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DISCRIMINATION REPORTED BY USERS OF MENTAL HEALTH SERVICES: 2010 SURVEY

RESEARCH REPORT FOR

MINISTRY OF HEALTH

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ACKNOWLEDGEMENTS

We wish to express our sincere gratitude to all those who gave their time to complete this survey. We also wish to thank all those who contributed to the research in other ways.

1 SUMMARY

INTRODUCTION

- This is the first survey that has sought to measure levels of discrimination experienced by a representative sample of New Zealand users of mental health services.
- A sample of 1,135 completed the questionnaire. Most completed the questionnaire mailed to them, but 57 opted to do it on-line and 30 completed it by phone.
- There was oversampling of Māori, Pacific, Asian and young persons (aged 16 to 24 years) to provide sufficiently large numbers in each group. The numbers completing surveys were 225 for Māori, 196 for Pacific, 152 for Asian and 190 for young persons.
- There was also an alcohol and other drug (AOD) sub-sample included, but this generated only 39 participants.
- The questionnaire was translated into four Pacific languages and there was also a Chinese translation. Persons in these groups were sent English and translated versions, but only 22 Pacific and 20 Asian translated questionnaires were returned.
- Prior to analysis the data was weighted so that the participants were representative of all users of DHB mental health services in terms of ethnicity, gender and young people.
- As agreed by the Multi-region Ethics Committee, the sample was drawn from the Ministry of Health PRIMHD data base for ten DHB regions covering persons who had used the DHB mental health services in the previous 12 month period.
- One DHB formed the pilot site and data collection took place between 18 November 2009 and late January 2010. Data collection for the main survey took place between 20 September 2010 and 19 January, 2011. The data from the pilot site was included in the final data set.
- The response rate was 18%, which increased to 21% among the higher user service group (those who had more than 10 contacts with DHB mental health services in the previous 12 months).

DESCRIPTION OF PARTICIPANTS

- There were 23% of the participants who had more than 25 contacts or bednights with DHB mental health services in the previous 12 months and another 21% who had 11-25.
- There were 45% of participants who had been using mental health services for less than five years, while 31% had been using them for more than 10 years.
- There were 31% who had been under the Mental Health Act (compulsory treatment order) in the last 12 months.
- There were just 43 (4%) of participants who were currently receiving in-patient/hospital services, while 57% were receiving community mental health services, 19% said they were receiving some other type of service and 23% said they were receiving none[1].
- In terms of all forms of care received over the previous five years, including current care, 33% had received in-patient/hospital services and 78% community mental health services.

DISCRIMINATION EXPERIENCED

- There were 89% who reported at least 'a little' unfair treatment in the last 12 months because of mental health problems on at least one of the 26 items asked about. The mean number mentioned was 7.4.
- When only the 'moderately' and 'a lot' responses were considered, there were 70% who mentioned at least one, with a mean of 4.1.
- When considering the proportions who had been treated unfairly at least 'moderately' (the right hand column of data in the graphs which follow), Family was most mentioned (30%), followed by

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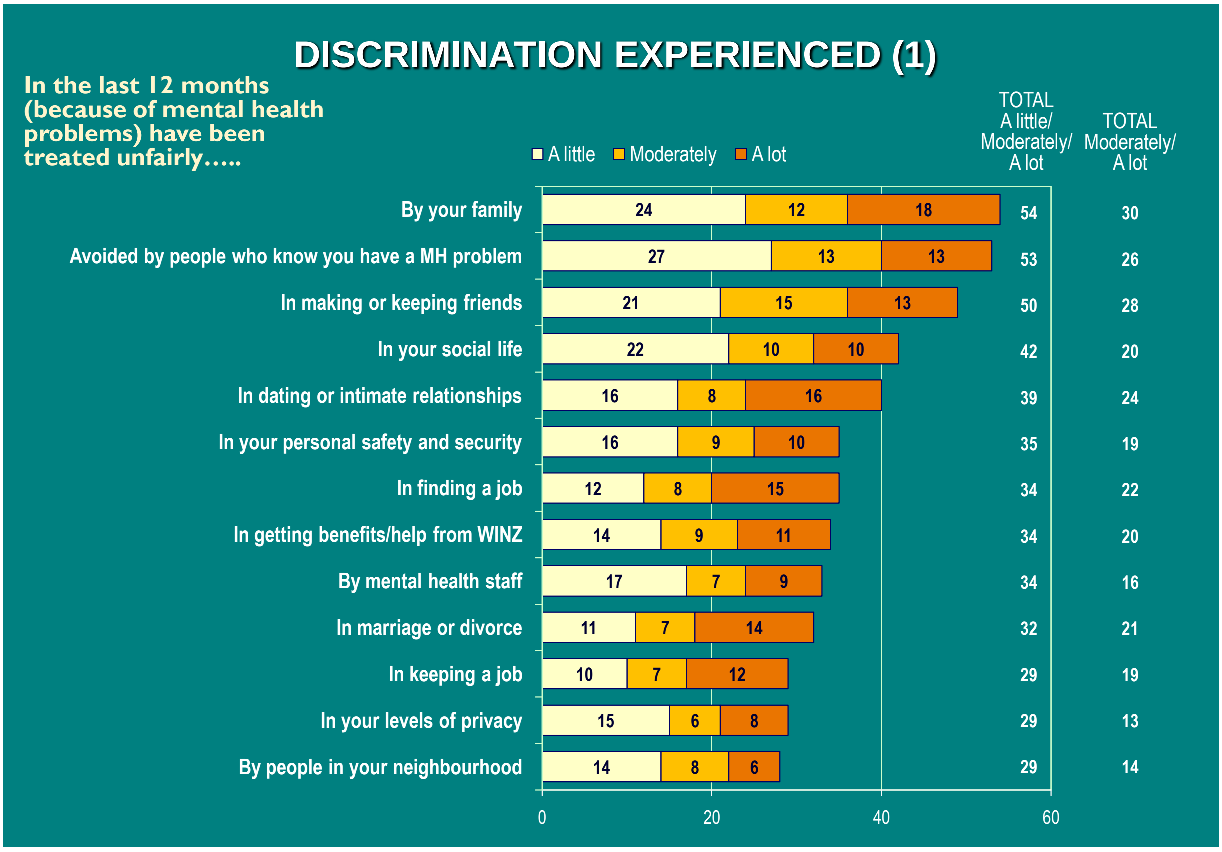
[1] People could mention more than one service, which is why the percentages total a little over 100%.

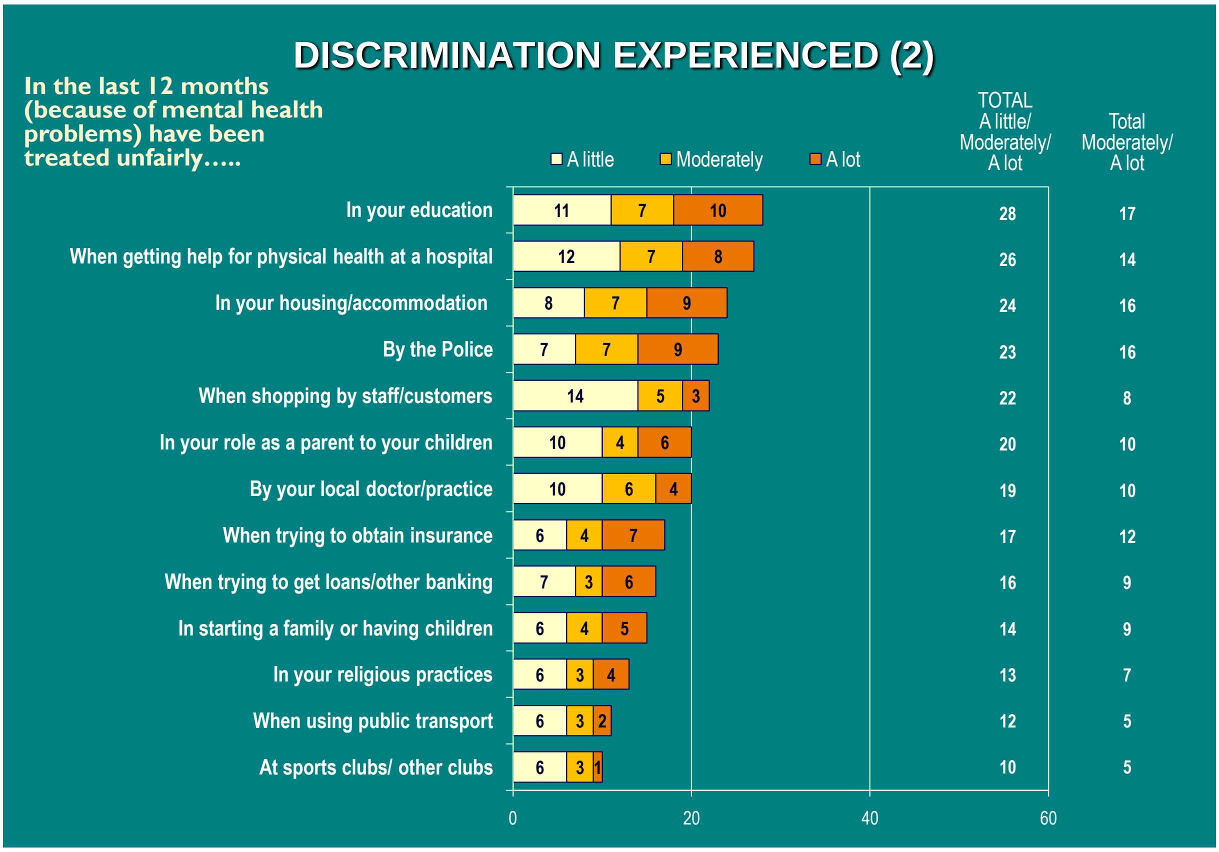
Making or keeping friends (28%), Avoided (shunned) by people who know you have a mental health problem (26%), Dating or Intimate relationships (24%), Finding a job (22%), and Marriage or divorce (21%).

- The survey results present mixed findings regarding mental health staff.
    - At the overall level it was twelfth most mentioned in terms of 'moderately' or 'a lot', at 16%, and it was also at the same position when just considering the proportions who reported 'a lot' of unfair treatment, at 9%.
    - When the 'Not Applicable' and no answer responses were removed, mental health staff was seventeenth most mentioned, at 18%.
    - However, those having the most contact with mental health services (more than 25 contacts in the year) reported a higher prevalence of being treated unfairly. Just over a quarter of this group reported being treated unfairly by mental health staff either 'moderately' or 'a lot', which was the fifth most mentioned form of discrimination.
    - Those who had been under the Mental Health Act in the previous 12 months did not report above average mentions for mental health staff.

Graph 1: Discrimination experienced (1)



Graph 2: Discrimination experienced (2)



ANTICIPATED DISCRIMINATION

- There were 84% who reported at least 'a little' on one of the four items asked about, and 70% at least 'moderately'.
- 57% had concealed or hidden their mental health problems from others either 'moderately' or 'a lot'.
- 37% had stopped themselves from having a close relationship, 33% from applying for work and 24% from applying for educational training courses.

OVERCOMING STIGMA AND DISCRIMINATION

- Forty-two percent had been able to use their personal skills or abilities in coping with stigma and discrimination.
- A similar proportion (43%) had made friends with people who don't use mental health services.

BEING TREATED MORE POSITIVELY

- On five items service users rated whether they had been treated more positively in the last 12 months because of their mental health problems.
- Four out of five service users (79%) reported at least 'a little' on at least one of the five items and 58% either 'moderate' or 'a lot'.
- There were 40% who felt they had been treated more positively (either 'moderately' or 'a lot') by their family because of their mental health problems.

  - This compared with 30% who reported being treated unfairly by their family, as noted previously.
  - There were 9% who reported treated both more positively and also unfairly by their family
- More than one in five (22%) reported being treated more positively by WINZ, which compared with 20% who reported unfair treatment.
- A similar proportion (21%) reported being treated more positively in their housing/accommodation, which compared with 16% who reported being treated unfairly.
- Fifteen percent reported they had been treated more positively in their religious activities, which compared with 7% who reported unfair treatment.
- The least mentioned example of being treated positively was for paid employment (including obtaining jobs and suitable working conditions), which was mentioned by 12%.

CHANGES IN DISCRIMINATION LEVELS

- 54% reported that there had been some improvement over the last five years when considering all ways of being treated unfairly because of their mental illness[2]. Conversely, there were 16% who thought it was now worse.
- When considering unfair treatment by mental health staff, there were 42% who thought it had improved over the last five years and 11% who thought it was now worse.

PERCEIVED IMPACT OF 'LIKE MINDS'

- There were 48% who thought the 'Like Minds Like Mine' programme, including the TV advertising, had assisted in reducing discrimination against people with mental illness 'a lot' or 'moderately'.
- Another 22% felt it had assisted 'a little'
- There were another 20% who ticked the 'don't know' box and 3% who did not answer
- 8% thought it had not assisted

OTHER COMMENTS

At the end of the questionnaire, participants were invited, if they wished, to add any of their own comments about their experience of discrimination over the last five years, or how it has changed. Some of the verbatim responses are included in the final chapter and provide a greater insight into their experiences of discrimination.

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[2] This percentage was based on the 531 respondents who had first been in contact with Mental Health Services at least five years earlier.

2 DISCUSSION

This survey has now provided benchmark levels of discrimination, against which to assess the performance of the 'Like Minds' programme and related initiatives moving forward.

Obviously there has been change already, given the programme has been running for over ten years. There were over half in the current survey who thought discrimination overall had got better over the last five years. Most thought the 'Like Minds' programme had made some impact in reducing discrimination, with almost half rating that impact 'moderately' or 'a lot'.

MOST PREVALENT FORMS OF DISCRIMINATION

Unfair treatment was most frequently reported for Family. This may in part relate to Family being the people who many service users will have the most contact with, and therefore providing more opportunity to be treated unfairly. On the other hand, it does reflect the real difficulties experienced by service users, given that these people may also be the people with whom they have the closest relationships. The difficulty of establishing other friendships/relationships was reinforced by most of the other highly mentioned items on the list relating to discrimination in the area of friendships and social life.

FAMILY ALSO A MAJOR SOURCE OF POSITIVE TREATMENT

There were higher proportions reporting being treated more positively by Family than there were reporting discrimination, and some were reporting both. This again reinforces the point that Family may be at the top of the discrimination list because of their level of contact with service users, rather than them necessarily being more discriminating than other groups. It does show that Family are often keen to be supportive and are doing positive things.

It is difficult to compare the discrimination reported for a group where contact is infrequent (e.g. trying to get loans) with ones where contact may be for many hours each day. The form of discrimination at the place of less frequent contact may be more severe, but frequency of contact increases the chances of encountering unfair treatment. The scales used in this survey are likely to result in participants making some kind of overall assessment that has to take into account frequency and severity. Trying to separate out these two dimensions via questioning would be a challenge, even for qualitative research.

Having noted this, we are still left with Family being the most mentioned source of discrimination and this also applies when just considering the proportions reporting 'a lot' of unfair treatment. So even if Family are at the top because of the frequency of discrimination rather than severity (and we cannot ascertain if this is the case or not), they still have to be identified as a group for attention in terms of efforts to reduce discrimination.

Qualitative research by Phoenix Research prior to the current campaign[3] included a focus on families. One of the conclusions was that families need as much support as service users. 'Like Minds' needs to be providing supportive family and extended family members with sufficient understanding that will allow them to communicate hope to their family members with mental illness. The website has an

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[3] Phoenix Research (2009), *Implications for Campaign Strategy Development: Qualitative Study to Brief Project Team How Priority Audience Now Relate to Issues of Stigma and Discrimination Associated with Mental Illness.*

important role to play in this regard. Research with families, undertaken by the Mental Health Foundation, also draws attention, among other things, to the discrimination that families experience[4].

IMPLICATIONS OF FINDINGS REGARDING MENTAL HEALTH STAFF

These survey results present mixed findings regarding unfair treatment by mental health staff. Overall it was twelfth most mentioned in terms of 'moderately' or 'a lot', at 16%, and it was also at the same position when just considering the proportions who reported 'a lot' of unfair treatment, at 9%. Those having the most contact with mental health services (more than 25 contacts in the year) reported a higher prevalence of being treated unfairly. Just over a quarter of this group reported being treated unfairly by mental health staff either 'moderately' or 'a lot', which was the fifth most mentioned form of discrimination. Those who had been under the Mental Health Act in the previous 12 months did not report above average mentions for mental health staff.

It is important to note that there were over four in ten participants who thought that unfair treatment by mental health staff had got better over the previous five years. The changing wider climate due to the 'Like Minds' programme[5], may be having some impact at the level of mental health staff. As well as the national media campaign, the 'Like Minds' programme has also run workshops with mental health staff. There has also been a lot of work by the Mental Health Commission and others in terms of promoting recovery. The Ministry of Health has also developed 'Let's get real', which sets out values and attitudes and a set of seven 'Real Skills', for people working in mental health and addiction.

It should be noted that this question was asking about mental health staff and not mental health services. There may be systemic issues that affect the level of discrimination experienced from mental health services. The extent to which these have impacted on perceptions of staff discrimination in the current survey cannot be ascertained.

While the majority of users of mental health services are not reporting being treated unfairly, there is still clearly room for improvement. Given mental health services are where people go for treatment of their mental illness, it is very important that service users do feel that they are treated fairly.

BREADTH OF DISCRIMINATION

There were 26 items included in the discrimination section and there could obviously have been more added. The proportions reporting discrimination across all of these items is a reminder of the breadth of discrimination that service users can be exposed to. Some of the levels would be higher, except that service users often choose not place themselves into situations in which they could experience discrimination, as evidenced by some of the comments that participants submitted.

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[4] The Mental Health Foundation have also undertaken research relating to families: Barnett, H. & Barnes, A. (2010), *Walk A Mile In Our Shoes: He tuara, nga tapuwae tuku iho o nga Matua Tupuna. Exploring Discrimination Within and Towards Families and Whanau of People Diagnosed with 'Mental Illness'*. Auckland, New Zealand: The Mental Health Foundation of New Zealand.

[5] Brown, R., Howearth, J., Wyllie, A. (2011), *Impacts of National Media Campaign to Counter Stigma and Discrimination Associated with Mental Illness: Survey 11: Initial Response to the Fifth Phase of Campaign*, Phoenix Research.,

SOME OVERSTATEMENT LIKELY

It is likely that there will be some degree of overstatement in the results. Although the questions asked about the last 12 months, it is likely the some people will have forgotten this as they went through and will have reported for a longer time period.

Overstatement is also possible in terms of people reporting being treated unfairly by some group, but forgetting that it had to be unfair treatment because of their mental illness. For example, if a service user feels treated unfairly by a person who ends a relationship with them, because they have found someone else, the service user might include this because they forgot that they had to answer only for unfair treatment resulting from their mental health problems (in this example we are assuming the mental health problems were not the reason for the unfair treatment).

On a related but slightly different issue, taking the example of family again, conflict can arise in any family and people can feel treated unfairly. If a person has a mental illness they may assume that the unfair treatment is related to their having a mental illness, whereas they may have received similar treatment and felt similarly unfairly treated if they did not have a mental illness. For this survey, the results must be based on service users' perceptions and attributions; it is not possible to know if responses would have been different if the individual did not have a mental illness.

THE REAL STORY BEHIND THE NUMBERS

It is important to finally have a benchmark survey, but it does need to be interpreted in conjunction with qualitative findings. The written comments that participants kindly provided at the end of the survey provide some sense of the real story behind the numbers. The Mental Health Foundation publication, *Respect Costs Nothing*[6], also provides more insight into what discrimination really looks like and what it is to experience it.

IMPORTANT TO ACKNOWLEDGE POSITIVE TREATMENT

The primary focus in the survey has been on discrimination, however it is also important to acknowledge the efforts that are being made to provide appropriate support to service users. The fact that the proportions being treated more positively outweighed those being treated unfairly on all the items asked about, is heartening testimony that there are a lot of people who are keen to be supportive and are putting this into action.

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[6] M Peterson, D, Pere, L, Sheehan, N and Surgenor, G. (2004) *Respect Costs Nothing: A survey of discrimination faced by people with experience of mental illness in Aotearoa New Zealand*, Mental Health Foundation of New Zealand

3 INTRODUCTION

BACKGROUND AND OBJECTIVES

The 'Like Minds, Like Mine' project to reduce stigma and discrimination associated with mental illness began in 1997. Tracking surveys undertaken by Phoenix Research[7] have shown that the campaign has been successful in improving attitudes within the general public. However, the most important question is whether it is succeeding in reducing stigma and discrimination, as reported by persons with experience of mental illness.

In 2009, Phoenix Research completed a review of all the existing and possible additional ways that could be developed for measuring changes in discrimination[8]. It was apparent that the alternatives were quite limited and that regular service user surveys were essential.

Phoenix Research undertook a previous service user survey for 'Like Minds, Like Mine' in mid 2003[9], but this had a small budget and the methodology relied on service user networks for sampling, so was not sufficiently rigorous to serve as an accurate benchmark.

The Mental Health Foundation undertook a self-completion survey relating to discrimination faced by people with experience of mental illness, which was completed by 785 service users in April to June 2003[10]. However, this was never designed with the intention of being replicated and therefore did not have a methodology that would allow for accurately tracking changes over time.

The current survey is therefore a benchmark survey, but it does include two questions to ascertain perceived changes over the previous five years.

This survey is at the forefront of such initiatives internationally, just as 'Like Minds, Like Mine' programme has been.

At the time this survey was planned, the researchers were unable to identify any similar projects internationally, apart from one planned in England. The English project, being led by Professor Graham Thornicroft's team at Kings College Institute of Psychiatry, is now in its fourth year. They are undertaking annual telephone interviews with samples of approximately 1000 service users. These Viewpoint surveys are being used to evaluate 'Time for Change', which has similar objectives to the 'Like Minds' programme in New Zealand.

Objectives

The primary objective was to provide benchmark data, to allow for tracking changes over time in service user experienced and anticipated discrimination (self-discrimination).

Other objectives were:

- To identify perceived levels of change over the previous five years
- To measure ways in which they have overcome stigma and discrimination

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[7] Brown, R., Howearth, J., Wyllie, A. (2011), *Impacts of National Media Campaign to Counter Stigma and Discrimination Associated with Mental Illness: Survey 11: Initial Response to the Fifth Phase of Campaign*, Phoenix Research.

[8] Phoenix Research (2009), *Monitoring changes in discrimination and social inclusion experienced by persons with mental illnesses.*

[9] Akroyd, S. and Wyllie, A. (2003), *People with Experience of Mental Illness: Perceptions of the Like Minds Project*, Phoenix Research.

[10] Mental Health Foundation of New Zealand (2004), *Respect Costs Nothing: A survey of discrimination faced by people with experience of mental illness in Aotearoa New Zealand*.

- To measure experience of being treated more positively because of mental health problems
- To identify the perceived impact of the 'Like Minds' programme

4 RESEARCH METHODS

NEED FOR RESEARCH METHODS WHICH WILL ENABLE CHANGE OVER TIME TO BE ACCURATELY IDENTIFIED

As the primary purpose of this survey was to establish a benchmark against which to track changes in discrimination based on service users' own experiences, it was essential to have sufficiently rigorous research methods to allow this. Methods were required which could be replicated each time the survey was repeated (possibly at five yearly intervals), so that there could be confidence that any changes (or lack of changes) did reflect reality and were not just a product of variations in research methods. If there were variations, there would always be question marks over the validity of the data. This had implications especially for the way the sample was selected, but also for things such as obtaining similar levels of DHB support each time.

SAMPLING FRAME

The implication of the need for rigorous research methods was that the best way of obtaining a representative and consistent survey over time was to draw the sample only from DHB service user data bases, covering both in-patient and community services. This was done by the Ministry of Health via the PRIMHD data base.

The option of also drawing sample through NGOs was explored, but it was decided that there was too much change within the NGO sector to be confident that a similar sample could be drawn for each survey.

Contacting people through service user networks was also explored. While this would have assisted in encouraging participation, there was no way that this method could ensure a similar sample was drawn for each survey or that it would be sufficiently representative.

ELIGIBLE PERSONS

All persons who had used the mental health services in the previous 12 months were eligible, with the following main exceptions, which were removed prior to sample selection:

- All persons who had died[11]
- Persons in psychogeriatric wards
- Those with intellectual disability

The specific exclusions used to extract the data are included in Appendix D.

METHODS OF DATA COLLECTION

The following methods of data collection were used:

- A mailed self-completion survey, which was completed by individuals and sent back to Phoenix Research in a freepost envelope.
- Online survey, which could be accessed by those sent the mail questionnaire, if they would rather do it electronically. This option was used by 57 persons.
- Phone survey, which again was an option for those mailed the questionnaire. Persons were offered the opportunity of ringing the Phoenix Research 0800 number and arranging a time to call back

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[11] Unfortunately in the pilot, the Ministry of Health forgot to remove persons who had died.

when an interviewer would be available, or doing the interview then if the interviewer was available. Alternatively, if they were willing to supply their contact details, an interviewer rang them back at the agreed time. This option was used by 30 persons.

The online and phone options were offered with the intention of enhancing the response rate.

Attached to the mailed questionnaire was a covering letter, on Ministry of Health letterhead (drafted in conjunction with Phoenix Research) and signed by the National 'Like Minds, Like Mine' Co-ordinator. The letter explained the purpose of the survey, how their name had been selected and invited them to complete the attached survey or do the online or phone versions. There was an accompanying information sheet which provided more details. The letter and information sheet are attached as Appendix A. Participants were asked to place the completed self-completion surveys in the supplied addressed freepost envelope, addressed to Phoenix Research.

A reminder letter was sent out at least three weeks after the main mail out, to those who had not responded.

To reduce the risk of participation by persons who had not been randomly selected, each questionnaire included a unique randomly selected code. Those completing the survey online needed to enter this code to be able to complete the survey. Likewise those phoning in needed to supply their unique code number to the interviewer. The codes were allocated in a manner that ensured that someone couldn’t just enter the next number from the one their friend had and be able to use someone else’s code (i.e. they were not consecutively numbered).

SAMPLE SIZE AND COMPOSITION

To obtain sufficient numbers for Māori, Pacific, Asian, youth and males, these groups were over-sampled (i.e. more were sent out than their share of the service users nationally). The numbers specified for selection within each DHB, in terms of age within gender within ethnicity, and AOD service use are shown in Appendix D. In some cases there were insufficient numbers in the Ministry of Health data base, so they supplied what they did have.

For the pilot mail out, a total of 1036 questionnaires were sent out. This included 123 persons who were also sent Samoan translations, 69 Tongan translations, 69 Cook Island translations, 58 Niuean translations and 116 Chinese translations.

For the main mail out a total of 5796 questionnaires were sent, which included 455 who were also sent Samoan translations, 143 Tongan translations, 257 Cook Island translations, 70 Niuean translations and 175 Chinese translations. These people also received English versions of everything.

The inclusion of Pacific translations was following discussions at Pacific 'Like Minds' provider fono, where there was a strong view that the questionnaire and associated material (covering letter, information sheet) would need to be translated to increase Pacific participation.

TIMING OF DATA COLLECTION

One DHB formed the pilot site and data collection took place between 18 November 2009 and late January, 2010. Data collection for the main survey took place between 20 September 2010 and 19 January, 2011. The data from the pilot site was included in the final data set.

SAMPLE SELECTION

The Ministry of Health agreed to undertake the random selection of the samples for the specified DHBs. DHBs are required to routinely supply data on the use of mental health services to the Ministry. This data base, PRIMHD, is updated monthly. The Ministry also have addresses from the NHI (National Health Index) data base, which they agreed to link to the selected sample. The Ministry were not able to undertake the mail out themselves and some of the DHBs indicated that they would not have the resources to do this. Phoenix Research therefore obtained ethical approval from the Multi-region Ethics Committee for the Ministry to send the selected sample with matching addresses to Phoenix Research, who then undertook the mail out on behalf of the Ministry.

This approach did mean that the identity of the survey participants became known to Phoenix Research, but none of the participants' mental health history was made available to Phoenix. Phoenix Research ensured this information remained confidential.

There were some people who contacted either Phoenix Research or the Ministry of Health to complain that their records had been used in this way. Most were surprised to learn that the Ministry of Health held such records. Some did not consider they had a mental illness, which was quite possible given they only had to have one contact with mental health services to be included. Although a record was not kept of the number of calls, it is estimated that it was in the range of 30 to 40 persons who contacted Phoenix Research. This was a very small percentage of the 6,832 service users who sent questionnaires; less than half a percent. When these persons did complain they were removed from the mailing list for reminder letters, if they had identified themselves sufficiently, which was not always the case.

When undertaking subsequent surveys, it is recommended that persons be given the option of ticking a form that says they have not had a mental illness (and therefore the survey does not apply to them) and just sending this back in the freepost envelope. There would also need to be additional comment in the covering letter to this effect. Another box to tick that could be included is 'This person is no longer at this address'. Having responses to these two categories would assist in improving the response rate.

Another option to try and remove persons without mental illness would be to not sample persons with just one to two contacts with mental health services in the previous 12 months. However, these people do report experiencing discrimination, so it would be important to retain them.

While removing persons without mental illness will address some of the concerns, it will not address those who are concerned about their information being provided to the researchers. It is difficult to see how this can be addressed and it may be a case of having to weigh up this disadvantage against the advantages for service users provided by the survey. A key advantage is that data from these surveys will play an important role in determining the on-going funding of the 'Like Minds' programme.

When planning the current survey, it was noted that persons currently using acute in-patient services would not be at the address to which the questionnaires were mailed, but it was likely that family/friends would be taking mail into them. It was felt that people at any stage of their illness/recovery process usually appreciate the opportunity to have their say on matters such as this. It was therefore considered important that these people were provided with the dignity of being able to choose for themselves whether they wished to participate.

For budget reasons, and also not to impose excessively on DHBs, it was necessary to limit to 10 the number of DHBs who provided sample. The DHBs were selected to provide a good spread in terms of: ethnic composition, geographic location, urban/rural, and level of deprivation. The DHBs included were: Northland, Auckland, Counties Manukau, Waikato, Taranaki, Mid Central, Capital and Coast, Canterbury, Otago, and Southland (these last two have since been merged into one DHB, but were separate at the time of the survey).

The selection process entailed the Ministry dividing the current service user data base for the 10 selected DHBs into 16 cells (4 ethnicity groups by 2 gender by 2 age). There were also separate cells for AOD service users in each DHB. There were none of this group included in the pilot, as the pilot DHB did not provide this service (other DHBs in the region did). The Ministry then randomly selected the required number from each cell, as specified by Phoenix Research (based on ethnicity of the New Zealand DHB service user population, allowing for males having lower response rates).

There were no quotas set for the sample mail out in terms of the clinical labels people had been given. While level of discrimination may be linked to specific labels, some people don't want to be labelled and some people have been given more than one label.

There were also discussions prior to the survey as to whether the sample should try and include some persons who used Accident & Emergency (A&E) services while they were mentally unwell. However, this would have probably required working with different parts of the DHB (e.g. Psychiatric Liaison) and people were unsure as to whether the DHBs would be able to identify such people from their records. It was also felt that some of these people may not have been aware that they had been labelled as having a mental illness, so it was considered best to not try and obtain sample from A&E admissions. The survey did include a question which identified discrimination while receiving treatment for physical health problems in hospitals (including emergency treatment).

The sample was selected from users of DHB mental health services for the 12 month period ending 30 June 2010.

ACHIEVED SAMPLE

A total of 1,135 completed the questionnaire. This included 225 Māori, 196 Pacific, 152 Asian persons. It also included 190 young persons (those aged 16 to 24 years). The alcohol and other drug (AOD) sub-sample generated only 39 participants.

There were only a small number of translated questionnaires returned: 8 Samoan, 5 Niuean, 5 Tongan, 4 Cook Island Māori and 20 Chinese. There was also one Samoan interview done by phone. The number of Samoan returns may have been affected by an error that the translation company made in the wording of the scale used to measure the level of unfair treatment. This was identified when a Phoenix interviewer attempted to do a phone interview in Samoan. A corrected Samoan questionnaire was mailed out to all Samoan persons, advising them of the error. No English version was included in this second mail out, but they were told that if they no longer had their English version and wanted to use this option, they could either do it on-line, phone Phoenix Research for another copy to be sent out, or do the survey by phone.

RESPONSE RATE

The researchers were conscious that it was going to be a challenge to get a good response rate, given the response rates being achieved for the Ministry of Health Consumer Satisfaction surveys, which are also mailed questionnaires completed by service users.

It was important that the survey was seen to have the strong support of the service user community and this was demonstrated by the front cover of the questionnaire featuring photos of ten service users from different ethnic groups endorsing the survey.

A poster was developed, based on the winning entry from a competition run by Phoenix Research with service users (see Appendix C). This was distributed to the DHBs and the 'Like Minds' regional providers, who were encouraged to display them in places frequented by service users. Over 200 were issued.

The survey was also promoted on the 'Like Minds' website, through various electronic newsletters and at the 'Like Minds' provider hui.

It was anticipated that the survey would be seen as a positive initiative by service users and they would be keen to participate once they knew the purpose of it and knew that it was anonymous (they were asked not to put their name on the questionnaire) and safe.

The questionnaires and covering letter were produced in colour, as the pilot identified that this option produced a much better response rate. In the pilot some were sent out as colour and some mainly black and white (the covering letter and front page of the questionnaire were in colour, and the information sheet and remainder of the questionnaire were black and white).

Given the efforts to enhance the response rate, the achieved rate of 18% was disappointing. It did increase to 20% among the higher user service group (those who had more than 10 contacts with DHB mental health services in the previous 12 months).

The response rate was affected by questionnaires that would never have got to the persons, due to changes of address. There were 282 which were sent back 'return to sender', but there would have been many more if this many got returned.

There were also 30 who replied saying they did not have mental illness. As persons could have had just one encounter with mental health services and not even realised that was who they were dealing with, there could have been a lot more people who did not consider they had a mental illness who did not respond to the survey for that reason.

The response rate was calculated by dividing the number of returns by the number sent out, minus these exclusions noted above (i.e. known to have not reached the person or person did not have mental illness).

The variation across the different groups is shown below.

Table 1: Response rate

RESPONSE RATE	%
Total sample:	**18**
Age:	
16 to 24 years	10
24 years or over	21
Gender:	
Male	18
Female	16
Ethnicity:	
Māori	15
Pacific	13
Asian	14
Other	23
Total contacts with DHB mental health services:	
1 to 2	13
3 to 10	16
11 to 25	22
26 or over	20
AOD versus Non-AOD:	
AOD	13
Non-AOD	18

QUESTIONNAIRE DEVELOPMENT

Professor Graham Thornicroft from The Institute of Psychiatry at Kings College, London agreed to their Discrimination and Stigma Scale (DISC) forming the basis of the questionnaire used in New Zealand. Professor Thornicroft and his colleagues are undertaking similar research in England and he is possibly the leading academic in this field. In return for allowing the use of their scale, they will have access to the data base and will be able to publish a paper using the data, with Dr Allan Wyllie from Phoenix Research being the second author and with the New Zealand Ministry of Health receiving appropriate acknowledgement.

The DISC questionnaire was established following a literature review and it has been tested in 28 study sites around the world. The validity and reliability of this measure, when administered face to face, has been established[12].

While this questionnaire had only been used in face to face data collection at that point in time, Phoenix Research believed it would be effective for self-completion, as did Professor Thornicroft's group. The face to face version requires people providing an example of each form of discrimination and this was not be asked for in the self-completion version used in New Zealand. This was expected to take the interview duration down from the 20-30 minutes for their face to face version to 10 to 15 minutes.

The questionnaire used almost all of the DISC items with the same wording. A small number had the wording changed to make them more appropriate for New Zealand and a small number of extra items

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[12] Thornicroft, G, Brohan, E., Rose, D., Sartorius, N., Leese, M., and the INDIGO Study Group (2009) Global Pattern of Experienced and Anticipated Discrimination against People with Schizophrenia, *Lancet* 373:408-15.

were added which were seen as relevant in New Zealand. One notable difference from the DISC used to date is that the current survey added two questions to ascertain the extent to which service users felt discrimination had got better or worse compared with five years ago.

Prior to the pilot study, the questionnaire was pre-tested among the different ethnic groups, to ensure it was measuring what it is intended to measure (i.e. that the measures have face validity). This process entailed asking service users to complete the self-completion questionnaire and once they had done this, to be interviewed either by phone or face to face. The interviewer obtained feedback on any questions that they had any difficulty understanding or answering, or that they thought other people might find difficult. They were then asked to give an example of each form of discrimination that they had reported experiencing (as in the standard DISC questionnaire), to check that they were talking about the form of discrimination that the questionnaire item was seeking to measure. There was a mix of people in terms of gender, age, ethnicity and time since first contact with mental health services. These people were recruited through service user networks and had to have used mental health services within the last five years (it was considered that this less stringent criterion would be sufficient for pre-testing purposes).

PEER REVIEW/ CONSULTATION

The methodology and questionnaire were peer reviewed by an international researcher and a New Zealand person with experience of mental illness who has research expertise.

The following groups were consulted regarding the most appropriate methods for the survey and for comment on the questionnaire:

- Ministry of Health
- Service User Advisory Group, convened by Phoenix Research, which includes Māori and Pacific representatives
- Like Minds Maori Caucus
- Like Minds Pacific Provider fono
- DHB mental health managers and clinical directors

The proposed research methods were also presented and discussed at two of the annual 'Like Minds' provider seminars.

WEIGHTING

Prior to analysis of the data, the achieved sample was weighted to provide Total Sample figures where the gender, age (16 to 24 and 25 years and over) and ethnic composition (Māori, Pacific, Asian, Other) matched the proportions for all DHBs supplying data to PRIMHD.

ANALYSIS

Analyses have been undertaken to identify differences within sub-groups. These sub-group comparisons are made against the Total Sample, unless otherwise stated. The exceptions are where there are only two categories and they can be compared with each other, these being: gender (males vs females), whether under the Mental Health Act (yes vs no), and whether an AOD (Alcohol or Other Drug) service user (yes vs no).

All differences reported are statistically significant at the 95% level of confidence. Those that are significant at the 99% level are denoted by an asterix (*).

5 MAIN FINDINGS

5.1 DESCRIPTION OF PARTICIPANTS

As noted in the Methods section, Pacific and Asian were oversampled to provide sufficient sized numbers for each group. This was then adjusted for by weighting prior to analysis, to reflect the ethnic composition of all service users in the 12 month period that the sample was drawn from. Table 2 below shows that there were 196 Pacific and 152 Asian persons who completed questionnaires. They accounted for 17% and 13% of the total of 1,135 completed questionnaires. After weighting, they accounted for 8% and 4% (as shown in the final column in Table 2).

Young people (16 to 24 year olds) were also oversampled. However, because they had a low response rate they were still under-represented in the completed questionnaires. There were 190 who completed the questionnaire, which was 17%, but this was weighted up to 20% to reflect their correct proportion among service users.

Gender was the other variable included in the weighting. Females accounted for 57% of the completed questionnaires, but were weighted down to 47% to reflect their correct proportion among service users.

The weighting did not have a lot of impact on most of the other classification variables used in the survey. The biggest change was in the lowest education grouping, where there were 38% in the unweighted sample and 42% in the weighted.

Level of contact with DHB mental health services over the previous 12 months was based on number of contacts plus number of bed-nights, as reported by the DHB on the Ministry of Health data base. There were 23% of the participants who had more than 25 contacts or bednights with DHB mental health services in the previous 12 months and another 21% who had 11-25.

There were 45% of participants who had been using mental health services for less than five years, while 31% had been using them for more than 10 years.

There were 31% who had been under the Mental Health Act in the last 12 months (it was noted on the questionnaire that this was a compulsory treatment order).

There were just 43 (4%) participants who were currently receiving in-patient/hospital services, while 57% were receiving community mental health services. There were 19% who said they were receiving some other type of service and 23% who said they were receiving none. People could mention more than one service, which is why the percentages total a little over 100%.

In terms of all forms of care received over the last five years, including current care, 33% had received in-patient/hospital services, 78% community mental health services and 28% other services.

Just 29 of the participants (3%) were users of alcohol and other drug (AOD) services, so their findings need to be interpreted with caution due to their small numbers.

Table 2: Description of participants

DESCRIPTION OF PARTICIPANTS	Total sample (n=	Total sample Unweighted %	Total sample Weighted %
Ethnicity			
Maori	225	20	20
Pacific	196	17	8
Asian	152	13	4
Other	728	64	80
Not answered	6	1	0
Age			
16 to 24 years	190	17	20
25 to 44 years	474	42	38
45 to 64 years	412	36	37
65 years or over	58	5	5
Not answered	1	0	0
Gender			
Female	643	57	47
Male	490	43	53
Not answered	2	0	0
Highest level education			
University degree/diploma	241	21	19
Other tertiary qualification	203	18	18
Tertiary study (not completed)	169	15	15
High school/other school	436	38	42
Not answered	85	7	6
In paid work			
Full-time (30+ hours a week)	158	14	14
Part-time	205	18	17
Not in paid work	723	64	65
Not answered	49	4	4
Under Mental Health Act last 12 months			
Yes	367	32	31
No	727	64	66
Not answered	40	4	3
Number of contacts and bed nights in last 12 months			
1 to 2 nights	259	23	24
3 to 10 nights	314	28	28
11 to 25 nights	248	22	21
26 or more nights	279	25	23
Not specified	35	3	3
Number years since first contact with mental health services			
0 to 4 years	517	46	45
5 to 9 years	173	15	15
10 to 19 years	179	16	16
20 or more years	152	13	15
More than 5 years but not stated	27	2	2
Don't know	40	4	3
Current main type mental health care			
In-patient/hospital services	43	4	4
Community mental health services	636	56	57
Other	207	18	19
None	264	23	23
Not answered	26	2	2

DESCRIPTION OF PARTICIPANTS	Total sample (n=	Total sample Unweighted %	Total sample Weighted %
Total types mental health care last 5 year			
In-patient/hospital services	364	32	33
Community mental health services	872	77	78
Other	305	27	28
None	89	8	8
Not answered	17	1	1
Users of AOD services	**29**	**3**	**3**

5.2 DISCRIMINATION EXPERIENCED

There were 89% who reported at least 'a little' unfair treatment in the last 12 months because of mental health problems on at least one of the 26 items asked about. The mean number mentioned was 7.4. When only the 'moderately' and 'a lot' response were considered, there were 70% who mentioned at least one, with a mean of 4.1.

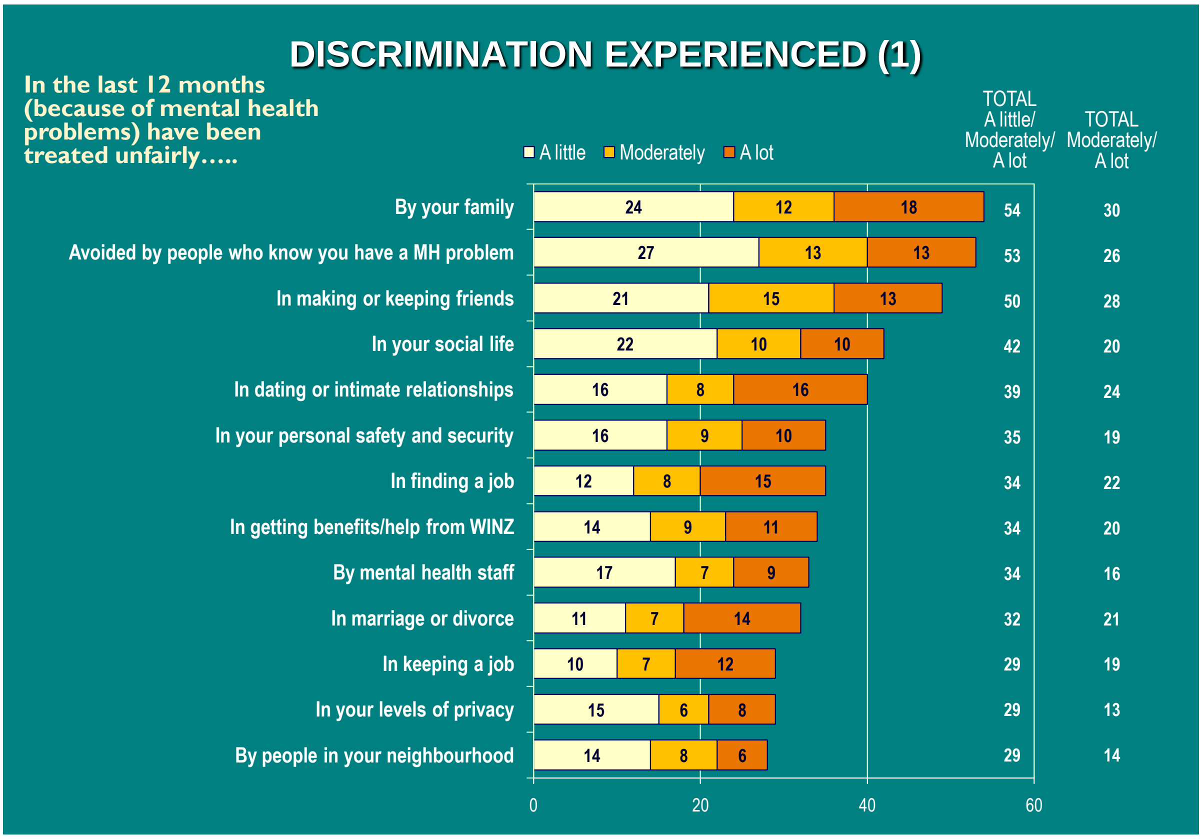
Graph 3 and Graph 4 show the proportion giving each rating for some level of unfair treatment. They are ranked in order of mentions based on the totals for those mentioning at least 'a little' unfair treatment. On the right hand side is firstly the proportion mentioning either 'a little', 'moderately' or 'a lot'. The final column is the proportion mentioning either 'moderately' or 'a lot'.

Most mentioned was Family (54% mentioned at least 'a little' harmful effect) and 'Avoided (shunned) by people who know you have a mental health problem' (53%). Next were a group of three items which all related to friendships and social life: Making or keeping friends (50%), Social Life (42%) and Dating or intimate relationships (39%). Personal safety and security was next most mentioned (35%) and this included 'any verbal abuse, physical abuse, assault'. Mental health staff was ninth most mentioned, at 34%.

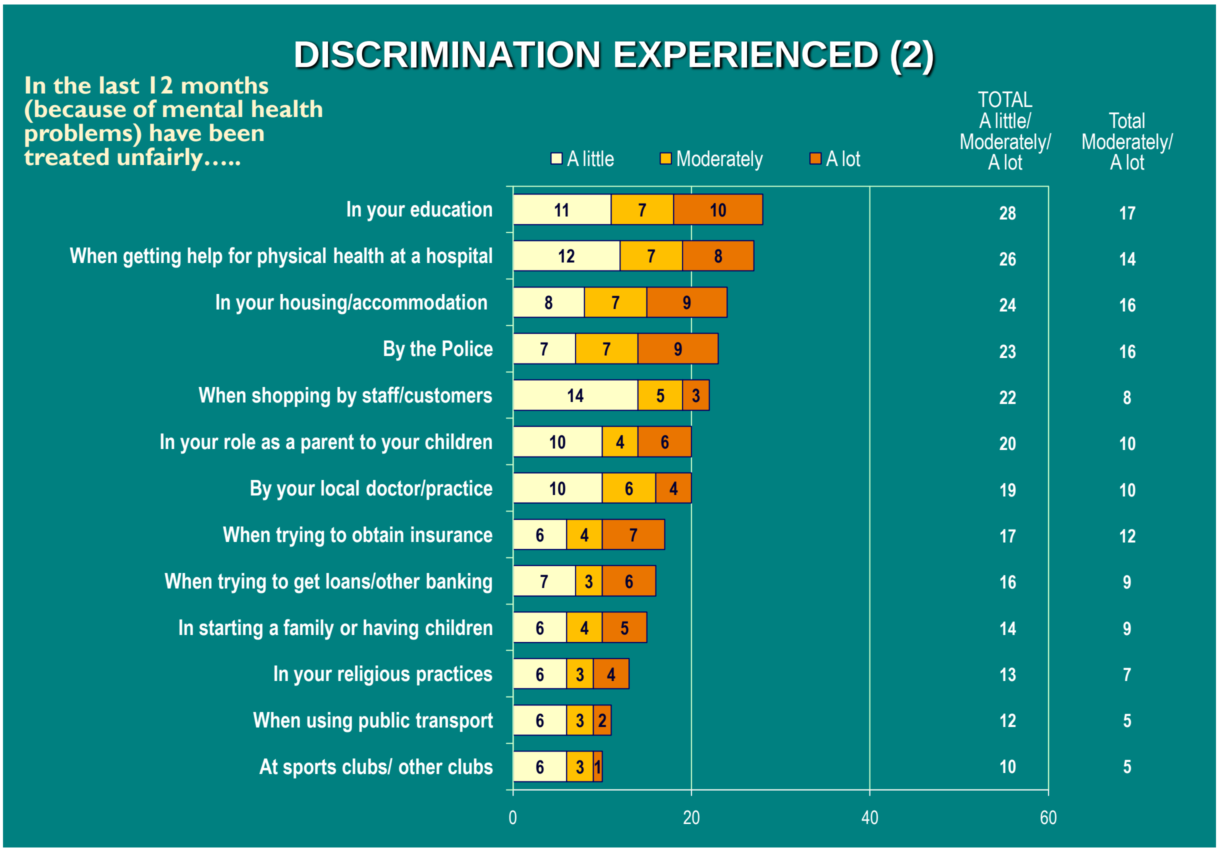
When the totals for just **''moderately' or 'a lot'** are considered, there was some reordering, but the general pattern remained. Family still remains most mentioned (30%), and was followed by Making or keeping friends (28%), ahead of Avoided (shunned) by people who know you have a mental health problem (26%) and Dating or Intimate relationships (24%). Marriage or divorce moved up to sixth mention (21%), compared with being tenth in the other total (32%). Mental health staff was twelfth most mentioned, at 16%.

When just those who reported being treated unfairly **'a lot'** are considered, the highest mentions were: Family (18%), Dating or intimate relationships (16%), Finding a job (15%), Marriage/divorce (14%), Avoided (shunned) by people who know you have a mental health problem (13%), Making or keeping friends (13%), and Keeping a job (12%). Mental health staff was twelfth most mentioned, at 9%.

Graph 3: Discrimination experienced (1)



Graph 4: Discrimination experienced (2)



The figures in the graphs are all based on the Total Sample. However, for each question there were some people who considered it was not appropriate and a few (one to two percent) who did not answer. Table 3 compares the results for the Total Sample with **those who gave ratings on each question**. The final column in the table shows the number, out of the total of 1,135 who gave a rating. There were nine items which received the highest mentions for 'moderately' or 'a lot' and these ranged from 25% to the high of 34%, these being:

- Finding a job (34%)
- Marriage/divorce (33%)
- Family (32%)
- Dating/relationships (31%)
- Making/keeping friends (30%)
- Keeping a job (30%)
- Avoided/shunned by people who know you have a mental illness (28%)
- Getting benefits of help from WINZ (26%)
- Education (25%)

Mental health staff was seventeenth most mentioned, at 18%.

Table 3: Discrimination experienced

WAYS IN WHICH TREATED UNFAIRLY BECAUSE OF MENTAL HEALTH PROBLEMS	TOTAL MODERATELY/ A LOT		
	Total sample	Those who gave a rating*	
	%	%	(n=
Family (including family of origin, i.e. parents, brothers, sisters or other relations, as well as partner/spouse or any children of your own)	30	32	1074
Making/keeping friends	28	30	1048
Avoided (shunned) by people who know you have a mental health problem	26	28	1055
Dating/intimate relationships	24	31	870
Finding a job (finding regular full or part-time paid work)	22	34	745
Marriage/divorce (e.g. ability to find a partner or spouse, problems during the relationship, divorce settlements, etc)	21	33	742
Getting benefits or help from WINZ (e.g. applying for benefits, level of benefits, support)	20	26	895
Social life (e.g. socialising, hobbies, attending events)	20	22	1004
Personal safety/security (including any verbal abuse, physical abuse, assault)	19	21	1017
Keeping a job	19	30	729
Education (e.g. school, college, university, tertiary courses, on the job training)	17	25	787
Mental health staff (e.g. behaviour of staff, feeling disrespected or humiliated by contact with mental health staff)	16	18	1058
Police	16	23	791
Housing/accommodation (including becoming homeless)	16	19	929
People in neighbourhood	14	16	1032
Physical health problems at a hospital (including emergency treatment)	14	17	931
Levels of privacy (including privacy in hospital and in community setting, e.g. private letters or phone calls)	13	15	991
Trying to obtain insurance	12	21	639
Role as parent to your children (e.g. behaviour of other parents, teachers, family or mental health staff)	10	19	630
Local doctor (i.e. your GP), or people who work in the doctor's practice?	10	10	1078
Trying to obtain loans or other banking services	9	15	710
Starting a family or having children (e.g. behaviour of health professionals, friends and family, as well as how you or your partner were treated during pregnancy or childbirth)	9	19	535
When shopping (e.g. by shop staff or other customers)	8	9	1000
Religious practices (e.g. attending church, other parishioners, church leaders, participation in spiritual practices)	7	11	737
Using public transport (e.g. by fellow passengers, drivers, etc)	5	7	839
At sports/other clubs	5	8	648

* Excludes those saying "Not applicable" or not giving an answer

DIFFERENCES ACROSS SUB-GROUPS

In this section and those that follow, sub-group comparisons within the current survey are made against the Total Sample, unless otherwise stated. The exceptions are where there are only two categories and they can be compared with each other, these being: gender (males vs females), whether under the Mental Health Act (yes vs no), and whether an AOD (Alcohol or Other Drug) service user (yes vs no).

For all comparisons of differences across sub-groups, all percentage figures represent the sum of responses where items were rated 'moderately' or 'a lot'. All differences reported are statistically significant at the 95% level of confidence. Those that are significant at the 99% level are denoted by an asterix (*).

Number of contacts with DHB mental health services

- A key finding was that among the highest users of services (those with more than 25 contacts in the last 12 months), 26% mentioned being treated unfairly by Mental health staff 'moderately' or 'a lot', which compared with the 16% for the Total Sample *. Among this group of high users, this was the fifth most mentioned source of discrimination after: Making/keeping friends (36%), Family (33%), Avoided by people who know you have mental health problems (27%), and Dating and intimate relationships (26%).
- This group with 26 or more contacts were also *more likely* to mention unfair treatment regarding:
    - Making/keeping friends (36% vs 28%)
    - *At least one of the 26 items* (77% vs 70%)
- People with 3-10 contacts were *less likely* than the Total Sample to report unfair treatment regarding:
    - Religious practices (3% vs 7%)
- People with 1-2 contacts were *more likely* to report unfair treatment regarding:
    - Social life (26% vs 20%)

Number of years been using mental health services

- People who had used mental health services for 5-9 years were *more likely* to report unfair treatment for:
    - Dating/relationships (31% vs 24%)

Current main type of care receiving

- The small group of people currently receiving in-patient/hospital services (n=41) reported unfair treatment with regards to a greater number of statements than the Total Sample (5.9 vs 4.1), and were *more likely* to report this for the following aspects in particular:
    - Avoided by people who know you have a mental health problem (43% vs 26%)
    - Finding a job (39% vs 22%)
    - Social life (34% vs 20%)
    - Personal safety and security (37% vs 19%)*
    - Housing/accommodation (29% vs 16%)
    - Levels of privacy (28% vs 13%)
    - Having children (19% vs 9%)

- Mental health staff was mentioned by 24% of those currently receiving in-patient/hospital services, which was the twelfth most mentioned item. This compared with 16% for those currently using community mental health services (although this difference did not qualify as significant).

Total types of care in last five years

- People receiving in-patient/hospital services over the last five years were *more likely* to report unfair treatment from Mental health staff (22% versus 16% for the Total Sample). This was their eighth most mentioned item. It must be remembered that the question was only asking about unfair treatment in the last 12 months, although it is possible that some people forgot to limit their answers to this time period.
- People receiving in-patient/hospital services over the last five years were *less likely* to report unfair treatment in regards to:
  - Shopping (5% vs 8%)
  - Using public transport (3% vs 5%)

Been under Mental Health Act in previous 12 months

- People who had been under the Mental Health Act in the previous 12 months on average reported unfair treatment for a greater number of the statements than the rest of the respondents (4.7 vs 3.9). They were *more likely* to report unfair treatment for the following statements in particular:
  - Finding a job (28% for those under the Act vs 20% for the rest)*
  - Getting benefits or help from WINZ (25% vs 18%)
  - Personal safety and security (23% vs 17%)
  - Education (22% vs 15%)*
  - Police (23% vs 13%)*
  - Housing/accommodation (20% vs 14%)
  - Religious practices (9% vs 6%)
- Mental health staff were mentioned by 18% of this group, which was not statistically significant from the 16% for the Total Sample.

Users of AOD services

- The small group of users of AOD services reported unfair treatment for more statements, on average, than non-users (6.9 vs 4.4). In particular, AOD users were *more likely* to report unfair treatment for the following statements:
  - Dating or intimate relationships (45% for AOD users vs 23% for the rest)*
  - Finding a job (38% vs 22%)
  - Marriage or divorce (38% vs 21%)
  - Police (30% vs 16%)
  - Getting hospital/physical help (31% vs 14%)
  - Obtaining insurance (27% vs 11%)
  - Using public transport (15% vs 5%)
  - Sports clubs or other clubs (15% vs 4%)

Ethnicity

- Compared to the Total Sample, Maori reported unfair treatment for a greater number of statements on average (4.9 vs 4.1). Maori were *more likely* to report unfair treatment in regards to:
    - Personal safety and security (26% vs 19%)
    - Education (23% vs 17%)
    - Police (23% vs 16%)*
    - *At least one of the 26 items* (78% vs 70%)
- Pacific peoples were *more likely* to report unfair treatment in regards to:
    - Using public transport (11% vs 5%)*
- Asian peoples were *less likely* to report unfair treatment in regards to:
    - Avoided by people who know you have a mental health problem (18% vs 26%)

Age

- People aged 16-24 were *more likely* to report unfair treatment in regards to:
    - Making or keeping friends (36% vs 28%)
    - Education (26% vs 17%)*

    And *less likely* in regards to:

    - Marriage or divorce (9% vs 21%)*
- People aged 45-64 were *more likely* to report unfair treatment in regards to:
    - Marriage or divorce (28% vs 21%)*
- People aged 65 and over were *less likely* to report unfair treatment in regards to:
    - *At least one of the 26 items* (34% vs 70%)*
    - Family (12% vs 30%)*
    - Making or keeping friends (6% vs 28%)*
    - Avoided by people who know you have a mental health problem(6% vs 26%)*
    - Dating or intimate relationships (6% vs 24%)*
    - Finding a job (1% vs 22%)*
    - Marriage or divorce (9% vs 21%)
    - Getting benefits or help from WINZ (8% vs 20%)
    - Social life (1% vs 20%)*
    - Personal safety and security (5% vs 19%)*
    - Keeping a job (0.5% vs 19%)*
    - Education (2% vs 17%)*
    - Mental Health Staff (3% vs 16%)*
    - Police (5% vs 16%)
    - Housing/accommodation (5% vs 16%)
    - People in your neighbourhood (4% vs 14%)
    - Getting hospital/physical help (1% vs 14%)*
    - Levels of privacy (3% vs 13%)

Gender

- Males were *more likely* than females to report unfair treatment in regards to:
    - Finding a job (26% vs 18%)*
    - Keeping a job (22% vs 15%)*
    - Education (21% vs 13%)*
    - Housing/accommodation (19% vs 12%)*
    - Police (19% vs 13%)
    - People in your neighbourhood (16% vs 12%)
    - Obtaining loans or banking (11% vs 7%)
    - Sports clubs or other clubs (6% vs 3%)
- Females were *more likely* than males to report unfair treatment in regards to:
    - Family (33% vs 27%)

Highest level of education

- People with a university degree or higher were *less likely* than the Total Sample to report unfair treatment in regards to:
    - Education (8% vs 17%) *
- People with tertiary education (not completed) were *more likely* to report unfair treatment in regards to:
    - Housing/accommodation (22% vs 16%)
    - Getting hospital/physical help (20% vs 14%)
- People with education up to high school /college/ other school were *less likely* to report unfair treatment in regards to:
    - Mental Health Staff (11% vs 16%)

Level of paid employment

- Compared to the Total Sample, people who worked full time (30 or more hours per week) reported unfair treatment in regards to fewer statements on average (3.2 vs 4.1). In particular they were *less likely* to report unfair treatment for:
    - Finding a job (14% vs 22%)
    - Getting benefits of help from WINZ (12% vs 20%)
    - Personal safety and security (11% vs 19%)
    - Education (10% vs 17%)
    - People in your neighbourhood (6% vs 14%)*
- People who worked part time were *less likely* to report unfair treatment for:
    - Having children (4% vs 9%)

5.3 ANTICIPATED DISCRIMINATION

In terms of anticipated discrimination, there were 84% who reported at least 'a little' on one of the four items and 70% at least 'moderately'. The question asked: "In this section we would like you to answer about the times in the last 12 months when you stopped yourself from doing things that are important to you because of how others might respond to your mental health problems."

There were 12% who reported at least 'moderate' anticipated discrimination on all four items. The mean number of items rated at least 'moderate' by the Total Sample was 1.5 out of the 4.

As shown in Graph 5, almost three-quarters had concealed or hidden their mental health problems from others at least 'a little' and 57% had done it either 'moderately' or 'a lot'. The levels for the other three items are shown in the graph and Table 4 which follows.

Graph 5: Anticipated discrimination

Table 4: Anticipated discrimination

WHEN STOPPED FROM DOING THINGS BECAUSE OF HOW OTHERS MIGHT RESPOND TO MENTAL HEALTH PROBLEMS	Total sample	Those who gave a rating*	
	%	%	(n=
Concealed or hidden mental health problems from others	57	60	1073
Having a close personal relationship	37	44	926
Applying for work	33	45	824
Applying for education or training courses	24	35	805

* Excludes those saying "Not applicable" or not giving an answer

DIFFERENCES ACROSS SUB-GROUPS

Number of contacts with DHB mental health services

- People with 1-2 contacts with mental health services in the last 12 months were *more likely* than the Total Sample to say that their mental health problems had stopped them from applying for work at least 'moderately' (64% vs 57%).

Number of years been using mental health services

- For these questions there were no significant differences in responses according to the time spent using mental health services.

Current main type of care receiving

- People currently receiving in-patient/hospital services were *more likely* to say their mental health problems had stopped them from having a close personal relationship (53% vs 37%).
- People receiving community health services were *more likely* to say their mental health problems had stopped them from applying for work (38% vs 33%).
- People who were not receiving any care were *more likely* to say their mental health problems had stopped them from applying for work (26% vs 33%).

Total types of care in last five years

- Compared to the Total Sample, people receiving in-patient/hospital services were *more likely* to say their mental health problems had stopped them from having a close personal relationship (43% vs 37%).

Been under Mental Health Act in previous 12 months

- Those who had been under the Mental Health Act in the last 12 months were *less likely* than the rest to say they had concealed or hidden their mental health problems from others (53% for those under the Act vs 60% for the rest).

Users of AOD services

- AOD service users were *more likely* to say this was the case in regards to the following:
  - *All four of the statements* (30% for AOD vs 12% for the rest)*
  - Applying for education or training courses (42% vs 24%)

Ethnicity

- Compared with the Total Sample, Pacific peoples were *less likely* to say they had been stopped from doing at least one of the things listed (61% vs 70%)

Age

- Compared to the Total Sample, people aged 16-24, were *more likely* to say their mental health problems had affected them in regards to:

  - *At least one of the statements* (81% vs 70%)*
  - Concealed or hidden their mental health problems from others (69% vs 57%)*
- People aged 45-64 were *less likely* to say they were affected in regards to:
  - *At least one of the statements* (64% vs 70%)
  - Concealed or hidden their mental health problems from others (50% vs 57%)
- People aged 65 and over were *less likely* to say they were affected in regards to:
  - *At least one of the statements* (35% vs 70%)*
  - Applying for work (8% vs 33%)*
  - Applying for education of training (2% vs 24%)*
  - Having a close personal relationship (11% vs 37%)*
  - Concealed or hidden their mental health problems from others (50% vs 57%)*

Gender

- Females were *more likely* to say their mental health problems had restricted them in the following situations:
  - Applying for work (36% vs 30%)
  - Applying for education or training (27% vs 22%)
  - Concealed or hidden their mental health problems from others (61% vs 54%)

Highest level of education

- People with a university degree or higher were *more likely* to say they had been restricted in the following ways:
  - *At least one of the statements* (78% vs 70%)
  - Concealed or hidden their mental health problems from others (67% vs 57%)*
- People with tertiary education (not completed) were *more likely* to have felt restricted in terms of:
  - Applying for work (41% vs 33%)

Level of paid employment

- People who worked full time (30 or more hours per week) were *less likely* to say they had been restricted in terms of:
  - *All four statements* (7% for those working full time vs 13% for Total Sample)
  - Applying for work (20% vs 33%)*
  - Applying for work or training (16% vs 24%)
- People who worked part time were *more likely* to say they had been restricted in terms of:
  - Applying for work (38% vs 33%)
- People who were not in paid work were *less likely* to say they had been restricted in terms of:
  - Applying for work (13% vs 33%)*

5.4 OVERCOMING STIGMA AND DISCRIMINATION

The two questions in this section were preceded by the following introduction: 'In this section we would like to ask you about some examples of overcoming stigma and discrimination because of mental health problems, in the last 12 months.'

There were 58% who rated at least one of these two statements 'moderately' or 'a lot'. Forty-two percent had been able to use their personal skills or abilities in coping with stigma and discrimination. A similar proportion (43%) had made friends with people who don't use mental health services.

Graph 6: Overcoming stigma and discrimination

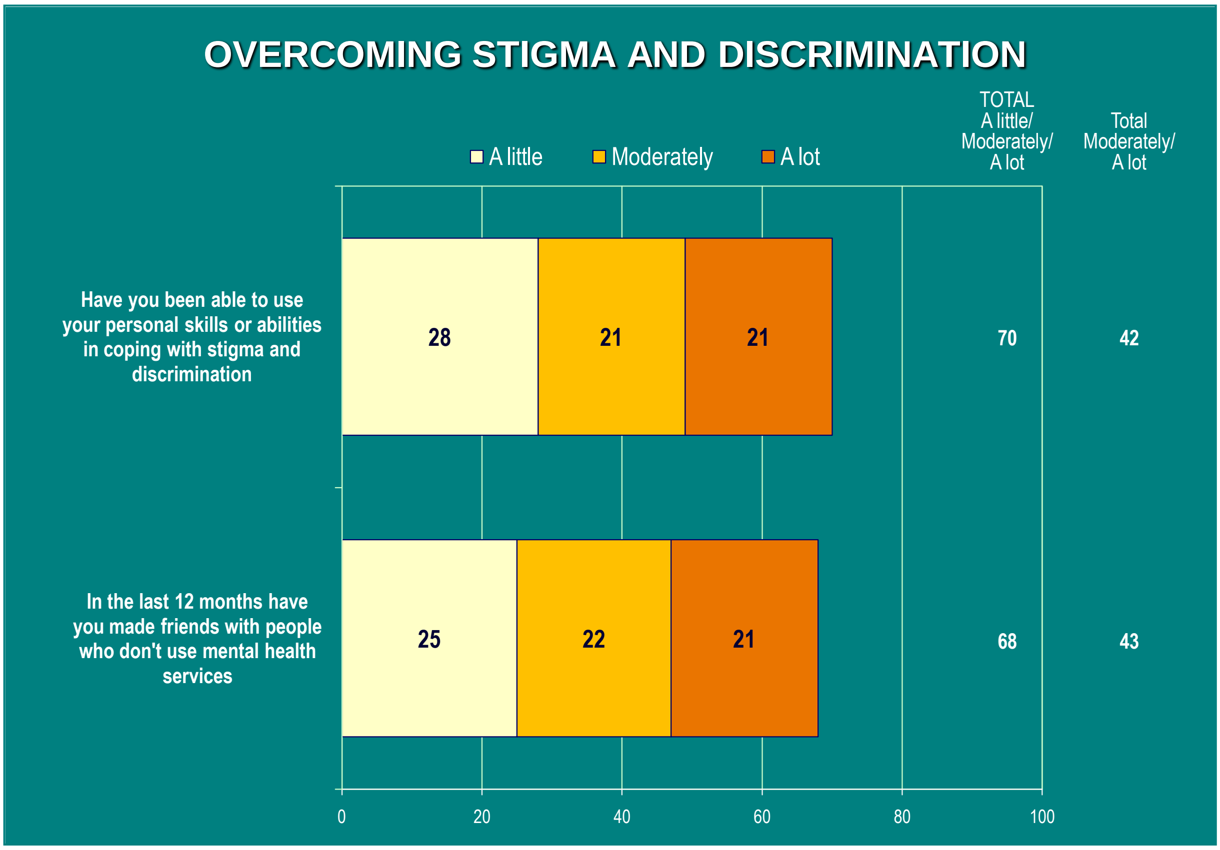


Table 5: Overcoming stigma and discrimination

OVERCOMING STIGMA AND DISCRIMINATION	Total sample %	Those who gave a rating* %	(n=
Been able to use your personal skills or abilities in coping with stigma and discrimination	42	50	935
Made friends with people who don't use mental health services?	43	47	1017

* Excludes those saying "Not applicable" or not giving an answer

DIFFERENCES ACROSS SUB-GROUPS

Number of contacts with DHB mental health services

- People with more than 25 contacts were *less likely* than the Total Sample to confirm they had:
    - Made friends with people who don't use mental health services in the last 12 months (36% vs 43%)

Number of years been using mental health services

- There were no significant differences in responses according to this factor.

Current main type of care receiving

- People receiving some other care currently (i.e. neither in-patient/hospital nor DHB community mental health) were *more likely* to say they had made friends with people who don't use mental health services in the last 12 months (53% vs 43%)*.

Total types of care in last five years

- People who were not receiving any care were *less likely* to say they had made friends with people who don't use mental health services in the last 12 months (30% vs 43%).

Been under Mental Health Act in previous 12 months

- Those who had been under the Mental Health Act in the last 12 months were *less likely* than the rest of respondents to say they had used personal skills or abilities in coping with stigma and discrimination (36% vs 45%)*.

Users of AOD services

- Users of AOD services were *more likely* than non-users to say they had used personal skills or abilities in coping with stigma and discrimination (68% vs 41%)*.

Ethnicity

- There were no significant differences in responses according to this factor.

Age

- People aged 16-24 were *more likely* than the Total Sample to say they had made friends with people who don't use mental health services in the last 12 months (57% vs 43%)* and those aged 45-64 were *less likely* to say they had done so (35% vs 43%)*.

Gender

- Females were *more likely* than males to say they had used personal skills or abilities in coping with stigma and discrimination (45% vs 39%).

Highest level of education

- People with a university degree or higher were *more likely* to say they had:
    - Made friends with people who don't use mental health services in the last 12 months (54% vs 43%)*
    - Used personal skills or abilities in coping with stigma and discrimination (52% vs 42%)*
- People with tertiary education (not completed) were *more likely* to say they had made friends with people who don't use mental health services in the last 12 months (51% vs 43%).
- People with education up to high school /college /other school were *less likely* to say they had made friends with people who don't use mental health services in the last 12 months (37% vs 43%).

Level of paid employment

- People who worked full time (30 or more hours per week) were *more likely* to say they had:
    - Made friends with people who don't use mental health services in the last 12 months (59% vs 43%)*
    - Used personal skills or abilities in coping with stigma and discrimination (57% vs 42%)*
- People who worked part time were *more likely* to say they had made friends with people who don't use mental health services in the last 12 months (51% vs 43%).
- People who were not in paid work were *less likely* to say they had:
    - Made friends with people who don't use mental health services in the last 12 months (38% vs 43%)
    - Used personal skills or abilities in coping with stigma and discrimination (37% vs 42%)

5.5 BEING TREATED MORE POSITIVELY

The question read: "In this section we would like to ask you about times in the last 12 months when you have been treated more positively because of your mental health problems." There were 79% who reported at least 'a little' for one or more of the five items and 58% either 'moderate' or 'a lot'. The average person mentioned 1.1 of the 5. These particular examples of being treated more positively were used because they were included in the DISC questionnaire that was used[13].

As shown in Graph 7, family was the most mentioned source of being treated more positively. There were 40% who felt they had been treated more positively by their family because of their mental health problems either 'moderately' or 'a lot'. This compared with 30% who reported being treated unfairly by their family, as noted previously. There were 9% who reported both being treated more positively and also being treated unfairly by their family.

More than one in five (22%) reported being treated more positively by WINZ, which compared with 20% who reported being treated unfairly. There were 3% who reported both more positive and unfair treatment from WINZ.

A similar proportion (21%) reported being treated more positively in their housing/accommodation, which compared with 16% who reported being treated unfairly. There were 4% who reported both being treated more positively and unfairly.

Fifteen percent reported they had been treated more positively in their religious activities, which compared with 7% who reported unfair treatment. There were 2% who reported both.

The least mentioned example of being treated more positively was for paid employment, which included obtaining jobs and suitable working conditions. This was mentioned by 12%, but this figure will have been affected by the numbers who were working or seeking work. However, when the 'Not Applicable' and no answer responses were removed, the level only increased to 13%, as shown in Table 6.

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[13] See Methods section for more details.

Graph 7: Being treated more positively

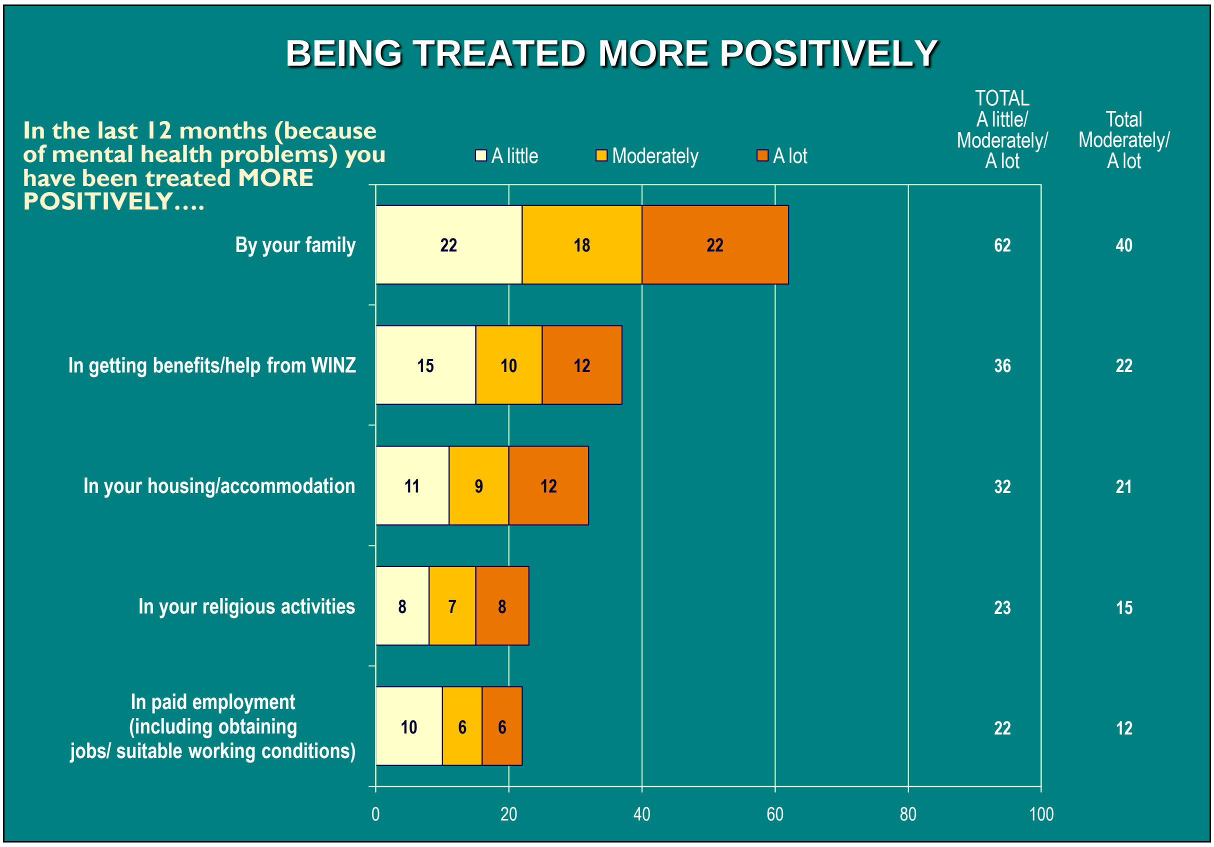


Table 6: Being treated more positively

BEING TREATED MORE POSITIVELY	Total sample	Those who gave a rating*	
	%	%	(n=
By family	40	44	1031
Getting benefits or help from WINZ	22	24	780
In housing/accommodation	21	23	678
In religious activities	15	16	529
In paid employment (including obtaining jobs and suitable working conditions)	12	13	558

* Excludes those saying "Not applicable" or not giving an answer

DIFFERENCES ACROSS SUB-GROUPS

Number of contacts with DHB mental health services

- People with more than 25 contacts were *more likely* than the Total Sample to say they had been treated more positively in terms of:
    - Getting benefits or help from WINZ (28% vs 22%)
    - Housing/accommodation (30% vs 21%)*

- People with 3-10 contacts were *less likely* to say they had been treated more positively in terms of housing/accommodation (15% vs 21%).
- People with 1-2 contacts were *less likely* to say they had been treated more positively in terms of getting benefits or help from WINZ (15% vs 22%).

Number of years been using mental health services

- People who had used mental health services for 5-9 years were *less likely* to say they had been treated more positively in terms of getting benefits or help from WINZ (14% vs 22%).

Current main type of care receiving

- Compared with the Total Sample, people receiving in-patient/hospital services confirmed more situations, on average, in which they had been treated more positively (1.7 vs 1.1). In particular this was the case for:
    - Getting benefits or help from WINZ (37% vs 22%)
    - Housing/accommodation (38% vs 21%)
    - Religious activities (29% vs 15%)
- Compared with the Total Sample, people receiving community health services were *more likely* to mention:
    - Getting benefits or help from WINZ (27% vs 22%)*
    - Housing/accommodation (27% vs 21%)*
- People who were not receiving any care currently confirmed fewer situations, on average, in which they had been treated more positively (0.8 vs 1.1) *. They were *less likely* to confirm in regards to:
    - *At least one statement* (49% vs 58%)*
    - Family (32% vs 40%)
    - Getting benefits or help from WINZ (13% vs 22%)*
    - Housing/accommodation (12% vs 21%)*

Total types of care in last five years

- There were no differences.

Been under Mental Health Act in previous 12 months

- On average, people who had been under the Mental Health Act confirmed more situations in which they had been treated more positively, compared with the rest of respondents (1.4 vs 0.9) *. They were *more likely* to confirm in regards to:
    - *At least one statement* (67% vs 54%)*
    - Getting benefits or help from WINZ (28% vs 18%)
    - Housing/accommodation (31% vs 16%)
    - Religious activities (22% vs 12%)
    - Paid employment (15% vs 10%)

Users of AOD services

- There were no significant differences.

Ethnicity

- Pacific peoples confirmed more situations in which they had been treated more positively, compared with the Total Sample (1.8 vs 1.1) *. They were *more likely* to confirm in regards to:
    - *At least one statement* (79% vs 58%)*
    - Family (51% vs 40%)*
    - Getting benefits or help from WINZ (39% vs 22%)*
    - Housing/accommodation (47% vs 21%)*
    - Religious activities (28% vs 15%)*
- Asian peoples also confirmed more situations in which they had been treated more positively, compared with the Total Sample (1.6 vs 1.1). They were *more likely* to confirm in regards to:
    - Family (52% vs 40%)*
    - Getting benefits or help from WINZ (31% vs 22%)
    - Housing/accommodation (32% vs 21%)*
    - Religious activities (30% vs 15%)*

Age

- Understandably, people aged 65 and over were *less likely* than the Total Sample to say they had been treated more positively in terms of paid employment (0% vs 12%)*.

Gender

- Compared to females, males confirmed more situations where they had been treated more positively (1.2 vs 1.0)*. They were *more likely* than females to confirm this was the case regarding:
    - Getting benefits or help from WINZ (25% for males vs 18% for females)*
    - Housing/accommodation (25% vs 17%)*

Highest level of education

- Compared with the Total Sample, people with a university degree or higher were *less likely* to say they had been treated more positively in terms of:
    - *At least one statement* (51% vs 58%)
    - Housing/accommodation (15% vs 21%)

Level of paid employment

- Compared with the Total Sample, people who worked full time (30 or more hours per week) were *more likely* to say they had been treated more positively in terms of:
    - Paid employment (25% vs 12%)*

    And *less likely* in terms of:

    - Getting benefits or help from WINZ (12% vs 22%)*

  - Housing/accommodation (11% vs 21%)*
  - Religious activities (5% vs 15%)*
- People who worked part time were *more likely* to say they had been treated more positively in terms of paid employment (30% vs 12%)*.
- Understandably, people who were not in paid work were *less likely* to say they had been treated more positively in terms of paid employment (5% vs 12%)*.

5.6 CHANGES IN DISCRIMINATION LEVELS

The first question asked, 'Thinking about all possible ways of being treated unfairly because of your mental illness, compared with five years ago, has this got: a lot better, a little better, no change, a little worse, a lot worse?' The second question asked just about changes in any unfair treatment by mental health staff. These questions were only asked of the 531 who had their first contact with mental health services at least five years earlier.

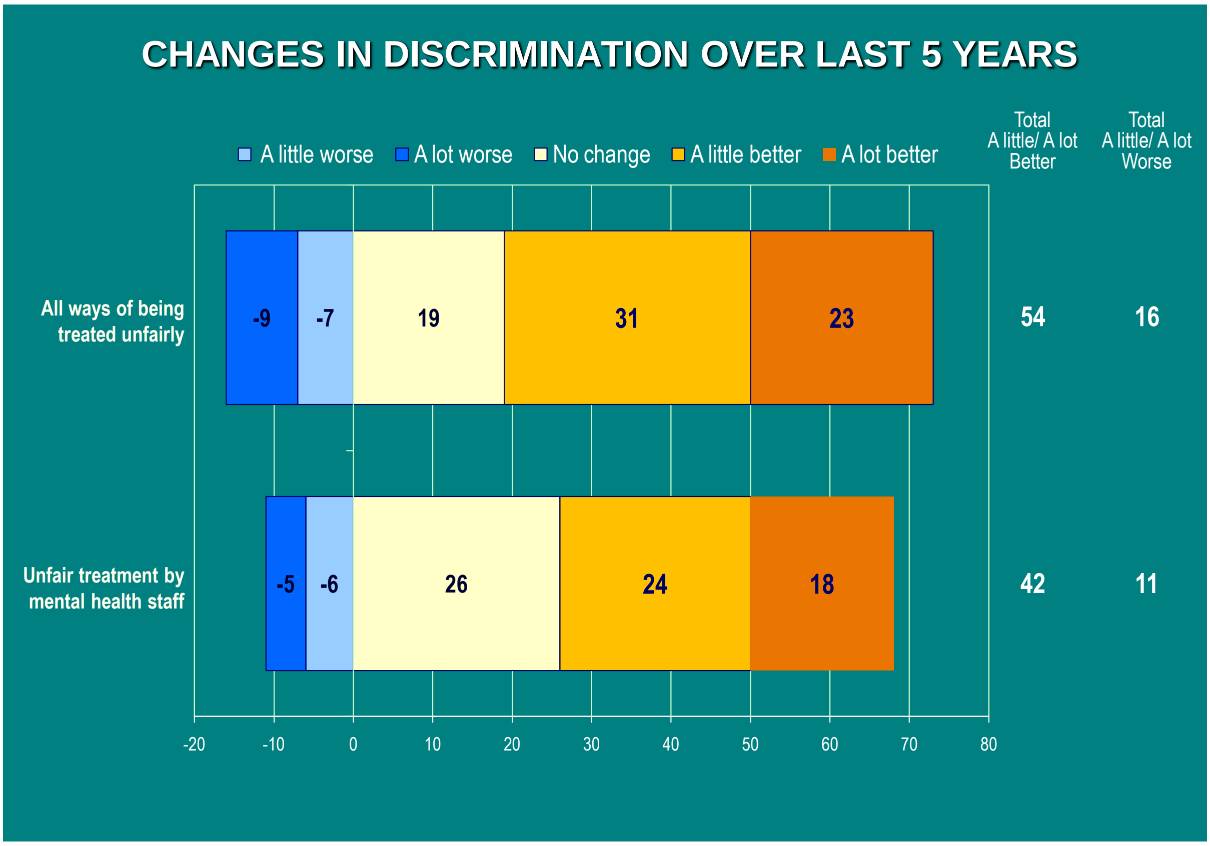
As shown in Graph 8**Error! Reference source not found.**, 54% reported that there had been some improvement over the last five years when considering all ways of being treated unfairly because of their mental illness. This included 23% who thought it had got 'a lot better'. Conversely, there were 16% who thought it was now worse, including 9% who thought it had got 'a lot worse'. There were 19% who thought there had been no change, plus 5% who coded 'Not applicable' and another 7% who did not answer.

With unfair treatment by mental health staff, there were 42% who thought it had improved over the last five years, including 18% who thought it had got 'a lot better'. There were 11% who thought it was now worse, including 5% who thought it had got 'a lot worse'. There were 26% who thought there had been no change, plus 14% who coded 'Not applicable' and another 6% who did not answer.

For analysis purposes the scale from 'a lot worse' (-2) to 'a lot better' (2); 'no change' was counted with a value of zero. Responses among sub-groups are compared by looking at the mean ratings of each group.

When considering all of the possible ways of being treated unfairly because of their mental illness, the mean level of change was 0.6. When considering any unfair treatment by mental health staff, the mean rating was also 0.6.

Graph 8: Changes in discrimination over last 5 years



DIFFERENCES ACROSS SUB-GROUPS

The mean rating differed significantly according to the following variables: number of contacts, type of care being received, ethnicity and gender.

Number of contacts with DHB mental health services

- On average, people with 1-2 contacts reported a lower level of positive change than the Total Sample for all possible ways of being treated unfairly (0.3 for those with 1-2 contacts vs 0.6 for Total Sample).

Current main type of care receiving

- People currently receiving in-patient/hospital services reported negative change for treatment by mental health staff (-0.2 vs 0.6 for the Total Sample)*
- People who were not receiving any care reported a lower level of positive change for all possible ways of being treated unfairly (0.0 vs 0.6 for the Total Sample)*

Ethnicity

- Compared to the Total Sample, Pacific peoples reported higher levels of positive change for:
    - All possible ways of being treated unfairly (0.9 vs 0.6 for the Total Sample)
    - Treatment by mental health staff (1.0 vs 0.6)*

Gender

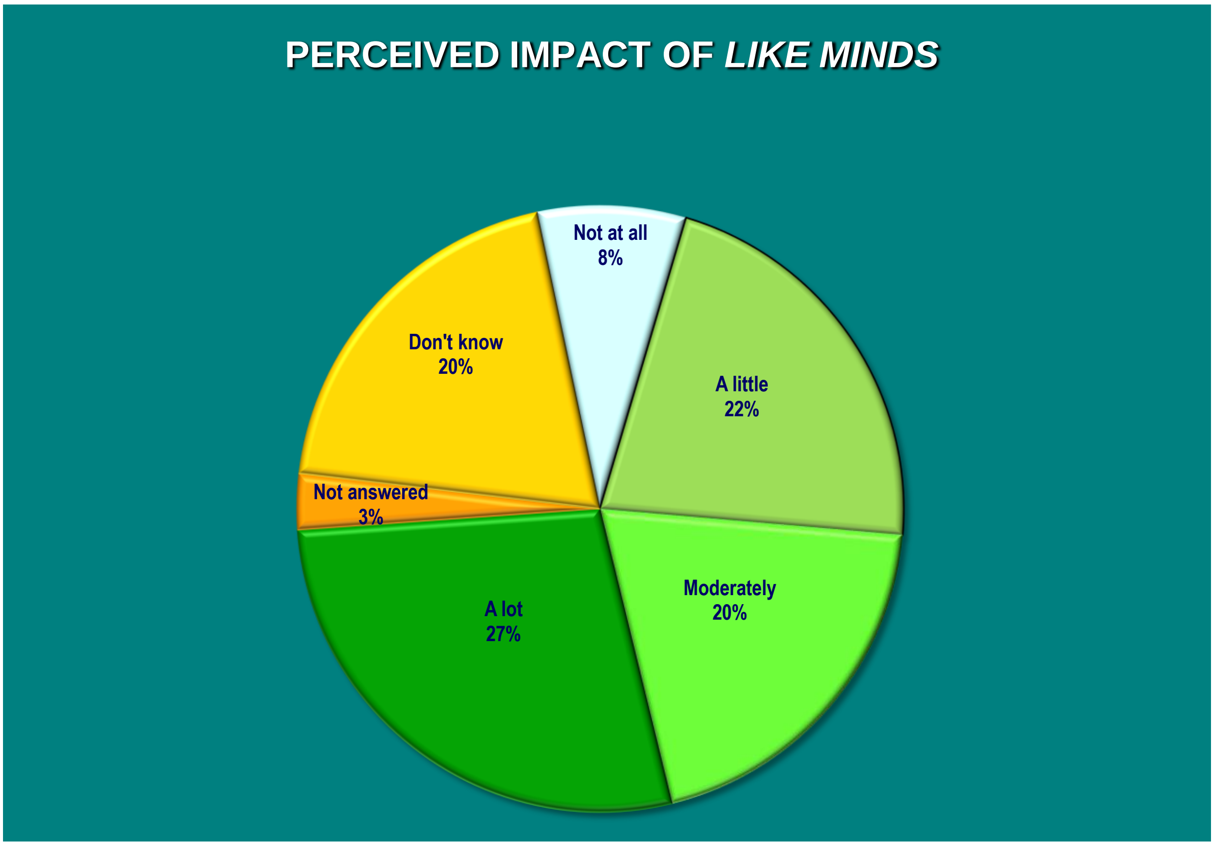
- Females reported a higher level of positive change than males in regards to all possible ways of being treated unfairly (0.7 vs 0.5).

5.7 PERCEIVED IMPACT OF 'LIKE MINDS'

There were 48% who thought the 'Like Minds Like Mine' programme, including the TV advertising, had assisted in reducing discrimination against people with mental illness 'a lot' or 'moderately'. There were another 20% who ticked the 'don't know' box and 3% who did not answer (Graph 9).

None of the sub-groups used in these analyses showed a significant difference.

Graph 9: Perceived impact of *Like Minds*



6 OTHER COMMENTS/ QUALITATIVE RESPONSES

At the end of the questionnaire, participants were invited, if they wished, to add any of their own comments about their experience of discrimination over the last five years, or how it has changed. The responses have been grouped into categories and the numbers giving each response are shown in Table 7.

The table does not do justice to the quality of information contained in these responses. Following the table are a selection of verbatim comments (Table 8), which have been grouped into categories that match the categories in the questions relating to discrimination. They provide qualitative data on the nature of the discrimination being experienced. The beginning of a new person's comment is denoted by a line. Often only parts of their full commentary are included. The only editing of the included sections is to remove any details that could possibly identify the person.

Table 7: Other comments summarised

OTHER COMMENTS SUMMARISED Negative comments (poor treatment from…)	(n=
Mental hospital units – high security ward/ psych emergency – discrimination, abuse of power by psychiatric staff/ facilities need to be improved/ felt more like a penal colony or prison/ man-handled by staff/ noise/ talking/ banging doors – need more care and empathy/ use of physical force/ didn't interact with patients as people but rather as animals	10
Mental Health Services – one size fits all attitude/ unhelpful/ need to meet clients' needs/ often assumed my position/ need to understand depression is a real physical illness, not a lifestyle choice	13
CAT teams – unsupportive, disinterested, unhelpful	2
Psychiatrists: don't ask relevant questions, their role seems to be just to prescribe medication and admit you to hospital/ dismissive, abusive, impatient/ place too much emphasis on the science of brain function	6
Psychologists/counsellors: dismissive, abusive, impatient/ think it's because I'm not coping – I have chronic depression brought on by pregnancy (ante-natal)	3
Key case workers/support people unhelpful/ discharged from service for not keeping appointments due to feeling unwell	8
Public hospital staff/emergency departments – felt inadequate and less valued, not trained in mental health/ talk down to mental health patients/ treat you differently when they find you have a mental illness	7
GPs: had to go over GP's head to get help for son/ bad experiences/ not reading my file/ fear and distrust/ not referred to mental health services/ not educated in mental illness	5
Ambulance staff: judgemental/ unhelpful/ need more training when dealing with people with mental illness	2
Police: when being admitted to hospital/ unhelpful when sick/ very unsupportive and callous when dealing with mental health problems/ discrimination/ have been discriminated by Police which left me totally humiliated and extremely suicidal	9
WINZ: told to lie to potential employers re having mental illness/ difficulty getting an appointment/ doing review system	6
Treatment in social situations – not being able to drink alcohol/ being made to feel different/ due to taking medication	2
Poor treatment from **friends** – didn't allow me to babysit/ couldn't accept my illness	6

OTHER COMMENTS SUMMARISED **Negative comments (poor treatment from…)**	**(n=**
Poor treatment from **other people** when told I have mental illness	15
Discrimination when **applying** for **employment** when told I have mental illness/ job prospects non-existent/ treated unfairly/ lack of employment opportunities for people with mental illness	7
Poor treatment from **family** – marriage break up/ don't change their attitude/ excluded from family decisions/ not supportive/ got me admitted to hospital when unwell/ lack of understanding of illness/ family don't understand my mental illness – just tell me to snap out of it	13
Social isolation – due to feelings of stigma and shame/ prefer to be alone	11
Hide my mental illness from other people – afraid of them walking away/ choose not to disclose my problem	11
Misunderstanding of mental illness – no physical signs/ not visible	3
Lack of investigation of physical/medical problems in people with mental illness	2
Lack of communication between doctors/nurses/hospital and psychiatrists concerning their patients	3
Given drugs/treatment I'm allergic to – makes condition worse/ ECT treatment	5
Lack of getting medication sorted/ medication not working but still prescribed/ due to prescription guidelines unable to access elective medications for eight months/ denied information of side effects of medication/ high dosage of drugs given/ treatments are heavily dependent on drugs/medication	9
Lack of other treatment options available	2
Lack of Police education re mental health/ lack of training	2
Discrimination in the **workplace** – work skills shouldn't be defined by mental illness/ treat staff badly when manic	3
Life insurance cancelled because of suicide attempt/ treated unfairly re life insurance/ not able to be covered due to being on medication for mental illness	3
Discrimination by **landlords** when renting – deemed to be an unfit tenant	2
No voice for mental health consumers when making complaints/ deemed as unreliable persons/ lack of ordinary conflict resolution	7
Mental health staff quite transient/ big turnover of staff in rural mental health services/ lack of continuity of staff	3
More help needed for people when they first develop a mental illness	2
Mental health education needs to be put into schools/ needs to be talked about more in schools	2
Like Minds reducing discrimination for depression, but not bi-polar/ other mental illnesses	3
Being labelled with mental illness is a life sentence of misery and poverty – all outcomes have been decided before you walk through the door/ stigma in every area of life/ we fight our demons daily	6
People don't appreciate or understand my mental challenges	6
New medications available/ better	2
Attitude towards people with experience of mental illness improved/ people more accepting/ aware	8
Better services for clients and residents – higher standards	3
Ad campaigns have reduced discrimination/ great/ "it can happen to anyone" makes people realise	14
Like Minds involvement has helped me to put a more positive perspective on mental health	5

OTHER COMMENTS SUMMARISED Negative comments (poor treatment from…)	(n=
Research and future on-going research very valuable and appreciated	3
Huge improvement across the entire field of mental health – last ten to fifteen years	3
Due to current awareness have been treated fairly by people through all levels of society/ wonderful support from everyone	3

Table 8: Verbatim comments

Making or keeping friends/social life

A real good friend whom I had a lot to do with as we had the same interests. "Get over it, you can change your thoughts, work at it". That caused extra sadness and anxiety. So I walk away from that eight year friendship, end of engagement. Untold loneliness!!!!!

The discrimination from the past, so bad it difficult to get people to break free from the belief you're not like that anymore. To break free, you either have to leave town or the country, so that where you go you are not known, to get a chance to start over!

Discrimination is hard. I had a friend that turned and walked away from me because she couldn't handle my illness. I didn't understand what was happening myself, it was like I took the back seat in my own body and let the negative side of me take over.

People's reactions to someone who has an illness makes it hard. I tend to hide my depression from people. I'm afraid of them walking away. The family and friends that I have now don't really understand or know what to say when I'm experiencing depression, but one thing I know, they ain't walking away from me, and that means they are true. That to me is very important to have. Find people who no matter what, will not walk away.

I find very regularly that as soon as people know you do not work full-time they immediately regard you differently. I always hate that question that people always ask when you first meet them "What do you do for a job?".

I tend to hide my illness, I am too scared to tell people in case they don't want to be my friend anymore, or if they are strangers they might not want to get to know me and might say nasty things about me.

Discrimination is definitely still out there. I have noted at work that those who I have disclosed my diagnosis to often ask me "how are you doing", with a look of concern. I find this patronising. I am a whole person with a personality, skills, strengths and weaknesses. I am **not defined** by my mental illness. I would like to be treated as any other working person.

I have been told that I am "talking to myself" when complaining quietly about the computer, and asked if I am unwell! Doesn't everybody curse at slow computers sometimes?

I hate that because I have been given a diagnosis my emotions are considered somehow less natural than people not diagnosed with a mental illness.

Housing/accommodation

A landlord would never ask you to explain your illness to them if it was anything other than a mental illness. The questions always come up because of my not working full-time like everyone else.

Family

The other biggest discrimination is from family (of birth) who always exclude me in family decision-making. My opinion is never sought. Most see me as a burden to the family. They also do not recognise that some of my behaviour has been as a direct result of my illness at the time. I have been very severely criticised/shunned/blamed for this behaviour – no matter that I have explained symptoms of my illness to them. In contrast my two grown up children (aged 19 and 23) support me fully and see my recovery as a huge accomplishment – due to my hard work over many years.

It has been hard for my family to understand my mental illness. At times they just expect me to snap out of it. If there was information available to give them, that would help…

Finding a job

Employers completely cut you off their short list if they are told of your disability. They **always** give the job to someone else on their list of possible candidates who doesn't have a mental illness. They appear to see me as too much risk to employ. Because of this I have **never** been able to use my academic abilities in paid employment even though I've always been an A+ student. I currently work three and a half hours a week as a **cleaner** as a result of this.

The biggest discrimination I have found is when applying for work. Many agencies in particular ask what medication you are on. The question should be, is there any medical condition you have which will affect your ability to do this job?

As soon as I write lithium, they ask what it is for and I can tell by the response they have excluded you. They don't even know to ask if your condition is stable, is it manageable with medication or do you require other support.

Due to the TV and other ADVERTISING of people who suffer with mental health issues, it makes us feel accepted by others. But it is hard to get a job when all the applications have a questions asking if you have suffered or ever suffered from mental health, and ten times out of ten times, if you answer yes, it means no job to you.

Police

My main area of concern when it comes to discrimination is the Police. The Police need a lot more training and education when it comes to dealing with people with mental health problems. I feel they have no understanding at all and treat you like any other criminal with no compassion.

When Police have been called to assist and take me to hospital, they have kicked me and been rough when handling me. Ambulance officers have at times been very rough and judgemental and unhelpful.

I have been discriminated in a big way by the ….. Police, which left me totally humiliated and extremely suicidal. I believe that there should be a better system put in place with the Police when dealing with people like myself.

I never committed any criminal offence, nor did I break any laws, and yet I was made to feel like I did. Please put something in place!!! This may help people like myself. I don't believe being locked up in a cell, body searched and treated like a criminal is such a good idea!!!. Thank you.

The New Zealand Police have treated me badly – they are very unsupportive and callous when dealing with people who have mental health problems.

Hospital/physical health

Firstly, thanks for the opportunity to give some feedback on my experiences with discrimination. Generally because of my great fear of being discriminated against, I keep my mental health difficulties to myself. In my life the main people I have felt discriminated against would be ED emergency doctors and nurses.

Any physical medical problems are generally not investigated. I'm just given more pills and sent on my way.

Over the past two years I have failed to receive adequate medical help for two physical problems. ….. DHB has continuously referred me to mental health saying nothing is "physically" wrong with me. As a result of this, my health deteriorated to the point where I was struggling to adequately care for my toddler. In a bid to find proper care I separated from my partner, left the …. and moved back to …. for more comprehensive care. It turns out that I had [serious physical health problems].

I find now that if my mental health problems arise, I will not seek help due to fear and distrust of GPs and mental health workers.

Mental health staff

I've been given ECT (Electric Shock "treatment") to the brain three times …… . I am **extremely** against this "brutal" treatment – especially as it makes me much much worse rather than better and I believe ECT is the **worst** evil, **worst** torture, **worst** horror etc on the earth.

On several instances in hospital ….., I have been denied a full explanation of the effects and side effects of the medication suggested for my use, ….. was cornered and manhandled by eight other people (hospital staff) who then half-stripped me and injected another, different medication. I had not been acting violently, nor shown any inclination to do so. Nor was I being unreasonable in my request. It is stated in the bill of Civil Rights that a patient has the right to know with what they are being treated and what that means for them.

As mental illness does come with stigma and I have been treated unfairly by some health professionals, I choose not to disclose my "problem" to anyone outside the health sector and even then on a need to know basis.

Hence, some of the questions were difficult to answer as most people don't know I have a mental disorder.

I would assume this is true for most people with a mental illness as the fear of doors closing, job-wise, would be great.

Judgement seems to be easily passed by those who are not qualified, i.e. those without any form of mental illness. "Walk a mile in my shoes" before venturing an opinion.

One thing my illness has given me is empathy. I look beyond the obvious when viewing others and their actions. I am a better person for it, although I could do without it – very ironic.

The main concern I have about the mental health system is **communication** between nursing staff and doctors concerning their patients. In one word, lack of COMMUNICATION, and professionalism.

I feel like, ironically, some of the worst treatment is from mental health care professionals themselves: psychiatrists, psychologists and counsellors. Some are good, but others can be dismissive and even abusive. They can seem impatient if they don't hear an answer they want or expect.

The worst part is that raising concerns about these issues goes ignored or is heard with scepticism. Mental health care consumers seem to have no voice when it comes to making complaints – after all, we're the crazy ones.

It is a bit disappointing to see that both the research survey and the "Like Minds, Like Mine" campaign appear to focus primarily on discrimination in a public context (e.g. in work, family or community settings) while the institutional side of things (e.g. mental hospitals, discrimination/abuse of power by psychiatric staff) are given little, if any, consideration. I feel that while the emphasis on "overcoming public stigma" is a good start, there remains much to be done on other fronts – particularly in terms of exposing the unpleasant reality of mental health institutions (psychiatric hospitals) and working towards improvement of these facilities. The following points are a summary of my personal experiences of discrimination/unfair treatment and the ways in which I believe this could have been avoided or minimised:

Admission to acute ward of psychiatric hospital after visiting a psychiatrist:

This was my first experience of the mental health system. After an interview with myself and family I was asked to leave the room while the psychiatrist talked to by parents alone. When he returned he did not speak to me again, but another member of staff informed me on his behalf that I was "under the act" and therefore obliged to accompany them (staff members) to the hospital.

I believe that this failure to explain or discuss was unacceptable and exacerbated what was already a very stressful and unpleasant situation. In the state I was in it resulted in more panic – where was I going, why, would I ever come back? The emphasis was on blind obedience, as opposed to informed consent. (I have raised this issue with the psychiatrist involved, who states that his recollection is otherwise: he believes he explained the situation at the time. Unfortunately this was not the case.)

Treatment within an acute psychiatric ward:

Many staff did not seem to have the interests of patients at heart, being more interested in ensuring smooth and efficient operation of the ward. Methods of doing so include:

Using physical force where consent or co-operation is not forthcoming: I was dragged down a corridor (twice) by three or four "nursing staff" because I did not immediately comply with a request to move from one room to another. I was told by a fellow patient that the same had happened to them. This constitutes a major breach of basic human rights (to be free from physical manipulation or abuse), and does nothing for staff-patient relations. It is also unnecessary.

Administering medication upon arrival: I experienced this, with the result being that neither I nor the consultant psychiatrist could positively determine what effects were due to the mental illness, and what were potentially side-effects of the medication.

General observations:

"Us against them" attitudes: I found that generally (there were a few wonderful exceptions) staff did not interact with patients as people, but rather as animals that needed to be guarded and kept under control at all costs. I found some to be downright disrespectful (e.g. sneering comments) or unfriendly.

I am deeply concerned by the state of psychiatric hospitals and the level of discrimination that I experienced there. I believe that many people across the country may suffer the same if not worse on a daily basis, but that this largely goes unnoticed and unheard. As with other forms of abuse, complaint is difficult, especially when it needs to be weighed off against "moving on" and "getting over it".

Therefore the balance of power lies firmly with the provider, and as it is all too easy for these providers to write off complaints or deem them as coming from unreliable persons, change will be slow unless this issue enters the public imagination.

The sooner New Zealand mental health people understand depression is **a real physical illness** and not a lifestyle choice the better!!!!

No wonder we have such high suicide rates!!!!

"Talking" and "coping techniques" don't cure it for us with a physical illness, brought on by physical changes, e.g. puberty, pregnancy!!!

I feel there is plenty of scope for psychiatric hospitals to be improved and "humanised", providing a variety of treatment options and perhaps even a pleasant environment in which to recover. Staff should be held accountable for their actions, and possibly some sort of impartial observer is needed to oversee admissions and ensure correct procedures are followed. Hospitalisation should not, and need not, be the soul-destroying experience it is at present!

Personal safety and security

I've always tried to be open and honest about my mental health experiences. But last year I was sexually harassed by my employer. When I made a formal complaint he used my mental health history to undermine my credibility and claimed that I was "crazy", even though I was quite well at the time.

Even though there was plenty of evidence around the harassment, his attacks on my mental health created enough doubt that the investigation was deemed "inconclusive". So he got away with the initial harassment, and then the discrimination about my perceived mental health status as well.

The whole situation has had a negative impact on my mental health, but now I am too afraid to tell anyone. I don't think I'll ever feel safe to be honest about it, in a workplace again.

Before last year I actually thought that there had been a lot of progress in society. I felt like the campaigns and education had made a difference, but I guess that it hasn't got through to everyone. When it comes down to it they know the "lingo", but they don't know what to do. Until the law and people in positions of authority are able to reinforce the messages and come down hard on discrimination, the rest of the community will still scramble to figure out how to react appropriately.

Local doctor/practice

I feel GPs and practice nurses need to be educated about mental illness. They need to assess and monitor their clients better. If I had been treated better in the first place I wouldn't have had to wait five months to get some help.

Obtaining insurance

My key discrimination has been accessing life insurance. My husband and I had arranged the insurance, however, when I was diagnosed with post-natal depression we were informed I was not able to be covered until I was no longer on anti-depressants.

Obtaining loans/banking services

I was disappointed recently when I needed to take time off work because of being severely depressed and was adjusting to my medication and my bank ….. declined my application to use my income protection insurance I had purchased to make repayments on a personal loan. Their reason was that depression is not recognised as an illness. I think this is unfair.

Self Stigma

The biggest boundary for me was accepting that I had an illness. I suffer from depression and it took a good year for me to understand and accept I had a mental illness.

My experience of living with a mental illness is one of Silence and Solitude. I still hide the fact that I have a chronic mental illness because in my experience people generally don't understand. Even though I am seen as relatively "high functioning" (e.g. I have a job), I think mental illness is a silent, lonely, hard thing to live with.

Have not been open about my mental health issues with many people – perhaps if I had I would have experienced more stigma. The worst stigma for me was how I experienced my self-image after being in the mental health system – self-stigma is the hardest to deal with for me.

Damage that has already been done to my outlook means I automatically do not consider looking for work as that would place me in similar situations conducive to being the recipient of ongoing humiliation like the treatment I received at school from peers. Such treatment was invited due to me presenting odd behavioural symptoms that resulted from my (as then undiagnosed) mental illness. So pervasive is my self-consciousness over my symptoms now that if I have stopped myself in the last twelve months from applying for work, it is no longer an active conscious decision.

Consequently this damaged my outlook on social participation – the intense avoidance and anxiety associated with it affects all aspects of my social functioning. Questions like: "Have I been treated unfairly in making or keeping friends or in dating or intimate relationships?" Such aspects have been affected negatively because of my mental illness symptoms rearing their head at primary school – my head was done in. The effect has been long-lasting, so much so that I can barely contemplate interacting with more people – it is just not a realistic option. So within the last twelve months I could answer "yes, discrimination has affected my ability to function socially, including over the last twelve months", or "no, since the discrimination which did the damage that I am still dealing with, including over the last twelve months, happened back in the 1990's". This same yes/no ambiguity dependent on symptoms obfuscating things would apply to questions like treatment by family.

At least with more word of mental health issues in the media, I think at the very least, people are more prepared to give the existence of such diseases credence at all. My own parents used to think that I had nothing wrong with me. Now they accept I have difficulties with certain tasks. Also as more people recognise that they can ask for certain services which are needed, like community workers, we get better and better services, and more ease of access to these services. I think this is a good development.

Other

I receive a benefit from ACC for a sensitive claim. At one stage ACC were trying to "help" me return to paid employment even though I was certified as being fully unfit for work and had numerous assessments by ACC specialists stating how fragile and unstable I was and that I wasn't fit for work. ACC and their work provider told me I had to lie to potential employers about my reasons for not working. I was not allowed to say I had mental health problems. I have heard from other mental health clients that they have also been told to lie about their conditions by WINZ case managers. Employers were not interested in even interviewing me when the ACC work providers would not answer direct questions about why I hadn't been working for so long. I have been bullied, threatened, about having my benefit cut even though I am still unstable.

I used to think mental health patients were relatively well looked after by the state, but I realise now that it is how society as a whole view this "disease" that really debilitates the affected person. As far as I'm concerned any normal looking person could turn into a mental patient at any given day and next thing they know, they could lose everything. At least this was my experience anyway.

Being labelled mentally ill is a life sentence of misery and poverty. All the outcomes have been decided before you walk through the door. You are a second class citizen who is talked down to, denied explanations of anything from medications, test results, file, and are expected to be extra grateful if a doctor gives you five minutes of their time, even if you are paying for it. Nothing you ever say will be listened to.

I get called lazy and unmotivated when in fact, some days it takes so much energy just to get dressed in the mornings. People constantly tell me I have "potential" and I just have to "work harder". There is a perception that people with mental illness just need to try harder. I wish people would try and understand how hard it is to live and function when there is so much noise in my head. Please keep up the campaign of not discriminating against people with mental illness.

Feed back on 'Like Minds'

I'd like to comment on the ads on TV (Like Minds Like Mine) if I may. Just to say that they are great and I think have brought depression into society in a normal way. I'd like to see however, more ads for anxiety, self-harm, eating disorders, PTSD, bi-polar, schizophrenia, etc.

I'd hate for depression to be all that is acceptable. In mentioning this I do think the ad campaign is VERY clean and possibly a little misleading around just how ugly and horrific life gets for some people in the mental health system.

I was on medication for six months and I still today battle with my depression. The TV ads with John Kirwan helped me a lot. It was great to see I wasn't the only one out there suffering from depression and it wasn't something to be afraid of.

A lot has changed over the years and I do find the advertisements very helpful for my own recovery, so I thank you for that...

Victoria University is very supportive of people with mental health problems. John Kirwan and Denise L'Estrange have both been great advocates for the sector. "Like Minds" is a fantastic programme.

Overall, I feel that I have been treated very kindly by people through all levels of society as a result of current awareness of mental health issues.

Thank you. This programme has helped me to be open and honest with most people so that I am able to help others in the same or similar situations.

Early on, I made a personal commitment (generally) to disclose my condition since I figured it would be public knowledge anyway! This strategy usually was helpful, and certainly facilitated others to feel **safe** in bringing forth their innate compassion, and open discussion.

This period coincided with the initial television campaign featuring John Kirwan. Every time I saw those TV ads I felt reinforced in my choice to challenge other people's prejudiced attitudes… **and**

ultimately seek social support to help my recovery to wellness (this is the important point).

As I realised I could adopt a stance which caused people to re-think entrenched (and strongly emotive!) assumptions, I was empowered, and kept going… sometimes encountering total rejection, and fearful self-protecting behaviours (from **them** not me!!!), but also sometimes reaching that sweet spot of feeling I had actually been the agent of real change in others' attitudes and resultant acceptance behaviours – providing ultimately support towards myself.

In conclusion, yes! I believe the prevalence of discrimination and intensity of prejudice is decreasing in New Zealand society, if even ever so slightly. I do believe the TV/media is the best/first medium to reach and affect the general populace. (The ads are very well conceived and executed.)

When people in my community view the most recent "Like Minds" spot on TV perhaps they think of knowing me, and how much I've recovered wellness with their support.

I am very familiar with the "Like Minds" work. I am grateful for my involvement in the work as it has helped me to put a more positive perspective on mental health and mental illness.

I think the work that has been done to make the public more aware of mental health problems is amazing. It has allowed me to be more open in telling people my story and has helped me make people I know that were afraid of admitting something is wrong to seek help.

Personally I can't wait to have mental health education put into schools and I am looking forward to seeing what the Ministry of Health does next. I hope to share my story more in the future to make people aware that it's not something to be ashamed of. More TV and print ads guys!!! While I am lucky enough to have faced less discrimination now than when I first got diagnosed, I know this is not the case with everyone.

Unfortunately this ad campaign does not assist the families, work colleagues, society in general to better cope with the issues facing mental illness. Addressing discrimination may increase people's awareness of its occurrence, but I think it would be more effective to educate society about the complex issues surrounding those who suffer and support those who are taking care of them.

Applicability of questions

Many of these questions are not applicable as only about four people are aware of my suicide attempt.

Research

This research and any future on-going research is very valuable and appreciated. Keep up the good work. I think over the past ten to fifteen years there has been a huge improvement across the entire field of mental health. Well done to all involved.

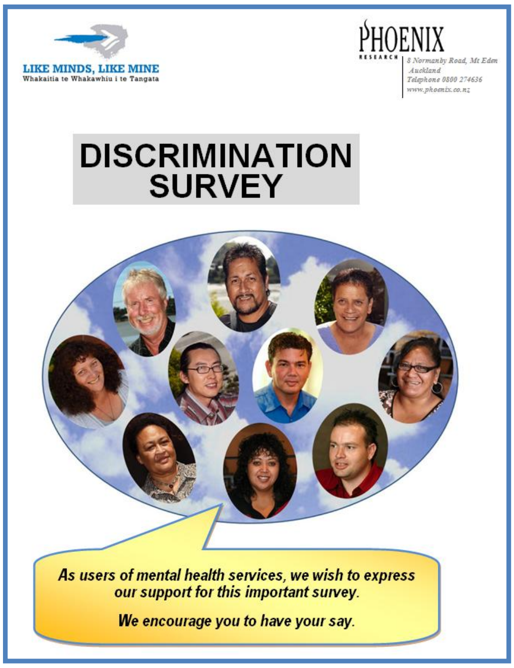
It is great to see that research into the degree of discrimination experienced by mental health users is being undertaken, and I would like to thank those involved for initiating the study.

APPENDIX A: COVERING LETTER AND INFORMATION SHEET

MINISTRY OF HEALTH
MANATŪ HAUORA

650 Great South Road
Penrose
Private Bag 92522
Wellesley Street
Auckland
New Zealand

Name
Address 1
Address 2
Address 3«Address_Line_3»
Address 4



LIKE MINDS, LIKE MINE
Whakaitia te Whakawhiu i te Tangata

PHOENIX RESEARCH
8 Normanby Road, Mt Eden
Auckland
Telephone 0800 274636
www.phoenix.co.nz

DISCRIMINATION SURVEY

As users of mental health services, we wish to express our support for this important survey.

We encourage you to have your say.

Dear Name

People with a diagnosis of mental illness often say that discrimination is a major hurdle in their recovery process. A lot of funding has been provided for the TV ads and other activities to try and reduce this. However, the only way of knowing if we are making a difference is to ask you your own experiences.

Therefore, the Ministry of Health have asked Phoenix Research to undertake a survey of people who are recent users of DHB mental health services. It asks questions about people's experiences of discrimination (ways in which you have been treated unfairly because of mental health problems). Questionnaires are being sent to a random selection of recent users of mental health services. You are free to decide whether to take part or not, but obviously we are keen to have as many of the selected people take part as possible.

You have been randomly selected by the part of the Ministry of Health who look after the DHB mental health information databases (the DHBs are required to supply the Ministry with the names of people who are using mental health services). The Ministry have supplied only names and addresses to Phoenix Research, who have organised this mail out. Phoenix Research has no access to your mental health records and will not share your name and address with anyone else. Your name will not be recorded on the questionnaire and no one will be able to identify who has completed it.

You can choose to fill out this questionnaire directly, or you may choose to do it on-line, or over the phone.

More information about this research is attached. We do hope you are able to take a few minutes to complete this important survey.

Yours sincerely

Darryl Bishop
National 'Like Minds, Like Mine' Co-ordinator
Ministry of Health
«Conseq_» «Hash»«Unique_Code»

PHOENIX
RESEARCH

8 Normanby Road, Mt Eden
PO Box 74-283, Auckland
Email: research@phoenix.co.nz
Telephone 09-623 9999
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DISCRIMINATION SURVEY
INFORMATION SHEET

Introduction

The "Like Minds Like Mine" programme, including the advertising on TV, has now been running for about 10 years. However, we don't really know how much difference it is making to people like yourself, in terms of reducing the discrimination you experience. This is why this research is really important, as it will be the most accurate data ever collected from New Zealand users of mental health services on this topic. The plan is to repeat the survey every five years, to see whether the situation is improving.

The questionnaire is easy to fill out (just tick the box with the answer you want to give) and should take most people about **10 to 15 minutes to complete**.

This is an important survey, which will be of interest to users of mental health services and other people involved in mental health throughout the world, as New Zealand/Aotearoa is leading the world in its efforts to reduce discrimination experienced by service users.

Why you have been invited to participate

We are sending questionnaires to a random selection of current users of mental health services, including yourself. As noted in the covering letter, you have been randomly selected by the part of the Ministry of Health who look after the DHB mental health information databases. They have supplied only names and addresses to Phoenix Research, who have organised this mail out. Phoenix Research have no access to your mental health records and will not share your name and address with anyone else. Your name will not be recorded on the questionnaire and no one will be able to identify who has completed it.

Invitation to participate

We would like to invite you to participate in this study. Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect any future care or treatment. You may withdraw from the study at any time up until your completed questionnaire has been sent in. You do not have to answer all the questions, and you may stop the interview at any time.

About the study

This questionnaire is being sent to 6,500 recent users of mental health services, randomly selected from 10 DHBs throughout the country.

Please complete the survey **within the next 2 weeks**, but we recommend you do it as soon as possible, so you don't forget about it. You have the option of **completing the questionnaire in one of three ways**:

1. You can fill in the questionnaire you have been sent and mail it back in the freepost envelope that is supplied
2. You can do it on line at www.phoenix.co.nz/esurvey6/dsurvey.htm
3. If you would prefer to do a phone interview, you can phone Phoenix Research at 0800 274 636 to arrange a time for an interview.

What is included in the questionnaire

Discrimination and stigma may happen when people are treated unfairly because they are seen as being different from others.

There are six parts to the questionnaire:

1. The first part asks you about times when you have been treated **unfairly** because of mental health problems
2. The second part asks you about times when you have **stopped yourself** from doing things because of how others might respond to your mental health problems
3. The third part asks you about some examples of **overcoming stigma and discrimination**
4. The fourth part asks you about times when you have been treated **more positively** because of mental health problems
5. The fifth section asks about **changes** over the last five years
6. The final section asks you for personal details such as age group and gender

Confidentiality

Your name will not be on the questionnaire you complete and no material which could personally identify you will be used in any reports on this study. As noted in the covering letter, this is an **anonymous survey** (you do not put your name anywhere on the questionnaire), so no one will ever know which person sent in which questionnaire. All the questionnaires will be combined to provide statistics for the different groups taking part (e.g. Maori, females etc).

All questionnaires will be kept securely at the Phoenix Research premises in Auckland, except if being viewed by those directly involved in the project. Once the data is entered on to the computer, it will be shared with the London based research team led by Professor Thornicroft. No one other than the researchers will have access to this data.

Benefits, risks and safety

This survey provides you with an opportunity to have your say on an issue that is important to most users of mental health services.

There is a slight risk that you might get upset recalling experiences of discrimination. If this does occur and you need to discuss it with someone, you should contact the person you would usually contact if you were feeling upset or unwell, or if they are unavailable, ring one of the helplines listed in the front of the phone book.

Ethical approval

This study has received ethical approval from the Multi-region Ethics Committee, which reviews National and Multi-regional studies.

Availability of results

A written report will be prepared for the Ministry of Health, and the key findings will be available on the 'Like Minds, Like Mine' website (www.likeminds.org.nz), plus results will be reported at conferences and hui. Results are expected to be available by the end of 2010.

Researchers

The principal investigator is Dr Allan Wyllie, Director Social Research, Phoenix Research, PO Box 74 283, Auckland (phone 09-623 9992). There are also other researchers and interviewers working on the project, including Maori, Pacific and Asian.

Professor Graham Thornicoft, who is a world expert in this field and is based in London, is going to work with Phoenix Research to publish a peer-reviewed paper about the findings.

Phoenix Research is a small private research company, based in Auckland. We have been undertaking research and evaluation for the 'Like Minds, Like Mine' campaign to reduce stigma and discrimination associated with mental illness for over 10 years.

ACC compensation

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator.

Further information

Please feel free to contact one of the Phoenix Research staff, Jo Howearth (0800 274 636), if you have any questions about this study.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone:(NZ wide) 0800 555 050
Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

Dated: 28 August 2010

APPENDIX B: QUESTIONNAIRE

LIKE MINDS, LIKE MINE
Whakaitia te Whakawhiu i te Tangata

PHOENIX
RESEARCH
8 Normanby Road, Mt Eden
Auckland
Telephone 0800 274636

DISCRIMINATION SURVEY

As users of mental health services, we wish to express our support for this important survey.

We encourage you to have your say.

Please DO NOT put your name anywhere on this questionnaire.

When answering each question, please tick one box to say whether each event has happened not at all, a little, moderately, or a lot.

If you feel the question doesn't apply to you, tick the "Not applicable" box. If you are unsure or don't feel able to answer, leave it blank.

For all of these questions please answer based on your experience over the last 12 months.

**In this section we would like you to answer about times in the last 12 months when you have been treated unfairly because of mental health problems.
There are 26 questions in this section.**

1. In the last 12 months, have you been treated unfairly in making or keeping friends, because of mental health problems?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

2. Have you been treated unfairly by the people in your neighbourhood?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

3. Have you been treated unfairly in dating or intimate relationships?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

4. Have you been treated unfairly in your housing/accommodation (including becoming homeless)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

5. Have you been treated unfairly in your education (e.g. school, college, university, tertiary courses, on the job training)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

6. Have you been treated unfairly in marriage or divorce (e.g. ability to find a partner or spouse, problems during the relationship, divorce settlements, etc)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

Still thinking about being treated unfairly in the last 12 months because of mental health problems…

7. Have you been treated unfairly by your family (including family of origin, i.e. parents, brothers, sisters or other relations, as well as partner/spouse or any children of your own)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

8. In the last 12 months, have you been treated unfairly in finding a job, because of mental health problems? (This means finding regular full or part-time paid work.)

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

9. Have you been treated unfairly in keeping a job?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

10. Have you been treated unfairly when using public transport (e.g. by fellow passengers, drivers, etc)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

11. Have you been treated unfairly in getting benefits or help from WINZ (e.g. applying for benefits, level of benefits, support)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

12. Have you been treated unfairly in your religious practices (e.g. attending church, other parishioners, church leaders, participation in spiritual practices)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

13. Have you been treated unfairly in your social life (e.g. socialising, hobbies, attending events)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

14. Have you been treated unfairly by the police? (Remember, as with all the questions, this is unfair treatment because of mental health problems.)

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

Still thinking about being treated unfairly in the last 12 months because of mental health problems…

15. In the last 12 months have you been treated unfairly when getting help for physical health problems at a hospital (including emergency treatment)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

16. Have you been treated unfairly by mental health staff (e.g. behaviour of staff, feeling disrespected or humiliated by contact with mental health staff)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

17. Have you been treated unfairly in your levels of privacy (including privacy in hospital and in community setting, e.g. private letters or phone calls)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

18. Have you been treated unfairly in your personal safety and security (including any verbal abuse, physical abuse, assault)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

19. Have you been treated unfairly in starting a family or having children (e.g. behaviour of health professionals, friends and family, as well as how you or your partner were treated during pregnancy or childbirth)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

20. Have you been treated unfairly in your role as a parent to your children (e.g. behaviour of other parents, teachers, family or mental health staff)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

21. In the last 12 months have you been avoided (or shunned) by people who know that you have a mental health problem?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

22. Have you been treated unfairly by your local doctor (i.e. your GP), or people who work in the doctor's practice?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

23. Have you been treated unfairly when trying to obtain insurance?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

Still thinking about being treated unfairly in the last 12 months because of mental health problems…

24. Have you been treated unfairly when trying to obtain loans or other banking services?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

25. Have you been treated unfairly at sports clubs or other clubs?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

26. Have you been treated unfairly when shopping (e.g. by shop staff or other customers)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

In this section we would like you to answer about times in the last 12 months when you have stopped yourself from doing things that are important to you because of how others might respond to your mental health problems.
There are 4 questions in this section.

27. In the last 12 months have you stopped yourself from applying for work?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

28. Have you stopped yourself from applying for education or training courses?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

29. Have you stopped yourself from having a close personal relationship?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

30. Have you concealed or hidden your mental health problem from others?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

In this section we would like to ask you about some examples of overcoming stigma and discrimination because of mental health problems, in the last 12 months.
There are 2 questions in this section.

31. In the last 12 months have you made friends with people who don't use mental health services?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

32. Have you been able to use your personal skills or abilities in coping with stigma and discrimination?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

In this section we would like to ask you about times in the last 12 months when you have been treated more positively because of mental health problems.
There are 7 questions in this section.

33. In the last 12 months have you been treated more positively by your family because of your mental health problems?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

34. Have you been treated more positively in getting benefits or help from WINZ?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

35. Have you been treated more positively in your housing/accommodation?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

36. Have you been treated more positively in your religious activities?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

37. Have you been treated more positively in paid employment (including obtaining jobs and suitable working conditions)?

Not at all	A little	Moderately	A lot	Not applicable
☐	☐	☐	☐	☐

This next section is about change over the last five years.

38. How many years is it since you first had contact with mental health services?
Please write in box:

☐ *If less than 5 years, please enter number of years and then go to Q41:*

39. Thinking about all possible ways of being treated unfairly because of your mental illness, compared with five years ago, has this got...

A lot better	A little better	No change	A little worse	A lot worse	Not applicable
☐	☐	☐	☐	☐	☐

40. Compared with five years ago, has any unfair treatment by mental health staff got...

A lot better	A little better	No change	A little worse	A lot worse	Not applicable
☐	☐	☐	☐	☐	☐

41. How much do you think the "Like Minds Like Mine" programme, including the TV advertising, is assisting in reducing discrimination against people with mental illness?

Not at all	A little	Moderately	A lot	Don't know
☐	☐	☐	☐	☐

PERSONAL DETAILS

The following details will assist us to know what types of people have completed the survey and provide information that will be useful when analysing the survey findings.
Remember you can choose to answer only the questions you want to.

42. Your age (in years)? ☐

43. Your gender? Female ☐ Male ☐

44. Highest level of education?

University degree/diploma	Other tertiary qualification	Tertiary study (not completed)	High school/ college/ other school
☐	☐	☐	☐

45. What ethnic group(s) do you belong to? *Please tick all that apply*

☐ NZ European/Pakeha
☐ Tongan
☐ Fijian
☐ Chinese
☐ Maori
☐ Cook Island Maori
☐ Fijian Indian
☐ Other Asian
☐ Samoan
☐ Niuean
☐ Other Pacific
☐ Other *(please write in)* ....

46. In paid work…

☐ Full time (30 hours a week or more) ☐ Part time ☐ Not in paid employment

47. Have you been under the Mental Health Act in the last 12 months (i.e. under a compulsory treatment order)?

☐ Yes ☐ No

48. Current main type of mental health care receiving at present?

☐ In-patient/ hospital services ☐ Community mental health services ☐ Other ☐ None

49. Other types of mental health care received in the last five years?

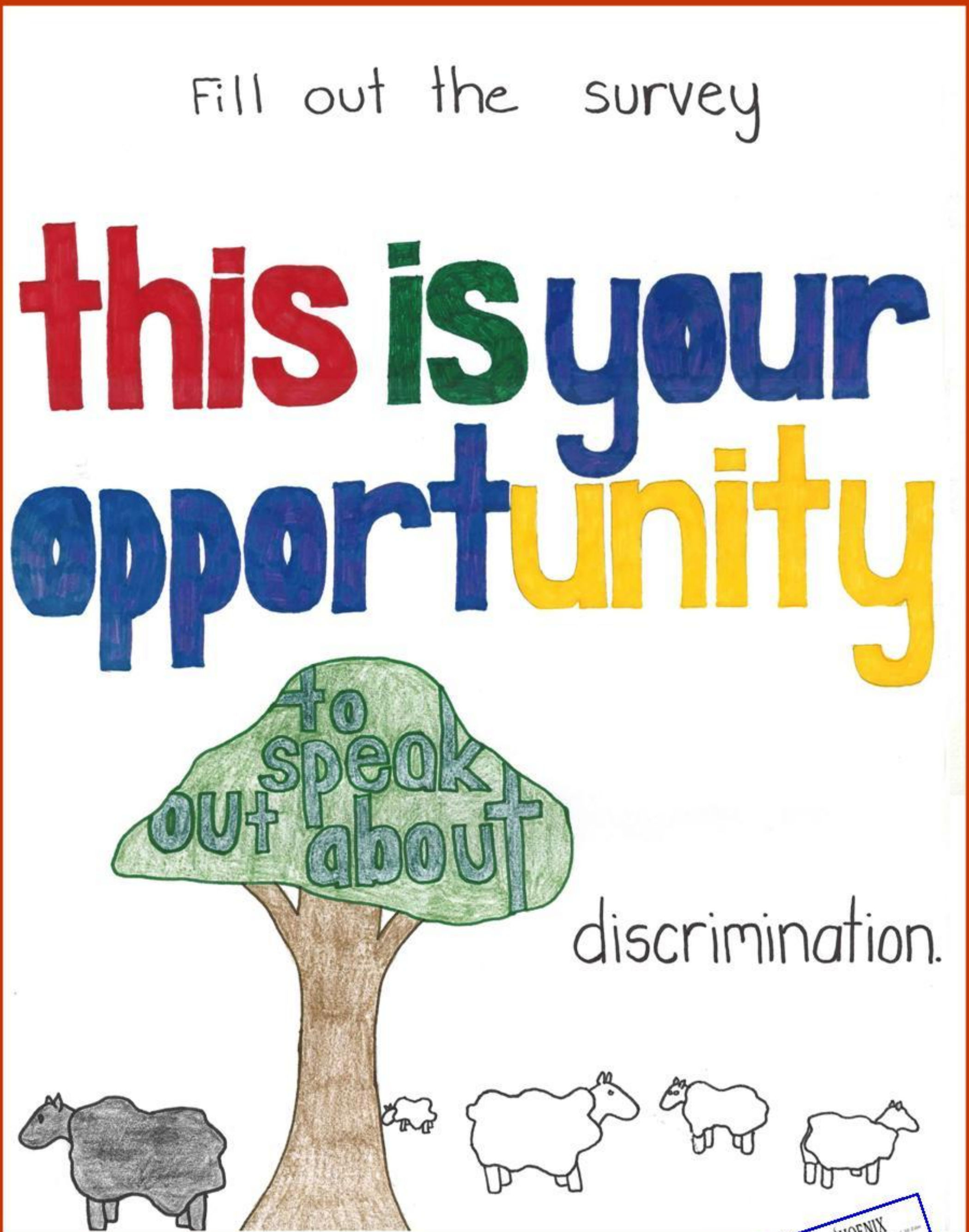
☐ In-patient/ hospital services ☐ Community mental health services ☐ Other ☐ None

If you wish to add any of your own comments about your experience of discrimination over the last five years, or how it has changed, please write these on spare paper and include with this booklet. This section is totally optional.

That is the end of the questionnaire.
Thank you very much for your time.
Please place your completed questionnaire in the freepost envelope provided, and post it to...

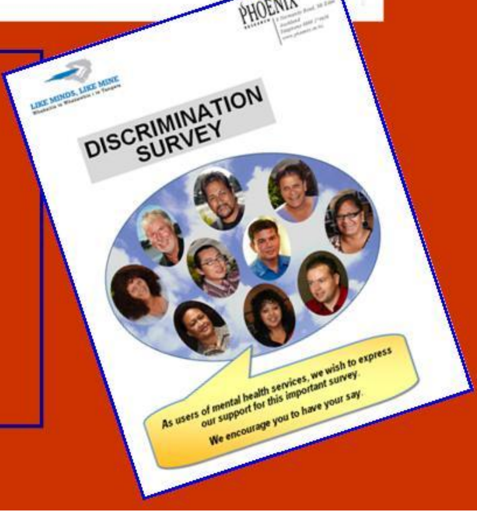
Freepost Remuera 008
Phoenix Research
PO Box 74 283
AUCKLAND 1546

APPENDIX C: POSTER



If you get a letter inviting you to take part in this *anonymous* survey, we encourage you to take the time to fill it out. The survey is about your experience of discrimination because of mental health problems.

Only a random sample of recent users of DHB mental health services have been selected and (unfortunately for anyone else) only they can take part.


PHOENIX

LIKE MINDS, LIKE MINE

DISCRIMINATION SURVEY

As users of mental health services, we wish to express our support for this important survey.

We encourage you to have your say.

APPENDIX D: METHODOLOGICAL DETAILS

CONDITIONS FOR SELECTION OF SAMPLE FROM PRIMHD

- Exclude everyone with a date of death in the NHI
- Exclude everyone who was less than 16 years old as at 1 April 2009
- Exclude Team Type Code = 03, 10, 11, 12,13, 21, 23
- Exclude Activity Type Code = T08, T35, T16, T17, T18, T19, T20
- Exclude Activity Setting Code = PH, WR, SM, AV
- Exclude Activity Unit Type = SECLUSION, LEAVE

SAMPLE SELECTION REQUEST

GENERAL MH SERVICE USERS						**AOD service users**	**Total mail-out numbers**
ETHNICITY	**16-24 Male**	**25+ Male**	**16-24 Female**	**25+ Female**	**Total**		
Canterbury District Health Board							
Asian	22	31	22	31	106		
Maori	37	42	37	42	158		
Pacific	10	29	10	29	78		
Other	84	252	84	252	672		
	153	354	153	354	1014	51	1065
Capital and Coast District Health Board							
Asian	21	29	21	29	100		
Maori	51	57	51	57	216		
Pacific	19	56	19	56	150		
Other	41	122	41	122	326		
	132	264	132	264	792	40	832
Counties Manukau District Health Board							
Asian	87	122	87	122	418		
Maori	81	91	81	91	344		
Pacific	100	292	100	292	784		
Other	44	131	44	131	350		
	312	636	312	636	1896	95	1991
Mid Central District Health Board							
Asian	5	8	5	8	26		
Maori	28	32	28	32	120		
Pacific	3	10	3	10	26		
Other	27	81	27	81	216		
	63	131	63	131	388	19	407
Northland District Health Board							
Asian	1	2	1	2	6		
Maori	67	75	67	75	284		
Pacific	4	11	4	11	30		
Other	24	72	24	72	192		
	96	160	96	160	512	26	538

GENERAL MH SERVICE USERS						AOD service users	Total mail-out numbers
ETHNICITY	**16-24 Male**	**25+ Male**	**16-24 Female**	**25+ Female**	**Total**		
Otago District Health Board							
Asian	10	13	10	13	46		
Maori	23	26	23	26	98		
Pacific	5	15	5	15	40		
Other	45	133	45	133	356		
	83	187	83	187	540	27	567
Southland District Health Board							
Asian	2	3	2	3	10		
Maori	16	18	16	18	68		
Pacific	3	8	3	8	22		
Other	22	67	22	67	178		
	43	96	43	96	278	14	292
Taranaki District Health Board							
Asian	2	3	2	3	10		
Maori	22	24	22	24	92		
Pacific	2	4	2	4	12		
Other	25	74	25	74	198		
	51	105	51	105	312	16	328
Waikato District Health Board							
Asian	15	21	15	21	72		
Maori	72	81	72	81	306		
Pacific	8	24	8	24	64		
Other	55	165	55	165	440		
	150	291	150	291	882	44	926
Auckland District Health Board (Pilot site)							
Asian	57	133	38	88	316		
Maori	23	54	15	36	128		
Pacific	68	158	45	105	376		
Other	39	91	26	60	216		
	186	435	124	290	1036	0	6946

NB: Auckland DHB does not have any AOD services