked and laughed about, and avoided. One person described a look of horror that came across people's faces when they found out she had experience of mental illness.

"I used to work at ... an art centre for consumers. They had a shop and I would work there selling art. People would say 'what kind of place is this' and I would say it is an art space for mental health consumers and people would do a double take, stare at me or look uncomfortable."

"Anger and insulting remarks about mental instability by a tall man I did not know ... I became alarmed and was afraid to respond as this retort might label me as sick and violent by bystanders and him."

Living in a small community often meant being the subject of discrimination, with little opportunity to do something about it.

"I live in a very small community and people just didn't understand. A lot of community discrimination. The small number of people who did understand were great."

"People in my community have gossiped about me, ignored me and given me a bad reputation around town. I couldn't do anything about it but confront people who gossip."

One person used the stereotypes of people with experience of mental illness to their advantage.

"I did get really cross at the [car] Dealership when three people were questioning me at once. I said 'stop'. I will tell you this only once. I am a psychiatric patient and you are starting to annoy me. The looks of their faces was priceless. My psychiatrist told me off, then chuckled."

Name calling ("nutter") and using offensive language were the most commonly mentioned types of community harassment, although physical violence and sexual harassment was also mentioned.

"We were eating at the mall and some guys called us nutters and we had to leave and return to the hospital."

"Yes, people calling you names or saying keep away from that person, he has been in a nut house and is mad and may harm you or kill you."



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

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

Some people confronted the discriminatory behaviour and attitudes. While most of the examples indicated a passive response – either hurt or tolerance – some were reasoned or reactive responses.

"While belonging to a group the conversation came up about homes for the mentally ill amongst the community. The group was appalled at such a thought. I asked would they mind if I lived next door to them. 'Well of course not' so I explained I had a mental illness and that some of us live and function well as everyone else. They did calm down and as I reminded them I had been a value to the group and should be judged on merit."

One person reported calling the police (who responded helpfully); others had learnt to stand up to the discrimination.

"It has only been within the last five years (perhaps) that I became reactive in my responses, as that was when I learned I was entitled to my rights by law. Previous to that, I would try to school myself to accept other people's attitudes towards me, although not always with success."

Physical violence was also mentioned.

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

"I got in the wrong crowd and one hit me for no reason. I told the police and they didn't really do much just talked to her. This happened about a year ago."

People mentioned having problems with their neighbours, especially when it came to supported accommodation.

"Went to a community meeting about setting up supported accommodation in that particular street. They did not want any part of it. They were thinking of paedophiles, home invasions, the works. NIMBY [not in my backyard]."

"I have lived in community accommodation especially for those with mental illness. One neighbour especially had barbed wire heightened security because of us."



An interesting phenomenon was that sometimes the perpetrators of the discrimination were also other people with experience of mental illness. One person suggested that this may have been because of the perpetrators' non-acceptance of their own experience.

When answering this question, people mentioned discrimination at work, when using mental health services, at schools, on public transport, at church and at pubs and bars. Some people mentioned being harassed by the police.

"I have found that church pastors treat me as though I'm demon possessed or that my illness has its roots in some sort of sin etc. I have found that I wasn't asked to participate in something (up the front of the church) because I might prove to be an embarrassment to them – it is a real risky thing to let someone with a mental illness do something up front and of course am I considered credible in what I say or am I just a nut case."

Many people said they had not experienced harassment in the community, but had not disclosed their experience of mental illness.

"I do not tell anyone so it is not always an issue if I overhear people talking rubbish I educate them as I am a worker in mental health field. My consumers/clients are aware of my mental illness but on the whole I do not advertise, why ask for trouble."

"I don't tell people about myself. Only people who need to know are told otherwise it is really nobody's business."

Discussion

Community harassment was not an uncommon occurrence. It took place in public, and was sometimes continuous. Rather than people with experience of mental illness posing a danger to the community, it seemed the community posed a danger to them. Many people reported general discrimination – discrimination in pubs and churches, and by friends, neighbours and employers. The most common forms of harassment were name-calling and using offensive language. Many people were called a "nutter" or "psycho".

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

People found dealing with public harassment difficult. Most seemed to put up with it or ignore it. A few mentioned more assertive, even aggressive, techniques to deal with it.

Fear of discrimination



Questions

People were asked:

Have you ever not done something because you were afraid of being discriminated against?

Please tell us about your experience (eg. What happened? When did it happen?)



Figures

- Of the 785 respondents, 360 (46%) said they had not done something for fear of discrimination (49% of female and 42% of male respondents); 323 (41%) said that they had not experienced this. This question was not applicable for 55 people (7%) and 47 (6%) did not answer it.
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- In terms of ethnicity, 47% of New Zealand European or Pākehā, 45% of Māori and 42% of Pacific people who completed the survey 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 paralyzing, interfering with all aspects of people's lives. It is a reflection of the stigma that people feel about experience of mental illness.

Responses to this question give a picture of the debilitating effects of such fear across all areas. The overall sense from the responses is that fear of discrimination can prevent people with experience of mental illness from leading full lives.

People feared what prospective employers might think of them and that they would be discriminated against when applying for jobs. They implied their confidence had been damaged and they were afraid that they were incapable of meeting the demands of employment. These feelings stopped people applying for jobs, and when they did apply, they were wary of admitting their experience of mental illness.

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

People chose careers outside their preferred field because they feared they would not be accepted in that field. This particularly applied to those interested in a career in policing or nursing.

"There are career paths that I would never choose even if I wanted to do them because I feel people with experience of mental illnesses would not be thought of as suitable candidates even if they could do the job as well as the next person in spite of their illness."

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



Fear of undertaking education or training, from sitting school certificate to attending university, was reported. Respondents were afraid of failing and not being accepted.

"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."

Many people mentioned their difficulties interacting with people, and the way this affected their lives. They reported minimising opportunities for social contact because of fear of discrimination and rejection. Some avoided all social situations, including essential meetings such as with Work and Income; others avoided forming relationships and became isolated.

"I stopped socialising because of [a] few silly people. I do not approach WINZ, doctors with my problems because it is not looked into but works against us. I stopped going to my daughter's school ... to discuss kids progress at school. Do not volunteer help at school. Have lost confidence to drive, stay at home, isolated myself totally and have started stammering, forgotten vocabulary, do not know how to converse with people."

One person reported that they wanted things to be different.

"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."

Often one of the first things asked in a social situation is "What do you do?" For some people the fear was that if disclosed that they did not work or were unwell, they would be discriminated against.

"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."

People described thinking that people would know that they had experience of mental illness just by the way they looked. They tried to look as if nothing was wrong for fear of being discriminated against.



"I have repeatedly in my life gone to great lengths to look as if I am all right. When I am not. Have repeatedly behaved 'well' when I have felt like shit because of fear of being discriminated against."

One person mentioned the difficulty created by the side-effects of medication and the effect this had when she was in public.

"Yes, heaps of times, my medication has made me put on a lot of weight due to my mental illness. Because of my size I am shy and have a low self-esteem, and sometimes I feel people talk about me because of my size and my mental illness also."

People felt they would have recovered quicker 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."

Many people had not disclosed their experience of mental illness, remained isolated, or had not drawn attention to themselves to avoid discrimination. People reported lying about their experiences to employers, flatmates and insurers, and on applications for jobs and driver licences. One person concealed his inability to work for fear it might incur discrimination. The consequence of this is a person then fears being found out to be a liar.

"I am afraid to let people know I have a mental illness and this often means pretending or putting on a mask so they do not see how unwell I am. I tend not to socialise with people who are not service users whenever possible. I would love to work more openly in the mental health advocacy or education field but am scared of the repercussions of being outed."

"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 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."

Joining and participating in sports and other clubs, and activities such as attending church, was also difficult.

"I would have liked to have gone to church but I know that eventually people would know that there is something amiss with me and would ostracize me and leave me out."

Some people reported being afraid to offer their services as a foster parent, to go out in public with their children, or to have children, because of a fear that their children would be taken off them.

"I have raised eight children and would like to be a foster parent. Do they let bipolar people foster children?"

"I had second thoughts about having another child because of CYPS."

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."

"Have never been afraid of nothing or no one. Have no intention of starting now or in the near future."

"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."



Discussion

Almost half the respondents said they had not done something for fear of being discriminated against. This fear seems to affect all aspects of people's lives, from employment and education to social encounters. There are significant implications for people with experience of mental illness if all their encounters are tinged with the fear that they may be discriminated against. It provides a daily reminder that they are affected by mental illness.

If people are not able to participate fully due to this fear, they will never reach their full potential. The impact of it on respondents' confidence appears to be great. People also reported lying about their experience of mental illness and then worrying that they would be found out.

The stigma that people feel, reflected in this fear of discrimination, is probably the most challenging type of discrimination the *Like Minds* project must address. 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

Questions

People were asked:

Please add any other comments you wish to make about discrimination and mental illness.



Experiences

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.

The comments fitted into five basic themes:

- the nature of discrimination
- education
- the *Like Minds, Like Mine* campaign
- disclosure
- the media.

Although some people reported good experiences, most people with experience of mental illness have been affected by negative experiences (that is, discrimination). The comments included clear messages about what can reduce discrimination. The responsibility of the media and health professionals to get their ideas and messages right was emphasised. Education was the main tool mentioned and the *Like Minds, Like Mine* project received a lot of positive comments.

Nature of discrimination

Many people talked about the nature of discrimination in general – what it is, its prevalence, its effects, and how things need to change.

"It's real, it's common and the way to rid myself of it is to accept it and build up tolerance to it and to find my own personal ways, methods and answers and reactions that will help overcome these types of discrimination."

"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."

Respondents recognised the stereotypes and assumptions about them.

"People have fears about mental illness that we are all violent or can't hold a conversation and are not capable of friendship because of mental illness."

"Although my illness is well maintained I feel I am always thought of as I was not as I am. Seems you can get better but when it suits you are judged by how you were not how you are now. Even after 10 years."



Education

People stated that there was a need for more education about mental illness to combat discrimination.

"We need to continue to break down the barriers to keep educating the public and hopefully one day people with mental illness will be treated like people [with any other illness]."

"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."

Like Minds, Like Mine

People commented on the *Like Minds* campaign

"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."

"I think it is unfair that people get discriminated against for having a mental illness. Isn't bad enough just having a mental illness? Your television ads are great."

"I like seeing the celebs and hope that they do not receive the same/similar discrimination that 'normal' people do."

Disclosure

Some people mentioned keeping their experience of mental illness hidden from other people to prevent discrimination.

"I do not tell people much my experiences in hospital as people would regard me as a silly nut case."

"I am a 40-year-old presentable white middle class male. I feel this can lessen potential for discrimination due to my 'invisible' illness."

"I guess I have been lucky as my mental illness is pretty well hidden most of the time, but it has affected my confidence and some discrimination has made me less likely to attempt some things I would otherwise have tried."



The Media

The media was the target of some people's responses.

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

"I find that people expect [us] to be like the evil and mad killers and zombies in the movies and the papers."

Tone of Comments

The other aspect of the comments was their tone which varied from resigned and angry to defiant and inspired.

Resigned

"Mental illness is like a broken leg. We have it everyday but we learn to cope with it. We work out ways."

Angry

"I just wanted to be treated like any other human being. Not someone to be ridiculed or treated like an idiot or controlled all the time. Do more of the asking us/helping us to find what we want and listening to us rather than trying to control us. Stop judging us and making us feel guilty because of our illness."

Tolerant

"Education and mental illness is one of the best weapons to combat stigma. I find letting people get close to me, talking honestly with them a great help so that they will understand me better especially when I am not well."

Impatient

"I hate being treated as stupid, a lot of people with mental illness have experienced being patronized."

Defiant

"I just don't tell anyone anymore that I have a mental illness because of discrimination, it's none of their business anyway."

Inspired

"My mum helps me a lot and tells me not to take notice and that I have awesome skill and talents."



Discussion

The comments received in this section illustrated respondents' thinking about discrimination against people with experience of mental illness. 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.

One area that stood out when people made comments in this section, but was not addressed in the rest of the survey, related to the media. The comments on the *Like Minds, Like Mine* campaign reflected its positive impact, but other comments about the news and entertainment media were not so complimentary. People reported how they perpetuate stereotypes of people with experience of mental illness.

Analysis of issues reported by Māori

"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."

Māori respondents report experiencing discrimination in all areas, but most commonly from whānau and friends. The majority of tāngata whai ora (57%) report such discrimination, due to their experience of mental illness. Many reported a fear of being discriminated against (45%). 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 looking for employment (35%).

What follows is a discussion of the major survey findings that relate to Māori. Many of the findings were similar across all three of the groups studied (Māori, NZ European or Pākehā and Pacific). Those findings have not been repeated.

Throughout the reported experiences of discrimination there were examples relayed that were not only due to the experience of mental illness, but were also racially based. For many tāngata whai ora, particularly Māori women, discrimination is multi-level, and for some the racism is a harder barrier to break down.

The inability to provide for one's whānau because of the experience of mental illness is a reality of discrimination for some tāngata whai ora, as is having financial decisions made on their behalf without consent or adequate explanation.

Tāngata whai ora most commonly reported a lack of understanding by whānau and friends about their experience of mental illness, discrimination borne of ignorance. Once whānau and friends became more informed and gained a level of understanding about mental illness, some showed an improvement in acceptance of this experience, which lessened the effects of the discrimination to a degree.

A common fear communicated to tāngata whai ora was "a fear for the children"- that is the whānau member or friend referred to being worried about children's safety around the person with experience of mental illness.

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. Some referred to being disowned or rejected by their loved ones, as a result of their experience of mental illness. They reported misinformed strategies such as "tough love", which enforces disassociation with whānau until the behaviour of the tāngata whai ora is more acceptable to the enforcer. This phenomenon varied from the shame experienced by some Pacific people or the "get over it" stance taken by NZ European or Pākehā.



The lack of support shown by whānau and friends may just be as a result of lack of understanding about how to deal with mental illness. Conversely, being too supportive and over-protective may be equally counterproductive.

Almost half of the Māori respondents reported they had been prevented from doing something for fear of discrimination, due to their experience of mental illness. The fear of discrimination that prevents so many tāngata whai ora from either securing employment or advancing employment opportunities was summarised by one tāngata whai ora who explained that the easier option was just not to step out of one's comfort zone. Education was another area where fear of discrimination prevented tāngata whai ora from undertaking something.

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. Although subtle, this discrimination is significant because for a number of tāngata whai ora it is something they keep in check every single day of their lives. For example, anger is a normal emotion felt and expressed by all, yet 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 tāngata whai ora did not allow themselves to dream fanciful dreams, for fear of discrimination, implying that their imagination may be interpreted as part of their mental illness.

A number of Māori respondents were discriminated against due to their altered physical appearance as a result of the side-effects of psychiatric medication, such as weight gain. Other side-effects can make tāngata whai ora look 'wasted', which deterred some from trying to get into places like nightclubs, in case of discrimination.

Some tāngata whai ora felt unable to confront racism, due to fear of discrimination, suggesting that their concerns would not be listened to because they experience mental illness.

Nearly two out of five Māori respondents also indicated they had experienced discrimination in other health services, due to their experience of mental illness. The vast majority of comments, however, made in relation to discrimination from health services were about mental health services (from 37% of Māori respondents).

Some Māori respondents referred to the discriminatory actions of mental health professionals which included enforcing heavy measures to make tāngata whai ora comply with their medication regimes and threatening tāngata whai ora with punitive action for being "non-compliant". The use of seclusion was also seen as a discriminatory action against people with experience with mental illness, taken by mental health staff.

Over a third of Māori respondents (36%) reported they had experienced discrimination in the community, and a similar number in employment (35% looking for a job), due to their experience of mental illness.



Some tāngata whai 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.

A number of tāngata whai ora were in employment positions as consumer advisors, advocating on behalf of others with experience of mental illness. For some of these tāngata whai ora discrimination was still an issue because of the attitude of other mental health professionals who appeared to struggle with the role of consumer advisor.

A quarter of all Māori respondents reported they had experienced discrimination as parents. The majority of these, most of whom were wāhine, referred to losing custody of, or access to, their children.

Almost one in five Māori respondents indicated they had experienced discrimination from government services, due to their experience of mental illness, particularly Work and Income and the Police. Work and Income was the agency most reported as being discriminatory (12%). Following closely behind was the Police (10%), where the vast majority of those reporting discrimination (over 80%) were wāhine. Some tāngata whai ora reported experiencing discrimination within other sections of the justice system.

Almost one in five Māori respondents reported experiencing discrimination in education, due to their experience of mental illness. 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.

Eighteen percent of Māori respondents indicated they had experienced discrimination in finding or keeping housing, due to their experience of mental illness. Most of those who reported discrimination of this sort described actually losing their housing, due to their experience of mental illness.

Not all Māori respondents felt they had been discriminated against in their search for housing. Some reported that they have been successful in independently securing housing for themselves without difficulty. For others however, finding housing was difficult. Landlords were questioning of their experience of mental illness when applying for housing and some found either living in supported accommodation or with whānau the better option.

Other tāngata whai ora simply did not disclose their experience of mental illness to prospective landlords either in order to avoid discrimination, or because they did not deem it necessary.



Whilst the vast majority of Māori respondents (85%) reported they had not experienced discrimination from financial institutions, due to their experience of mental illness, 15% indicated they had.

Inadequate sharing of information about banking processes was identified by tāngata whai ora as a form of discrimination. Tāngata whai ora were also discriminated against by financial institutions, due to their experience of mental illness, through what were perceived to be more stringent application processes.

The majority of Māori respondents (94%) reported they had not experienced any discrimination in sports clubs or other organised activities. However, 6% of tāngata whai ora reported they had, indicating that either the actual effects of their mental illness or the fear of being discriminated against, due to their experience of mental illness, prevented them from participating. The number who had experienced discrimination is far fewer than the number of NZ European or Pākehā or Pacific people.

Many tāngata whai ora 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 whānau to understand about mental illness. Without understanding, whānau just add to the discrimination.

Many Māori respondents carried hope for a better future, and undertook positive steps and actions to improve their lives. One way tāngata whai ora were able to combat discrimination was by moving into the role of providers, to teach others strategies to deal with stigma and discrimination. People who have lived the experience are the best advocates for many reasons, not the least being that they are far more readily accepted messengers. Some tāngata whai ora in these positions suggested that their roles were not just to aid others however, but are also beneficial for their own wellbeing.

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

Other Māori respondents refer to time being a great healer. One wāhine implied that as she has aged, so has her management of her mental illness improved. She offered this information as encouragement for younger tāngata whai ora.

Most of the Māori respondents' concluding comments however, based on their life experiences, were simply pleas for action against discrimination.

"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

"My families are now not closer like before. Never ask me to join for family functions and activities. Even my brothers hardly come home and see me."

Pacific people's worldviews need to be considered in any analysis of responses from Pacific respondents. Amongst these are general expectations for structured cooperation 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 bring pride to self for achievements is to bring pride to the extended family. 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. But this can be heavily influenced by the quality of the personal leadership within the family unit, as some of the experiences reflected. 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. This has been proven to be so within Pacific services practice and was reflected again in some of the experiences described by the Pacific respondents.

For Pacific people responding to the survey, friends and family were the most common area where discrimination took place (49%), followed by fear of discrimination (42%), looking for a job (33%), and discrimination while in a job (31%).

The most reported area of discrimination was from family and friends (49%). The percentage was slightly lower than for NZ European or Pākehā or Māori respondents, which may reflect a difference in the level of care and protection Pacific respondents received from their families. The examples of discrimination ranged from feelings of being avoided by family and friends to openly hostile and abusive behaviour, and showed how divisive the issue of mental illness can be within a family unit, if the family allows it to be so. However, the experiences described also showed that discrimination can be localised, coming from certain individuals within the family or friends' network, rather than a commonly held attitude.

One Pacific respondent related an example of discrimination within their family where names were called in their first language. The connotation of the words in their first language can be more hurtful to Pacific people with experience of mental illness, than if they are spoken in English. This is because of the multi-layered contextual nature that verbal abuse is interpreted at, eg. shame to the individual, the parent, family, extended family, land-holding unit. This may also be due to the context the name was used or the disdain with which it was delivered.

Other 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. The isolation brought about by the sense of 'shame' the family has about mental illness can be made more acute by actions that essentially result in their social abandonment by family members.

Fear of being discriminated against was noted by 42% of Pacific respondents (slightly lower than for either NZ European or Pākehā and Māori) as having a limiting factor in their lives. Pacific people described consciously limiting their opportunities for social connection, of being so overwhelmed by a sense of unworthiness that they had tried to commit suicide on several occasions, and of being unable to move past their illness and resume their previous life.

Discrimination in employment (31%) was slightly lower than for either NZ European or Pākehā and Māori. It ranged from abusive name calling to being ostracised within the workplace. One person commented that they preferred a certain type of medication that allowed them to continue to work effectively and therefore earn a living. Others commented on application forms being identified as a source of much anxiety, and some respondents did not disclose they had a mental illness or found it difficult to explain their illness. For some, the fear of being discriminated against because of their experience of mental illness was enough to prevent them from moving past the application phase. This reduced or eliminated their opportunities to participate in the job market.

Three Pacific respondents made reference to their perception of not being paid equitably or not being paid for the work they completed. The common theme amongst these comments was a sense that employers felt their work was worth less. One person made reference that there was an expectation that they should "work for nothing".

Hostility or harassment by people in the community was reported by 26% of Pacific respondents, less common than for Māori and NZ European or Pākehā. With Pacific the term 'community' more often relates to an 'island' or 'Pacific' community, and many of the quotes related to Pacific people's experiences with their own island communities rather than the general public. This sort of discrimination can diminish a person's sense of place and erode their social context. Examples included a sense of awkwardness from members of the wider community and being "kicked out" of a congregation. One respondent relayed his experience of being openly bullied and abused. The resulting disempowerment would further exacerbate a person's sense of social isolation. One young respondent gave an example where confidentiality about their illness was not respected. The respondent's teacher disclosed their experience with mental illness to the whole class, leaving the person with an even more acute sense of shame and betrayal.



Discrimination from government agencies was reported by 28% of Pacific respondents. Some commented that the discriminatory behaviour could have been racially or physical-impairment influenced 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. The level of discrimination was much lower than that for Māori and NZ European or Pākehā. This may be more of a reflection of Pacific people's use of health services rather than less discrimination. Some of the discrimination may have been racially based, for example Pacific respondents being made to feel ashamed for not being fluent in English, and their lack of fluency being used as an indicator of their mental competency.

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. They contrasted this to their previous experiences with mental health workers who could not speak their language and with whom they felt they needed to agree "for fear of shame". These examples underline the value of "by Pacific – for Pacific" strategies. If a Pacific consumer of mental health services is fully able to understand the issues at hand they are then better able to appreciate the strategies necessary for their recovery.

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. One Pacific respondent reported being so disempowered that support workers had to advocate on their behalf.

Discrimination by banks or insurance or other financial institutions was reported by 14% of Pacific respondents. As well as the experiences of ineligibility, and cumbersome procedural issues mentioned by other respondents some Pacific respondents said that they were made to feel unworthy of the responsibility of insurance cover or a bank account and service. Some examples were provided where family members helped manage some respondents' finances. Some of the most acute examples of discrimination were due to the inability of the bank to service their needs in their own language.

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. Examples of discriminatory behaviour ranged from not being allowed to play through to being made to do excessive amounts of exercise.



Several Pacific respondents commented on activities organised through Pacific providers that were enjoyable, but that do not seem to be available any more. For those Pacific respondents who had participated in these organised activities, the sense of community and wellbeing was appreciated, and the activities were obviously looked forward to. 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. Some comments referred to the quality of the work undertaken by Pacific agency staff. These included support and advocacy for the needs of Pacific consumers, which consumers themselves may have had trouble articulating. The comments reflected a sense of community with references to "us" and "we". Not all experiences with Pacific providers were positive, however, reflecting the need for continued monitoring and support for these services.

The responses generally reflected a lack of examples of positive coping strategies from Pacific respondents towards those who reflected discriminatory behaviour.

"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. This project has shown that discrimination against people with experience of mental illness, in both a legal and broader sense, 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.

Every time a person with experience of mental illness is limited from playing the best part they can in society, our society is poorer for it. 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.

In each of these cases, New Zealand lost – through more people on a State benefit, a less educated population, children brought up without their family's support, or any of a range of other negative effects.

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 was reflected in the pain with which people described rejection or other discriminatory treatment by their family or friends. This demonstrates the need for education for everyone about mental illness. We cannot expect family and friends to understand if they have little knowledge of the issues. Education, alone, however, is not the answer. We also need to find more creative solutions to combating discrimination. This is part of our ongoing work.

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 – intentional, accidental, or by another person – 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. For many, this fear permeated all aspects of their lives, preventing them from doing activities that most other people would take for granted. Fear held people back from fully participating in society.

Some of the examples given related to actions in the distant past. These experiences clearly influenced the people who experienced them, affecting their expectations and behaviours even now.



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.

This was not a "numbers" survey. We were aiming to better understand the areas of daily life in which people experienced discrimination, and how that discrimination manifested itself. Nevertheless, some of the numbers are significant.

The survey was responded to by 785 people – considerably more per capita than in comparable British surveys. The survey aimed to elicit responses from people with experience of discrimination, and all but a minority (16%) of respondents reported discrimination in one or more parts of their life. Most people reported discrimination in several parts.

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.

Some people noted that they were unable to decide whether the discrimination was because of their illness, gender, ethnicity or sexual orientation, but few significant differences were apparent when the responses were analysed for these factors.

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. There was a strong sense of social dislocation in their comments and a desire for acceptance. The comments reflected Pacific respondents' need for the public to look past the illness and see a person who needs access to opportunities so they too can contribute fully in society. There was a strong sense of exasperation about the negative portrayal in the media of consumers of mental health services.

The other issue that stood out was from the NZ European or Pākehā respondents who reported an attitude of "you could get over it if you tried" from some people who discriminated against them. It is not possible to determine whether this reflects a different perception of mental illness by NZ European or Pākehā, compared with other groups.



The purpose of this survey was to describe issues rather than offer solutions, but the nature of the experiences reported suggests that education is still a key factor in reducing discrimination. Many respondents reported that education had helped when they were faced with discrimination from friends and family.

The accounts of discriminatory practices or at least unfair treatment and bad 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 and education about working with different people. It is not surprising that those agencies with which people with experience of mental illness might come into contact were the ones in which most discriminatory practice was noted. (They were also the agencies identified in the questionnaire.) The resistance by staff to providing acceptable service to people with experience of mental illness will only lengthen the time for which support is needed and may even ensure some people never move past requiring support.

Many people could have complained to the Human Rights Commission about the experiences they reported, for example about banks and insurance companies, government agencies, and mental health and other health services. The few accounts of people taking direct 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 with experience of mental illness can take if they experience discrimination. As long as few examples of discrimination against people with experience of mental illness 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, for example, sports clubs, friends and family. 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.



Appendix One



Discrimination Survey

The Like Minds, Like Mine Project wants to hear about how people with experience of mental illness are discriminated against, in particular, situations where you have been treated unfairly due to your experience of mental illness.



The information gathered in this survey will be used to:

- powerfully communicate how discrimination impacts on peoples' lives
- focus the efforts of anti-discrimination work
- provide valuable information for lobbying and advocacy to change government policy.

Your experience and stories are vital information for the campaign to reduce discrimination.

This survey is completely confidential and you can rest assured that you will not be named in relation to any of the information that you provide.

If you have difficulties thinking of specific situations that you may have experienced then you can use the following tips to help you through the question survey.

- Fill it out with a friend, or have someone write up your thoughts as you speak.
- Keep it simple but provide as many details as you can.
- One example is great, but feel free to provide more if you feel you can and want to.
- Feel free to use any extra paper if you run out of space.

As you go through you will find that some questions have tick boxes, please tick as you feel necessary.

Please return the survey **by 30 May** to the address stated below:

**Freepost
LMLM Survey
Mental Health Foundation, PO Box 12154, Thorndon, Wellington**

Thank you in advance for participating in this survey.

If you would like to receive a report of the results of the survey, or would like to enter the draw for one of five \$100 gift vouchers, please fill in this form.

This form, including all names and other details, will be removed from the survey when we receive it. Any personal details will remain confidential to the survey team.

The information that you provide here will not be linked to the survey results.

- I would like to receive a summary of the results of the discrimination survey when completed
- I would like to be entered into the draw for one of five \$100 gift vouchers
- Please indicate your preference Farmers or The Warehouse

Name: _____

Address: _____

Contact Telephone Number: _____

Mental Health Foundation Telephone 04 4624325



Discrimination Survey



The Like Minds project is conducting this survey to find out people's experiences of discrimination. Your responses will help to build a strong, clear picture of the specific ways that people with mental illness are discriminated against. Thank you for your participation.

1 Have you experienced discrimination due to your experience of mental illness:

a while you were looking for a job?

Yes No Not applicable

b while you were in a job?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):

2 Have you experienced discrimination due to your experience of mental illness while you were in an **education or training course**?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):



Please return the survey by 30 May 2003 to Freepost, LMLM Survey, Mental Health Foundation, PO Box 12-154, Thorndon, Wellington



3 Have you experienced discrimination due to your experience of mental illness in finding or keeping housing?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):

4 Have you experienced discrimination due to your experience of mental illness:

a With **mental health services**?

Yes No Not applicable

b With **other health services**?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):

c With **government agencies** (e.g. Work and Income, the Police, Courts)?

Yes No Not applicable

d With **local government services** (e.g. libraries, swimming pools)?

Yes No Not applicable

➤ Please tell us about your experience (e.g. Which agency was it? What happened? When did it happen? What action did you take?)



5 Have you experienced discrimination due to your experience of mental illness:

a with **banks or insurance companies or other financial institutions?**

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):

b In sports clubs or other organised activities?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):

c In your role as a parent?

Yes No Not applicable

➤ Please tell us about your experience: (e.g. What happened? When did it happen? What action did you take?):

6 Have you ever experienced any discrimination from families or friends because of your experience with mental illness?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):



7 Have you ever experienced any hostility or harassment by people in the community because of your experience with mental illness?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen? What action did you take?):

8 Have you ever not done something because you were afraid of being discriminated against?

Yes No Not applicable

➤ Please tell us about your experience (e.g. What happened? When did it happen?):

Please tell us about yourself:

What gender do you identify with? Female Male

Which ethnic group do you identify with? (If more than one group, please indicate your order of preference by numbering the boxes)

NZ European Maori Samoan Cook Island Maori

Tongan Niuean Chinese Indian

Other – Please state: _____

What age group do you belong to? under 25 25–39 40–59 60+

➤ Please add any other comments you wish to make about discrimination and mental illness:



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Thank you for completing this survey. Your responses will help us in our work to fight discrimination faced by people with experience of mental illness.



Mental Health
Foundation
of New Zealand

***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.

National Office

PO Box 10051, Dominion Road, Auckland 1003
81 New North Road, Eden Terrace, Auckland
Ph: 09 300 7010 Fax: 09 300 7020

Resource Centre

Email: resource@mentalhealth.org.nz

The Resource Centre is open to the public from Monday to Friday 9am-4pm.

Wellington Office

Level 5, Education House, 178 Willis Street, Wellington
Ph: 04 384 4002 Fax: 04 384 4003

Christchurch Office

4th Floor, Securitas House, cnr Madras and Gloucester Sts, Christchurch
Ph: 03 366 6936 Fax: 03 365 5079

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 www.mentalhealth.org.nz or www.likeminds.govt.nz



LIKE MINDS, LIKE MINE
Whakaitia te Whakawhiri i te Tangata

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 www.likeminds.govt.nz and for copies of the *Like Minds National Plan* contact moh@wickliffe.co.nz





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