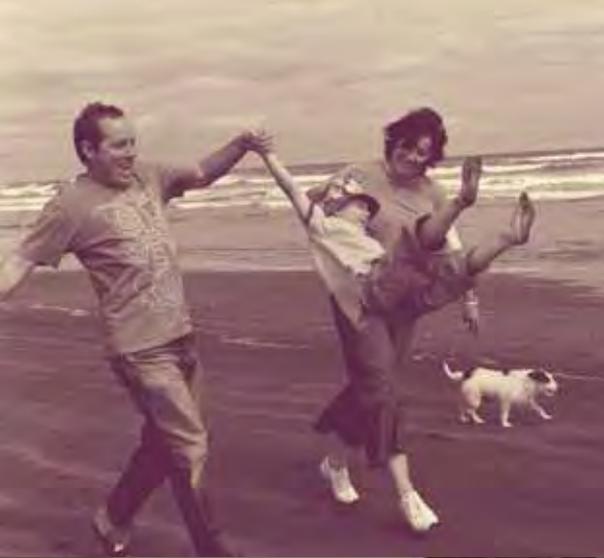


2007



I Haven't Told Them, They Haven't Asked:

The Employment Experiences of People
with Experience of Mental Illness

Written for the
Mental Health Foundation of New Zealand
by Debbie Peterson



Mental Health
Foundation
of New Zealand

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There are many people we would like to thank for their contributions to this research – in particular, and most importantly, the research participants. By allowing your stories to be shared you will hopefully inspire other people with experience of mental illness to participate in employment, and, where necessary, challenge discrimination.

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The title

The title of this report is a quote from one of the research participants. It raises the issue of disclosure of the experience of mental illness in the workplace. Under the Human Rights Act 1993 it is illegal for employers to ask a prospective employee about their history of mental illness for the purpose of negative discrimination. Legally, employers may not ask, and there is no obligation for an employee to tell.

The responses to the question on disclosure were the most varied of all those raised in this study. Some people firmly believed that disclosure was necessary and a good tactic to avoid discrimination, others felt that it encouraged discrimination. Some believed that employers had a right to know, others that it was none of their business.

The title quote may also be seen in the light of another, related, issue. Many of the participants in this study dealt with discrimination by leaving their employment, without stating the real reason why. This highlights the responsibility of employers to continue to challenge themselves about whether they are providing an environment where employees can contribute fully, and challenges employees to address discrimination when it arises.



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Preface

Employment is recognised as a vital contributor to well-being. Charlotte Perkins Gillman wrote *The Yellow Wallpaper* in 1891. When asked about why she wrote this short story, she said:

For many years I suffered from a severe and continuous nervous breakdown tending to melancholia – and beyond. During about the third year of this trouble I went, in devout faith and some faint stir of hope, to a noted specialist in nervous diseases, the best known in the country. This wise man put me to bed and applied the rest-cure, to which a still-good physique responded so promptly that he concluded there was nothing much the matter with me, and sent me home with solemn advice to “live as domestic a life as far as possible,” to “have but two hours’ intellectual life a day,” and “never to touch pen, brush, or pencil again” as long as I lived. This was in 1887. I went home and obeyed those directions for some three months, and came so near the borderline of utter mental ruin that I could see over.

Then, using the remnants of intelligence that remained, and helped by a wise friend, I cast the noted specialist’s advice to the winds and went to work again – work, the normal life of every human being; work, in which is joy and growth and service, without which one is a pauper and a parasite – ultimately recovering some measure of power (Perkins Gillman, 1913: 1).

This quote encapsulates the value of employment – purpose, independence – and highlights why lifting the barriers to employment should be a focus for social policy.

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



Foreword

The Board and staff of the Mental Health Foundation are proud to be part of the Like Minds, Like Mine Campaign and are committed to reducing discrimination and increasing equity and promoting social inclusion.

Access to paid employment and positive experiences at work are important components of life and need to be available on a fair and respectful basis. As the earlier report *'Respect Costs Nothing'* showed, prejudiced attitudes and discrimination percolate the lives of people with experience of mental illness. We know from research that the public's attitudes may have improved over the years but behaviors and practices still need to change if we are to create a nation that values and includes people with experience of mental illness.

This original New Zealand research gives more than a glimpse into people's lived experiences and in so doing gives a good basis for proposals and recommendations for improvement.

We acknowledge those who took time to give their personal accounts and commit ourselves to making good use of that in promoting the learning and recommendations contained in this report.

Judi Clements
Chief Executive
Mental Health Foundation of New Zealand

Executive Summary

This report presents the findings of research undertaken by the Mental Health Foundation for the *Like Minds, Like Mine* project funded by the Ministry of Health.

The aim of the research was to find out the specific issues that affect people with experience of mental illness in employment. Twenty-two people from the Wellington region with experience of mental illness were interviewed for this study.

Findings

Most of the participants reported that employment was a positive experience for them. It provided financial and social benefits, and a focus in their lives. The negative aspects they reported, apart from discrimination, were similar to those of most people's working lives.

Mental illness affected the confidence of participants when applying for jobs, but the main effect was on people's concentration in their day-to-day work. Most participants had become unwell at some stage while in employment, and many had left their jobs because of this. Some had been unable to negotiate accommodations with their employer. One person was dismissed from her job because of her mental illness. Others returned to work successfully.

Most people said their employer was aware of their experience of mental illness. Several had chosen to tell their employer when they first started their job, others were using supported employment agencies, and for some, their experience of mental illness was a requirement for the position. The employers' reactions were mixed, with some being very supportive, others not. Fewer people had told their colleagues, fearing repercussions. Most people had felt pressure to disclose their experience of mental illness to their employers or colleagues. When asked if they would advise others to disclose their experience of mental illness, there was a mixed response.

Almost all of the participants said that they had been asked questions about their health in the process of finding work. Some disclosed in response to this, others did not. Several people recounted their experiences of discrimination, both in applying for jobs, and from employers and colleagues. This discrimination included not being offered employment, being teased by colleagues, and being treated differently compared with workers without experience of mental illness. This discrimination also took place while some participants were working in the mental health sector. Others also reported being

discriminated against for different reasons, such as gender and ethnicity. Despite these accounts of discrimination, the laying of official complaints was rare.

A variety of support mechanisms were used by people when applying for jobs. These included supported employment agencies, mental health organisations, training courses, and help from Work and Income and friends and family. Mostly, people found supported employment agencies useful, although some participants sensed reluctance from agencies to work with people with experience of mental illness. People reported that mental health services were generally supportive of them working.

Participants reported a variety of accommodations that they had negotiated with their employers, including flexible hours and sick leave. This meant that, for some, they were able to continue working. For others, though, they were unable to negotiate the accommodations they needed, and ended up leaving their employment because of this.

Introduction

This report presents the findings of research undertaken with 22 people with experience of mental illness that asked them about their employment experiences. It was conducted as part of a contract that the Mental Health Foundation has with the Ministry of Health, and follows on from a nationwide survey of people with experience of mental illness that the Foundation carried out in 2003. That survey focused on the discrimination that people with experience of mental illness face in New Zealand, and was part of the *Like Minds, Like Mine* project. The *Like Minds, Like Mine* project to counter stigma and discrimination associated with mental illness was established by the Ministry of Health in response to the 1996 Mason report (an inquiry under section 47 of the Health and Disability Services Act 1993 in respect of certain mental health services).

The report has been supported by a review of literature (Duncan and Peterson, 2007), published separately, focusing on the issues regarding employment and mental illness. The review gathered evidence from over 70 different papers and resources.

Previous *Like Minds* employment research

“*Respect Costs Nothing*” findings

In 2003, 785 people with experience of mental illness participated in a written survey that asked them about their experiences of discrimination associated with mental illness in New Zealand (Peterson, Pere et al, 2004). Thirty-four percent of respondents said that they had been discriminated against while looking for a job, and 31 percent said that they had been discriminated against while in employment.

The major findings related to employment were:

- Many people who disclosed their experience of mental illness to potential employers reported being turned down for a job. Others reported they had avoided this type of discrimination by not disclosing their experiences.
- Questions, pre-employment, asking people about a disability, their health history or whether they were on medication, were common.
- People had lost their jobs because of employers' attitudes to their experience of mental illness. They either lost their job when they became unwell, or left because of the attitudes of employers or colleagues, or found it too difficult to work because of their experience of mental illness. Few people made official complaints about discrimination in the workplace.
- The attitudes of employers and colleagues could be a problem. People reported not being trusted, being considered unreliable or incapable, having difficulties with colleagues, or not fitting in. Sometimes these problems escalated, leaving the person concerned feeling hurt or unwell.



- People with experience of mental illness did not always get the same reasonable accommodations as others in the workforce. In order to obtain reasonable accommodations, disclosure is required, leaving people vulnerable to discrimination.
- The encouragement and support by mental health services for people with experience of mental illness to gain employment is likely to improve their experiences of obtaining and remaining in employment.

Employers' research findings

The 2005 report *Employer Attitudes and Behaviours Relating to Mental Illness* (Lennan and Wyllie, 2005) summarised research undertaken on behalf of the Ministry of Health questioning 25 organisations about their practices and attitudes as employers with regard to people with experience of mental illness.

Employers expressed several concerns about hiring people with experience of mental illness. These included fear based on a lack of understanding and not knowing what a person with experience of mental illness might do, worry that such a person may not fit into the organisation, safety issues, and a fear that they may affect the productivity of the organisation.

Many of the employers interviewed had experience of employing a staff member with experience of mental illness. The majority reported positively handling times of unwellness by these staff members, supporting them through the period of being unwell, and reported good outcomes. Some reported a less positive outcome, however, with the person concerned not returning to work, citing lack of communication and support from caregivers or mental health services. The employers indicated that they would have continued to employ the person had these issues been resolved.

The research reported an apparent inconsistency. Employers were often reluctant to employ someone who disclosed experience of mental illness in an interview, but if a person became unwell while working, the emphasis would shift to trying to retain valued staff, including employers going out of their way to make reasonable accommodations.

Literature review

A review of the international literature relating to employment and people with experience of mental illness was undertaken as a forerunner to this current study. The results of that review are summarised in the next chapter, and are published as a separate report.

Research question

The findings of the three studies outlined above – the survey of people with experience of mental illness, the study of employers and the literature review – suggested further in-depth information was needed about the discrimination in employment experienced by people with experience of mental illness. This led to the development of the research question.

The research question for this study was: What are the specific issues that affect people with experience of mental illness in employment? In particular:

- how does discrimination manifest itself, and what affect does it have on people's employment?
- what affect does mental illness have on employment?
- do people with experience of mental illness disclose their experiences to employers, and what affect does this have on their employment?
- what (if any) reasonable accommodations are made in the workplace, and do these help people with experience of mental illness?

Method

The questionnaire

Face-to-face interviews were used to gather information for this project. A semi-structured questionnaire was developed (see Appendix 1), and this was peer reviewed by mental health researchers and people with experience of mental illness.

The interviews

The research was advertised mainly through using email networks and word of mouth. Prospective participants contacted the Mental Health Foundation after hearing about the research through these mechanisms. They were then sent a package of material comprising a letter advising that they would be contacted by an interviewer in a few days' time, an information sheet outlining the purpose of the research and what would be involved (see Appendix 2), and a consent form. One of the interviewers then contacted each participant and arranged the interview. Participants, when they first made contact, were given a choice of a Māori or non-Māori interviewer. Interviews took place in locations agreed to by the interviewer and participant, usually in the participant's home, occurred during June and July 2005, were digitally recorded and then transcribed.

The interviewers



It was identified that interviewers for this research needed to meet two criteria. They needed interview skills, and they needed an understanding of mental health issues. By sourcing interviewers through an agency that specialises in placing people with experience of mental illness we met the second of these criteria. We then provided additional interview training for the interviewers we selected, where required. Research participants were not told that the interviewers had experience of mental illness – it was left to the interviewers to decide if they wished to disclose their previous experience during the interview. In most interviews they did disclose.

Analysis

Transcripts of the interviews were analysed using the software package Nvivo. Themes were identified for each question asked from the interview schedule, and responses sorted, then analysed.

Limitations

The location of the participants was limited to the Wellington region because of budget constraints. This had the potential to limit the type of employment experiences raised in the research, for example, from people located in small towns or rural areas. Several of the participants worked for government agencies, which reflected the location of the research.

For the purposes of this research, people self-identified as having experience of mental illness. The definition of ‘being in employment’, while wide, may have been a limitation. The information sheet asked for participants who were in employment, had recently been in employment, or were looking for employment. The emphasis was on paid work, but that employment could be full-time, part-time, self-employment or casual.

Several of the questions we asked related specifically to people’s current jobs, but participants did not limit their answers to just their current employment. The answers often focused on this and then moved to previous employment. Usually, when this happened, the participant was talking about their immediately preceding employment.

One participant, who was self-employed, found many of the questions not relevant to his situation.

Findings

The research findings are outlined in the following three sections. The first gives a summary of the literature review, the second provides a demographic profile of the participants, and then summarises the responses to each of the interview questions. The third section discusses these findings in the context of the literature review.

Literature review findings

The literature review found that work is important for social inclusion, aids mental health, contributes to recovery and leads to improvement in outcomes, increased self-esteem, self-respect and confidence for people with experience of mental illness. Most people with experience of mental illness enjoy working. People with experience of mental illness who are working are more likely to be socially integrated, married and living in independent housing. However, the review also found that there are high levels of unemployment for people with experience of mental illness, and, in certain circumstances, work may place additional stress on people.

The literature review also found that people with experience of mental illness may be less educated because their illness interrupted their education, that they tend to pursue low-paid or part-time jobs, and may be discouraged from seeking work because of past failures. It found that symptoms and side-effects of medication can lead to job loss, but the most significant effect is on the confidence of the person with experience of mental illness. People with a work history were more likely to gain employment after a period of absence because of illness, and people with a positive attitude to work had higher employment levels, but also people limited themselves through self-stigma, and people with more extensive periods of illness were less likely to be employed. Employers and colleagues sometimes responded positively to people becoming unwell, but the majority of those who became unwell at work were treated with hostility and unfairness.

On the matter of disclosure, the literature review found that decisions on whether to disclose were based on the perceived character of the employer and, sometimes, the general environment or workplace culture. People with experience of mental illness preferred to not disclose, whereas employers preferred disclosure. Disclosure had the potential for better relationships with the employer, more open communication, employers who could respond appropriately to employee's needs and for access to supported employment services and reasonable accommodations. The review also indicated that people may be exposed to discrimination if they disclose, and be exposed to unsympathetic and abusive co-workers. If they do not disclose, they may have to lie to their employer and live in fear of people finding out. The review suggested that people needed to plan a strategy for disclosing, and that it can be especially empowering to disclose experience of mental illness and then be offered employment.

Employers' preconceptions about mental illness were also highlighted by the literature review. There was a lack of knowledge about the services employers can access, about the potential for litigation or the impact on liability insurance. Employers thought people with experience of mental illness could only work with other people with similar experiences, were unable to cope with work stress, needed excessive time off, put the workplace under extra strain, and were inappropriate to work in the mental health field. They thought that people with experience of mental illness were all the same, were dangerous and different from other employees.



The literature review also identified that it is illegal to ask questions for the purpose of negative discrimination, and that people with experience of mental illness had the right to work and be free of discrimination. There were actions that employers could take to combat discrimination, including providing workplace information on mental illness, having equal employment opportunities policies, utilising positive discrimination and making use of existing anti-discrimination resources.

The literature review also found that people with experience of mental illness fear being discriminated against in all parts of the employment process, are met with hostility, excessive scrutiny, undue pressure and patronising or derogatory comments from employers and colleagues.

There are several types of support in employment services mentioned in the literature review. The most common and effective model is the individual placement and support model. Studies show that it is less expensive to support people with experience of mental illness in employment using models such as these, than to not have them working at all. Savings in productivity may also make up for the costs of providing support and reasonable accommodations. Findings from the literature review indicate that it is more efficient for vocational and mental health services to be integrated, and that this integration helps people retain employment when they experience mental illness. The literature review also focused on the attitudes of mental health staff. These staff may not see people with experience of mental illness as competent workers, may not value employment, and may not be interested in people with experience of mental illness gaining paid work.

Provisions under the Human Rights Act 1993 mean that it is discrimination (and therefore illegal) to not provide reasonable accommodations to people with experience of mental illness, if necessary, so they can be employed and maintain employment. The literature review highlights several types of these reasonable accommodations – the most common being flexible work hours and flexibility in other employment conditions, such as part-time work and increased sick leave. Accommodations are most commonly identified in the hiring process or first two months of work, may not always be necessary, and are generally not too costly. To obtain reasonable accommodations a person must usually first disclose their experience of mental illness to their employer. Not wanting to disclose, often through a fear of discrimination, means that many people with experience of mental illness may miss out on accommodations that could make their working life easier. Reasonable accommodations must be tailored to meet the needs of individuals, rather than a one-size-fits-all approach.



Results

Demographics

Twenty-two people from throughout the Wellington region were interviewed for this research – 14 women and eight men. In terms of ethnicity, 14 people described themselves as New Zealand European or Pākehā, three as Māori, two as Pacific peoples and three as other ethnicities. Two people were aged under 25, 11 were aged from 25–39, eight were aged from 40–59 and one person's age was unknown.

People's employment histories varied. Some were employed part-time, others full-time. Several had been working successfully for years, some were no longer in regular employment, and others were engaged in work experience as part of training courses. Some participants had received help from supported employment agencies, many had not. All but two participants had been employed before they were diagnosed with mental illness, and all had worked since. People worked in a wide variety of jobs, at varying skill levels. Three people were self-employed, five were working or had just finished working for government departments, and six were employed in some capacity in the mental health sector.

Role of work

On the whole, all the participants in this research seemed to enjoy working. One said he was miserable when not working. Only one participant was unable to identify any positive aspects to her employment, because she had been in her job for just a short time and felt it was too soon to tell.

Many positive aspects of working were identified. These included learning new things, increased independence and responsibility, and improved social skills.

I learned heaps, like how to get on with people and how to work for my own money.

Other positive features were the training received, especially where that involved one-on-one relationships, having a focus and establishing purposeful routines. One participant enjoyed identifying as a person who contributed to the organisation, even though the work was not very enjoyable.

... you've got a real job, with a swipe card and your own desk and a computer... It's nice because you've got flash offices...

One person mentioned the benefit of self-employment.

I really do enjoy working for myself actually... my motivation does kick in.

Some people enjoyed the inter-relationships with clients and colleagues that resulted from their work, and several liked to feel they were making a difference in other people's lives by working. This was especially so for those employed in the mental health sector, who saw themselves as role models, empowering others, and helping them to resolve issues and work within the mental health sector.

... positive is helping whānau, and when I mention whānau I'm just saying like tangata whai ora and how they reconnect with their families.

Other gains identified by the participants included monetary benefits, having something to do during the day, and social contacts. While voluntary work was recognised as an option, paid work was seen to have increased benefits, such as people "being part of mainstream society". Financial independence was also important.

Although most people enjoyed working, many had at least one negative aspect to report. The most common was discrimination, and this is discussed in further detail later in the report. The other negative aspects included office politics, work-related stress, being insufficiently challenged by the work content, an employer taking too close an interest in the employee's personal life, and balancing work and home commitments.

It can be a little bit over-taxing, some of the work, but it's manageable.

Self-employment brought special challenges. Some were similar to issues for any self-employed people, such as finding time to get training, and getting up on a wet day. Mental illness also had impact, however.

It's been hard to... run a business with sort of mental health issues intertwined with it.

I've got to be there at quarter to seven [am] and that kills me, cos I'm on medication... I've actually have to get off to bed at least by 8.30[pm]... to be able to get up.

One person was not able to identify negative aspects of his work.

Every job's got its good and bad, I mean, you're not going to find the perfect job, and I can't remember anything negative.

In summary, most people in the study reported that employment was a positive experience for them. It provided financial and social benefits, and a focus in their lives. The negative aspects they reported, apart from discrimination, were similar to those of most people's working lives.

Mental illness and work

Mental illness and job seeking

People were asked if their experience of mental illness had affected them when applying for jobs. Some people reported effects, because of their illness, which prevented them from applying for jobs at certain times. These effects included problems with medication and tiredness, or just being too unwell to work.

I found it very difficult to get up in the morning... you know when you're quite sedated it's hard getting out of bed to attend an interview, at 10.00 o'clock in the morning even... I didn't actually have the motivation or energy to go out looking for a job, so I actually stopped looking.

For another person, full-time work was difficult.

I would find it hard to do 40 hours a week, to get looking for jobs.

People identified lack of confidence and self-esteem as the main effect that experience of mental illness had on job-seeking. This lack of confidence and self-esteem manifested itself for people in fear of failure and, in some cases, was based on bad past employment experiences, or the expectation that their disability would make them less desirable as an employee.

I don't know if I'd get the job so... it's no use going to the interviews.

Yeah, and also I suppose when I'm not well, not feeling well in myself and not well enough to actually even look at employment, I just have a real lack of confidence and self-esteem when things aren't good for me.

One person feared becoming unwell at work, especially because this had been an issue in a previous job.

I had a really good job and... I got really, really sick... Recently I've thought that [a job] is probably going to be too stressful, so I wouldn't apply.

Two others said that lack of confidence had been an issue in the past, but wasn't any longer.

I have gone into interviews in the past not feeling very confident and not feeling like I have the self-esteem, and that certainly makes a difference.

Overcoming this lack of confidence was a positive step.

... when I was out of the workforce, I had no confidence in myself that anyone would want to employ me after I'd been out of the workforce for so long, even though I'd been quite lucky and always managed to get jobs.

Some people reported applying for jobs that were less demanding than the work they were qualified for.

I have a degree... I won't go for high-powered jobs.

One person feared other people finding out about her experience of mental illness.

My biggest thing is the scars on my forearms. I wouldn't apply for any customer-related jobs because it's too obvious. I couldn't [work] without people asking all the time... most people who are mentally well now would never have to disclose their history, whereas I'm always faced with it because I cut myself in an obvious place.

Another person had been wary of returning to work in the mental health service where she had also been a patient.

Others said that their experience of mental illness had not affected them in applying for jobs.

Participants mentioned many strategies for overcoming the difficulties associated with mental illness when applying for jobs. The most common was the help of other people – giving them a push to look for work, being coaxed to overcome their fear, or supporting them at an interview.

No, I've had a whānau support person. A person who worked with me came to my recent interview and he asked questions if he thought I was going off the track in the interview and... his comments about me were accepted and the questions really helped.

Others were selective about the type of jobs that they applied for. One person looked for jobs where the evidence of their self-harm would not be seen. Some jobs were also considered as being more supportive of people with experience of mental illness than others.

Well, I decided to really strategise my applying for jobs in places where I felt... they are supportive of people with mental illness... I decided to only look for certain jobs and not look for jobs that I felt that I would have to stand up and be counted for my mental illness and that somewhere along the line that might come back and bite me in the butt.

Faith in God helped one person overcome the difficulties in applying for work.

For me, I suppose it's my faith, because I think what's holding me together and keeping me going is my faith in God, and that helps me a lot, because having that to look to otherwise I sort of sometimes may feel oh, when am I going to get a job, or this is taking ages or, oh my gosh, things like that yeah, keeping positive.

One person had been unable to find work after experiencing illness so had stopped applying for jobs altogether and set up his own business. He said:

It hasn't been the ideal passion for me, but I've been able to hold it together and keep my mental health, I suppose up until the last year or so, under a reasonable control.

One person spoke of the impact of the side-effects of medication on his ability to work.

I stopped taking my medication, which is something I wouldn't advise everybody to do. But it came down to a choice for me, of either living on a benefit and not doing anything and sitting at home, or trying to get off the medication and manage myself and actually be able to work. I was in a position where my doctor said I wasn't eligible for a sickness benefit... I was on an unemployment benefit at the time, but I couldn't actually look for work while I was on medication, so I was sort of stuck.

Another person reported that he was able to return to work once he was recovering from his illness.

I just, through better treatment, got better, significantly better, so I've been able to return to work.

Difficulties at work because of mental illness

People were asked if they had faced any problems in their job related to their experience of mental illness, for example, difficulty in performing the job, or in concentrating, being easily distracted, lack of motivation, taking time off sick or for appointments, side-effects of medication.

The most common issue described by people with regard to difficulties experienced in the workplace related to problems concentrating, particularly when they were stressed.

... my concentration level, my application, my self-discipline, would vary differently, perhaps from others with the same degree of knowledge and training, and I just have to manage that as best I can, I'm very aware of it.

I've been pulled up because of my poor concentration at times. My boss has said that I have a poor memory and I thought, well, that's probably due to my medication and empathy and things like that. I have been pulled over the coals a few times for basically things that have been my illness, I suspect.

Difficulty in concentrating resulted in some people giving up their jobs.

I was working in the position after I was first diagnosed and I went back after three months and I was doing 20 hours a week, and I just couldn't concentrate.... I was trying to cope... that's when I made the decision to leave and take a year off and just do casual work.

One person mentioned difficulties at work because of an increase of symptoms from mental illness, and another recalled a lack of understanding by colleagues of the effect of the illness.

Although I said to people I have a mental illness, and I told them what it was, people thought that I'd be over it really soon, and one person even advised me that I'd be able to wean myself off my medication soon, so I was getting lots of advice but, in actual fact, I wasn't really well, I know I wasn't well.

Another major issue was dealing with the side-effects of medication. These included extreme tiredness as well as other unwanted effects.

I'm just on sedatives for sleep at night, but anybody who's ever taken them, knows what they're like in the morning, and there's been a couple where I've had to be at meetings.

At lunchtime I'd be so tired, I'd go lie down... instead of having lunch, and try to keep looking at my watch every five minutes so I knew when to go back to work.

One person mentioned how she solved the difficulty in having to take time off to see mental health staff, because she had not disclosed her experience of mental illness to her employer.

I've actually had a good psychiatrist that's seen me during my lunch... I didn't have to say I was going off to see a doctor or anything.

For the self-employed participants, issues included difficulty with early morning starts, the stress of not knowing the extent that their mental state would impact on their work from day to day, or on their motivation or energy levels.

Mental illness at work

Participants were asked if they had ever become unwell whilst working. If so, did they need to take time off, did they return to work and how did the people around them react?

The majority of participants said that they had become unwell at some stage while working. The difficulties encountered meant that many had to leave their jobs. Some did not disclose to their employer that mental illness was the reason they were leaving. Other employers did not appreciate that the problem would resolve, only not in a few days.

... I rang [my employer] when I was really emotional and nearly crying and telling him I couldn't work any more. He said 'oh, just take a few days off'.

Some people took time off from work because of their mental illness. One found it was not easy to return. She tried to go back to work before she was well enough, even though her employer had offered unlimited sick leave. Some people also thought their relationship with colleagues had been affected because they knew about their illness.

... I sort of felt... alienated and isolated from the rest of the team... I resigned because I had had enough, and I could not face going back to work with people knowing.

Several people talked about negative reactions that they received on returning to work after being off for a period. One person talked about the difference in how her supervisor treated her after she took three weeks off work, while another mentioned how her colleagues would not talk with her about her experience.

... I just wanted somebody to say 'how was it', or 'how are you now', and the only person to do that was actually our admin person who said 'you're not ready to come back, are you', so that was, that was really hard.

One person said that their work performance had suffered because of their mental illness. Despite trying to return to work on several occasions, they needed more and more time off, and eventually found it too difficult to continue, so decided to leave.

Three found their employers were unwilling to make reasonable accommodations when they were ill, and this led to their resignations.

One person was actually dismissed from her job.

... I was pushing myself to keep going to work to impress and please my boss 'cause I had only been there for a short time... my body sort of got a reaction because I couldn't handle the work, the illness and the stress... with the flu as well, it was... causing me mental distress, because I was just trying to push, impress my new employer at the time... I was pretty much fired as soon as I returned to work, right from my boss.

One person thought that she might have had to resign from her position, but didn't because of the support she received.

I would get sick and think I would end up by resigning but... they were actually really quite supportive, they said 'look take as much time as you like'. I think they really did... appreciate my work. I hated getting sick while on the job.

The nature of the support from colleagues impressed one person.

... they were much more caring, 'how are you', 'I hope you're okay', and every now and again they'd say 'are you doing okay', you know, and actually much more open, like 'we really appreciate your work, your job', you know, 'thank you very much, you're doing a really good job'.

Other people also talked about the support they had received from their employers and colleagues, with one person saying that she received more support from them than she did from the mental health services.

Some people tried to hide their mental illness from colleagues, and reported how difficult and taxing hiding their experience was, and the toll that this had taken on them. One person wasn't successful at keeping her illness a secret. She was surprised at how supportive her co-workers were when they found out.

Another person talked about his experience of becoming unwell while being self-employed, and how he was aware that his employees had taken advantage of him because of his experience of mental illness.

One person was accused by her colleagues of not taking her medication and told that was the reason why she became unwell. Although this view was incorrect, she felt too unwell to counter it. Another person talked about the unhelpful work environment when she became unwell, despite working for a mental health organisation.

I became unwell not long after I started... It just confirmed [for the employer] that the job was too much for me... I had patronising comments

Some people had received positive responses from their workplaces when they became unwell. They were able to negotiate mental health leave, or different duties on their return.

Participants were also asked why they returned to work. Most of the people who answered this question responded that this was the expectation of the mental health services, employers or society.

I was discharged from hospital, and they probably said, you know, go back to work next week or something... I did run out of sick leave, so I tended to be taking leave without pay.

One person said encouragement from friends and family was the main reason why he returned to work. Others reported financial reasons and a need for independence, as well as work occupying them during the day. One person reaffirmed the value of work to self-esteem.

I feel like work's sort of contributing to the community, and you're earning money... I know how difficult it is without working and trying to fill in your day.

In summary, mental illness affected the confidence of participants when applying for jobs, and the main effect of mental illness on people's day-to-day work was on their concentration. Most participants had become unwell at some stage while in employment, and many had left their jobs because of this. Some had been unable to negotiate accommodations with their employer. One person was dismissed from her job because of her mental illness. Others returned to work successfully.

Disclosure

Employers' awareness

Most people said that their employer knew about their experience of mental illness.

One person disclosed his experience of mental illness on an application form that asked health questions. Another person was upfront from the very beginning about his experience of mental illness.

I told them, I've got it on my CV, it's not something I hide, and I tend to put it in my application letters as well... When I first started... they went through the normal thing of asking questions around whether I need reasonable accommodation in my workplace, but I was generally okay... I don't want it overly highlighted because I don't want people to tip-toe around me either, and in which case I can't do the job that I'm supposed to.

For some people, having experience of mental illness was a requirement for their position, either because they worked for a consumer organisation or as a consumer advisor.

I wouldn't have got the job if I hadn't had an experience, so they were certainly looking for someone with experience [of mental illness] when they employed me.

Another person talked about how she was a role model for others in her position in a mental health organisation.

My employers are fine. Within the team that I work in there are attitudes that are quite entrenched in seeing tangata whai ora people who need treatment... I don't see an empowering model there, although they say they are using a recovery model. The language they use and their attitudes are something that I am determined to change. I'm working on that, but there are ways of doing that so, you know, so I don't put myself out on a limb... I suppose I'm modelling really.

Not everyone had a choice as to whether they disclosed their experience of mental illness to their employer. One person talked about how the organisation she worked for found out.

Someone else told them... It slipped out in a conversation with a number of people in a meeting... Well, they were a bit stunned, yeah, just a bit stunned.

When asked if she was treated differently when they found out, she replied, "I suppose... I felt there was a bit more pussy footing around".

Some employers were very supportive after they knew about their employee's experience of mental illness.

My manager's been really supportive and reinforcing all the good things that I've been doing, which has certainly made me feel worthwhile and that I am on the right track, you know, which is really beneficial and I have found that really helpful.

The employers of another person knew about his experience of mental illness because he was employed under a supported employment scheme. When asked if he was treated differently because of his experience of mental illness, he replied:

I don't feel different or anything like that, but part of my manager's [role] is to monitor my workload and things like that, so... there is some allowance for my condition... I don't discuss it with other staff.

One person talked about difficulties that she had with her employer, resulting in a meeting with her employer and a supported employment person, because she was not performing well in her job. The outcome of the meeting meant she could change the hours she worked, resulting in increased performance, which, alongside a medication change, seemed to resolve the situation.

Other employers were not supportive when they found out about their employee's experience of mental illness. Some treated people differently from before they found out. One person disclosed her experience of mental illness, and was given less interesting projects. She felt as if she was being patronised. Another had a very negative experience, resulting in her being fired from her job.

About the week before I was fired... I chose to tell them, hoping that... they would be a bit more lenient with me going to counselling appointments and so on... At the time, I thought I was doing myself a favour... but after... I realised I had pretty much screwed it up for myself by telling them, I felt like a bit of an idiot really... He just went 'oh, oh', and you could see in his face he was a little bit semi-shocked or annoyed, but he tried to keep it hidden, you could also see in his face, he tried to seem like it meant nothing to him.

Some people who had not told their employer about their experience of mental illness were unsure whether their employer knew or not. They wondered if, from their employer's behaviour, they suspected something.

I haven't told them, they haven't asked and I'm not aware that they know anybody that I know who knows... because people with mental illness obviously cope differently from others from time to time, they may suspect... It's not to say it's not going to become a problem. You do feel a little bit like, perhaps you're living a lie, but I'm not too guilty, I don't feel too guilty about that.

Other people had no intention of telling their employer about their experience of mental illness for fear of a negative reaction. The responses feared included being the target of office politics, having their work discredited, and having behaviour, that in another colleague would be dismissed as 'because of a late night', being attributed to their illness.

I've seen the reactions afterwards from team members... if you are emotional that's because you have a mental illness, if you are late that's because you can't get your act together.

Colleagues' awareness

People were asked if their workmates were aware of their experience of mental illness and what that was like for them.

Several people said that their colleagues did not know about their experience of mental illness. This was because they were afraid of the consequences, or because they did not want everyone to know and talk about them, or ask too many questions. Previous experiences also put people off telling their colleagues. At least one person was afraid of getting too close to their workmates in case they found out about their experiences, others were afraid of office gossip.

... they have no need to know, so you know, I don't feel like blabbing, they don't tell me about their lives, so why should I tell them about mine.

Another person, who had told only one colleague, had been given advice not to tell the rest of her colleagues because of the fear of repercussions.

... 'if you ever think of wanting to come back here don't disclose that you have had a mental illness, because you might not get a job back here again'. Or, you know, 'people might not think of you as someone credible or someone who is able to do the work'.

Some people did not have the opportunity to keep their experience of mental illness a secret. They were on supported employment programmes and their colleagues had been told. Their work experiences were generally positive, although one person wanted more control over who was told.

... I was on this [supported employment] programme... and there was one point when I think it was [the supported employment worker] or my supervisor who had suggested maybe to tell the rest of the floor... but I, I felt uncomfortable with that, with everyone sort of knowing I guess.

Another person, who did not disclose, found herself in a situation where a colleague seemed to know anyway. This put her in an awkward position, because she did not want the rest of her colleagues to know.

One lady was, she was more senior... and her son experienced depression. And so she seemed very, she was very sympathetic and reassuring and had offered me to talk to her at any time... I didn't really know her, and also because I really didn't want it disclosed, you know, so I didn't want to talk to people too much about it. But she picked up on it because she worked opposite me and she could see that I was sort of a bit all over the place at different times.

Several other people decided to be upfront about their experiences to their colleagues. In general, the reactions were very supportive.

Very, very supportive, 'what can we do to help you' type scenarios, 'what support do you have at home', it was that sort of thing. Very holistic type support and especially around me being a Māori woman and all. I felt that they met my cultural recovery side as well, even though... people... were non-Māori, they had a very good way of making me feel, you can get out of this, and this is what we can do to help you.

One person challenged one of her colleague's behaviour in a staff hui, with a positive outcome, another disclosed his experiences in a team member profile.

... There were a few other closer team members who also knew so, it's come out in general conversation, but I've also made the whole directorate aware by sending out my bio... There's quite a level of comfort, and people haven't emphasised that as an issue, there's been, I think a couple of times, there's been people who actually recognised it as a strength for the position.

One person, however, while being upfront about her experience of mental illness in a previous job, found the attitudes of her colleagues very difficult to deal with. This was despite her employer being a mental health service.

The people in the interview panel went around and told the other people that I was a consumer, which was not okay. It was about me disclosing when I wanted to... so I was turning up... for orientation, and I knew from the way people were treating me that... they knew I was a consumer, and that I didn't fit the stereotype of what they had expected. They expected someone like one of their clients to turn up, and they had a lot of doubt as to whether or not I could do the job... That made me feel really self-conscious... 'cause I knew people were talking about me... But here they were trying to make out that I was crazy, but, you know when people are treating you in a patronising way... It's like they treated me like one of the clients.

Workplace information

People were asked if they had given any information to their employer or colleagues regarding mental illness.

Only one person reported giving out information. In his workplace a 'hearing voices' workshop was being organised, and colleagues had also approached him separately for information regarding mental illness.

You tend not to get too many responses... the 'hearing voices' workshop [is] probably going to be the really big one and the eye opener for everyone, but there has been a few people here who have got family members in early stages of mental illness who are just going through the system at the moment, and, as a result of me declaring and sending

out information, a lot of them have actually come to me and asked for information about particular illness and what the system's like... I get a lot of queries that aren't necessarily related to my job, it's actually related to the fact that I've been through the system before.

Pressure to disclose

People were asked if they had felt any pressure to disclose their experience of mental illness to their employers or colleagues. Only one person said that they had not felt any pressure.

There's never been any pressure for me, but when I was at [name of employer], I thought, well, if I had said something to them would I have been treated any differently or supported in some way, but, no, I've never been pressured to actually tell anyone or say anything.

Some people reported feeling obligated to tell others. For one person, this was a need to explain her behaviour.

Whereas, part of me wishes I didn't have to feel like I had to explain it, it was sort of in order for people to accept me as being okay, I felt like I had to explain my situation, because it wasn't seen as normal behaviour.

Another person also felt the need to explain absences from work for appointments and why they were taking medication. One person talked about how she had felt a need to tell others in the past, but now realised that there was no need to tell, especially if her work was okay.

But, I have to admit, sometimes when I'm in an interview... I do feel sort of obliged to tell them... You know, like some will ask 'do you have a criminal record', it feels like on par with that, and I would like to get past that actually. I don't see why I have to, especially if my work performance is fine.

Another person said how important it was for her to be upfront at the start.

I never disclosed it, the first time I went to get a job. After a few years off work, I just wanted to disclose, it was very important to me, and I still got the job.

Advice about disclosure

Participants were asked what advice they would give to others with experience of mental illness about whether to tell their employer or colleagues about their experience. The response to this question was mixed, with some people saying, yes, disclose, some, no, do not disclose, and others, maybe, it depends on the situation.

The people who said they would advise others not to tell, explained it was because of the potential for discrimination.

I'd advise not to... at the moment, people aren't prepared to hire people with either depression, or just quite mild mental illness really.

Some participants advised people to disclose their experience of mental illness only when applying for a job in the mental health sector. One person pointed out there is no obligation to disclose, and it is unlawful for potential employers to ask questions about having experience of mental illness.

I had a very good case manager who... said it's worse if you don't tell them, and then they find out later that you've lied. Rubbish, it's not true at all, you know, they can only ask lawful, certain lawful questions, the rest of the questions aren't lawful.

One participant also advised people not to disclose to their employers immediately afterward they had been employed. Another advised that people should do research about the job and the organisation before applying, to see whether they had a good reputation regarding employing people with experience of mental illness.

Choose your employer carefully and then, I think, test the boundaries.

Another person said that it was important to have good support from outside the workplace, such as from a mental health professional. They felt that having this support would mean that disclosure wasn't necessary.

I make sure I have a good doctor... a reliable support person that you trust, you can talk to... when things go wrong in the job... and give you encouragement and everything... Definitely have that support behind you, because if anything goes wrong in the job you need someone to talk to.

For others, the situation was not so clear cut, it would depend on the job or the circumstances as to whether to disclose or not, and people needed to be cautious. While progress has been made on reducing stigma and discrimination, they advised, it's still an issue that people with experience of mental illness have to face, and often people cannot tell what the reaction will be to their disclosure until they have disclosed.

... I think it is up to the individual really, and the type of work that they are choosing. I can think of some organisations where it may not be appropriate to disclose or it might not be safe to do so. I would say to people to really think it through and talk to your peers about whether there is a need to disclose.

One person said that the decision to disclose should depend on whether the experience of mental illness would affect their work, and noted there is a difference between being slightly unwell, and not being able to do the job at all, and how this affects the employer. When asked about whether colleagues needed to know or not, the same person said that they did not need to know.

Other people said that it was an individual decision, but one person pointed out that, once disclosed, it can't be taken back, so people should think very carefully about doing so.

You alone can make that decision, be mindful that it can be helpful, but it may not turn out to be. If you feel you must then, do, if you feel you mustn't, don't. Just make sure you're not putting yourself at risk, obviously if you don't [disclose] you can change your mind, but once you have you can't.

Another person advised people to disclose only if they wanted their employer to make reasonable accommodations, or if their illness was going to impact on their work.

I don't think it's particularly helpful to tell them, because I suffer from schizophrenia, so they will immediately think you're an axe murderer or something, so you're not really helping people understand by just saying you suffer from that, you really need to explain it more, and mostly it isn't an issue at work, so you don't really need to bring it up.

Others said people should disclose their experience of mental illness. Some recommended being upfront, right from the start, since if the employer discriminates because of the disclosure, then:

... is that an employer that you really want to work for, and is that going to be an environment that's actually supportive of you.

Telling employers upfront, according to one person, reduces the chance of being discriminated against, and allows people to offer, or negotiate, reasonable accommodations.

Be upfront with the employer... that way everything's out on the table, there's no employment issues about having a mental illness, there's no discrimination, there should be no discrimination, and perhaps when they're looking at the employment side of things in their contract, and I'm saying only perhaps, there needs to be a bit more leniency around sickness depending on how unwell the person gets throughout the year, and instead of getting what's it, nine days, they might maybe get 18 sick days.

Other people felt that to tell prospective employers was the right thing to do.

Oh, you can't not tell, you can't not tell your employer something, if you're on medication they need to know, I think. But hiding it, trying to hide it, you're getting the message across that you've got something to hide.

In summary, most people said that their employer was aware of their experience of mental illness. Several had chosen to tell their employer at the start of their job, others were using supported employment agencies, and for some, experience of mental illness was a requirement for their position. The employers' reactions were mixed, with some being very supportive, others not. Fewer people had told their colleagues, fearing repercussions. Most people had felt at least some pressure to disclose their experience of mental illness to their employers or colleagues. When asked if they would advise others to disclose, there was a mixed response.

Discrimination

Health questions

People were asked if they had ever specifically been questioned if they had mental health problems, or health problems in general, when applying for jobs.

Two people said that they had not been asked health questions, and one said that he was quite open about his experiences anyway because it was in his curriculum vitae, so there was no need for potential employers to ask.

Most people reported that they had been asked about health issues, usually on an application form when applying for a job. Many said they did not disclose their mental health issues when asked.

I just say excellent, or ordinary, you know, I just don't even tell them I have a mental illness.

Others interpreted the questions literally, arguing that their experience of mental illness did not affect their work.

Yes I have, but usually they ask the question in such a way that I can answer no. Like they say, 'do you have any health problems that will impact on your work', and I can quite honestly say 'no'.

Others felt that they were obliged to disclose their experience of mental illness.

There is a form you fill out... asking whether you have an illness or take medication and, yeah, I usually say that yeah 'cause I am still on medication.

If I'm asked, I will put it down, but there are some people that don't ask.

There were consequences for this disclosure, however, and these are discussed further in the next section.

I have told them but, no matter, as soon as I tell them, I look at them and I know something's wrong with the whole thing after that.

Discrimination while looking for work

Several people said that they had been discriminated against when looking for work. People recounted how, after disclosing their experiences of mental illness, they were told that the position would be too stressful for them. This was interpreted as discrimination by these participants. Their feeling was that they had done the honest thing by disclosing, even though, legally, they did not have to, and that they had been disadvantaged by that disclosure.

Just comments like ‘well, at this point in time we don’t think you are quite the person we are looking for’, ‘we think that this job might be a bit too stressful for you’... where they are sort of telling me that I’m not the person that they are looking for because I have disclosed personal information... trying to be honest, you know, and I have that thrown back at me.

Another person answered yes, when asked if she had a condition that could affect her performance. She felt that she missed out on an interview because of this.

One person reported being declined a job by the Navy.

Well, I did once apply to work for the Navy and they did turn me down, because I had a history of schizophrenia.

Other examples of discrimination included being given a clear impression that the panel “*didn’t want a nutter*”, or having the employment agency refuse to have any dealings with them, even when, in one case, the agency had been keen to place the person until they found out that the reason for working part-time was on a psychiatrist’s advice.

... they were very understanding, but after that the phone never rang.

Another person said that she was unsure whether she had been discriminated against, but had a sense it had happened. She felt that after saying she had a mental illness in previous interviews people had looked at her differently. Another person felt it was important to make a good first impression in an interview, and even though she had, she was discriminated against after she disclosed.

... as soon as I tell them I have a mental disability it goes down hill, but at least I’ve proved to them in the first experience with them that I am no different than anyone else.

Several people responded that they had not disclosed their experiences of mental illness to potential employers, and that was why they had not been discriminated against.

I haven’t really been discriminated against, but I haven’t told them that I have a mental illness either.

One person reported lying to a potential employer, saying that he didn’t have experience of mental illness, and then getting the job he had applied for. Some people were worried that, even though they had not disclosed their experience of mental illness to a potential employer, the employer might deduce it in an interview situation.

I found, because I felt quite self-conscious at the interview, that I started to kinda maybe act the part... I could sense that she wanted to ask.

One person surmised that gaps in their work history could also lead an employer to suspect mental illness, and discriminate on the basis of that suspicion.

There were three years when I was unwell... I got a feeling that people might have looked at my CV and sort of gone, well ...

Others said that they had told their prospective employer about their experience of mental illness, either at the interview or from having it on their curriculum vitae. They reported that they had not been discriminated against, and had been employed.

When I first applied for a caregiving job I went to the boss at the time and told her straight up that I had a mental illness, and she still employed me, and during that time when I was working for her I became unwell and I needed three weeks' sick leave, and that was okay.

This same person said that, although she had one positive experience in terms of gaining work after disclosing her experience of mental illness, she decided not to disclose for another job interview because she was unsure how this information would have been received.

Discrimination at work

People were asked whether they had ever been discriminated against or treated unfairly in their work because of their experience of mental illness. Several people replied that they had not experienced any discrimination at work, either because they hadn't disclosed their experience of mental illness or, where they had, the discrimination had occurred before they were employed, so they did not get the job they applied for. Others said that they didn't know whether they had been treated differently because of their experience of mental illness.

I wonder, but I don't know.

People reported being discriminated against by their colleagues, one to the point where she was considering leaving.

Where I am now, the first three months were hell, really. It was so bad I was looking for other work... that person [who was discriminating] was leaving, so I thought I'd hang on in there, and everything has changed since then.

Another mentioned being teased by a workmate.

I've had one comment from a workmate who said 'oh, you'd be the kind of person that'd come around here with a gun, wouldn't you'.

Other people reported being discriminated against by their employers. The discrimination included inappropriate comments, and being given less satisfying work to do.

... my employer gave this [document] to me to file in order, but she put chapter 15 with 'mentally disturbed people' on the top with a little giggle, which I really didn't find

amusing... and I also told her that mentally disturbed... should actually be changed to mentally ill because it perpetuates a stereotype, and mentally disturbed is a bit derogatory.

After I'd told my employer that I had bipolar... the quality of the work [I was given] went drastically down, from consultancy training to indexing and filing.

One person talked about the discomfort of being treated differently.

... I have definitely faced discrimination, for sure... and it's uncomfortable, you know... It's really uncomfortable when someone's looking at you in a different way, where only last week they looked at you like you were part of the [general] population... And when you told them, you are sort of sub-human or something, which is totally inappropriate.

Another person talked about how the lack of reasonable accommodations, which she needed in order to work in her position, was discriminatory.

... I needed conditions that people without a mental illness didn't need, they could function in the atmosphere quite well, and they expected me to function in the same environment they were functioning in, and to me that was discriminatory.

Those working in the mental health sector were not exempt from discrimination, either.

Some of the hostility... I feel, is because we are mental health consumers ourselves, and it's known... so we're sort of looked down upon, and... we're kind of scrutinised for signs of illness.

One person had a word of advice for people with experience of mental illness when seeking employment.

I think the answer would be, if you go for a job and have a history of mental illness, get a reference from your psychiatrist, arm yourself with that, and he will say 'so and so is on so much medication, when he does such and such, he is not dangerous he can do a good job', something like that, always get a reference, there are so many misconceptions about mental illness, mostly we are not dangerous, are we, even on our medication.

Discrimination because of other factors

People were asked if they had been discriminated against while looking for work, or in work, because of other factors. The issues people reported were ethnicity, gender and sexual orientation and height.

Everybody knows I'm a homosexual... that has caused me more trouble, more stigma than my mental illness.

Most people said they had not been treated unfairly while in work. Two people talked about being discriminated against because they were female, another because he was older than other colleagues, and another because he was gay.

No, I don't think so, perhaps my age, you know, like I'm older than most people, I'm sort of doing jobs that people in their 20s would be doing, I haven't had that long in the workforce, so that's been interesting.

Discrimination complaints

People were asked if they had ever made a complaint about discrimination when looking for, or being in, a job because of their experience of mental illness (for example, with the Human Rights Commission, a personal grievance, or the Employment Relations Service).

One person summed up his feelings about laying discrimination complaints:

Never, I've just been grateful that I've got a job.

Two people had laid complaints, one for a reason unrelated to her experience of mental illness. The other complaint, about a non-governmental organisation, was made to the government agency that funded the organisation. The outcome was:

The [government agency] manager... basically told them that they were probably bordering on a breach of the Human Rights Act.

Two others had almost laid complaints, but the situations were resolved before this became necessary. In one case, the person causing the problem had resigned, so a complaint was no longer necessary. In the other, a colleague was challenged on their behaviour, and the situation was resolved. Another person was, at the time of being interviewed, contemplating laying a complaint and was seeking advice on the correct procedure from a community law centre.

Although other people had grounds for laying complaints, there were various things that stopped them from doing so, especially the thought of repercussions, such as not being able to find another job because of being labelled a troublemaker. One person said that what she knew about how complaints were handled by the employer made her reluctant to complain at all.

It's always the consumer's voice, versus psychiatrists and nurses, and it's not like the consumer is trusted for all the other reasons, like he or she is emotionally unwell and delusional and manipulating and attention seeking, you know... If you did something on mental illness, because people know that you actually have an illness, it would be pretty damn hard to get a job again.

One person said that discrimination, based on mental illness, is different than discrimination based on other factors.

Who is going to want to employ you, because they would have the same sort of attitudes in their workplace, too... if you sue for sexual discrimination it's not like there is something wrong with you sexually. Well, yeah, people might think that you, you know, wear short skirts and you ask for it, but it's not like a mental illness where people are going to say 'well, she's got a mental illness' now everybody knows.

The effects of being unwell at the time stopped one person from laying a complaint – she just did not have the energy required to do so.

I was advised that, legally, I did not have to disclose the information. What they had done was incorrect and wrong, but at the time... what energy I did have, I needed to use healing myself and working on my own recovery and not fighting an employer over discrimination, it just wasn't the right time.

The same person said that she still felt angry about the discrimination, but at the time was “so blocked up with other emotions, I just was not capable of going there”.

One person reported that they had never needed to lay a complaint because they had always managed to resolve the issues before they got to that stage.

In summary, almost all of the participants said that they had been asked questions about their health in the process of finding work. Some disclosed in response to this, others did not. Several people recounted their experiences of discrimination, both when applying for work, and from employers and colleagues. This discrimination included not being offered jobs, being teased by colleagues and being treated differently compared with workers without experience of mental illness. The discrimination also took place while some participants were working in the mental health sector. Others also reported being discriminated against for reasons such as gender and ethnicity. Despite these accounts of discrimination, the laying of official complaints was rare.

Support in employment

Help applying for jobs

People were asked if they had received help when applying for jobs, including supported employment services, training, or receiving benefits or grants from Work and Income.

Several people had used supported employment services while looking for work, either intentionally, or because they had contacts within the service.

One person mentioned receiving help from an organisation run by people with experience of mental illness. They assisted by contacting a potential employer and accompanying the person to a job interview. Another received help from an employment agency that particularly targets people with experience of mental illness.

Some people received help from several sources, including placements with Mainstream, an employment programme run by the State Services Commission for people with disabilities.

Other forms of support in applying for jobs included training courses and work experience, assistance from Work and Income, and help from friends and family.

Most of the whānau that I had... assisted me in how many pages I should have in my CV, what should be the most important thing to put up front and the least important.

Some people said that they had not received any help, either preferring to rely on their own resources or because there was no support available for them.

No, I've always advocated for myself.

One of the questions participants were asked was how useful was the support that they had received. Generally, at least some aspects of the assistance received from supported employment services were useful, especially with finding jobs, although the placement was not always successful.

... she was helpful in helping me to motivate, to have someone to support me, and get that placement... it didn't quite work out, but I suppose these things happen.

One person, who had help from a supported employment agency, also received financial assistance. This was very important because it enabled him to move out of supported accommodation so he could start work. Financial assistance was also needed to overcome other barriers.

... the relocation allowance was really, really important too, to move away from supported accommodation. I wouldn't have been able to work, you know, living in supported accommodation, so living on my own has really helped. There are still other barriers that are really difficult I've found... like getting clothes to work in, you know, there's costs associated with starting work.

Another person, when undertaking a training course, made a useful contact while on the course, which resulted in him finding employment. Someone else found that the course she had done was useful, but realised that the responsibility for finding work was hers.

... because it's up to me to put my best forward for them... It's my responsibility to turn up there on time and do things properly, it's up to me really... getting me to the start of it's good, but it's my responsibility to carry on.

One person talked about the assistance she had received from a support worker, in highlighting her strengths rather than focusing on negatives.

... she [the support worker] sort of pointed out my strengths... and she's quite good at saying 'hey, you're good at that' and 'hey, you're good at this'.

Another person talked about the vocational assistance that he had received, whereby, with the help of the provider, he had established what were his:

... skills, passions, your likes and dislikes and all of that. So it starts from not what your qualifications are, but from basically who you are as a person.

Some people mentioned their experiences with receiving help from Work and Income. One person obtained a feeling of independence and self-reliance while on a sickness benefit.

It meant that I could, for the year I was off, teach voluntarily in a kindergarten... I could just choose, give me flexibility in terms of working... So help transition back to work.

Others, however, sensed that, because of their experience of mental illness, the supported employment agency was reluctant to help them find work. One agency employee “seemed reluctant to do anything ‘cause she would have to disclose my mental illness”.

Another person who received help from a supported employment agency thought that the agency appeared doubtful she would get the job because of her experience of mental illness.

But I did get the job, you know, I had a lot of skills.

One person, whose area of expertise was in information technology, had difficulties with a supported employment worker who did not have sufficient knowledge of the industry in order to find her an appropriate placement.

I think she worked quite hard to try and find the placement, but maybe it was just difficult because her expertise wasn't in computers.

The role that mental health services play in employment

Participants were asked if mental health services had played any role in their employment and whether these services were supportive of them looking for work, or being in a job.

Most people said that mental health services had not played any role in their employment, apart from supplying medical certificates. Experiences were mixed, however, when it came to how supportive mental health services or general practitioners had been in regard to employment.

One person was encouraged by a mental health professional to take a break from working for a while. This was welcomed and found to be helpful.

He actually advised that I take a wee break from work and take a holiday, if I could... he was eventually supportive of me getting back to work.

Another person was supported in her initial decision to go back to work, but when it made her more stressed, her doctor advised of alternatives, and supported the decision she made.

She suggested to me that I needed to think about whether work was for me, and whether I needed to make other choices. She knew of people who had never been able to work again, and that was an okay choice to make, and she actually wrote a letter to that effect to WINZ so I could go on a benefit, saying that I wasn't capable of working.

One person talked about how she had higher expectations for herself than the mental health services did, because of their fear that she may not be able to handle the stress.

... I think they always tried to get me to aim lower than I thought I was capable of because I wouldn't be able to handle it. It really annoyed me, because why should I be content with doing something less than I think I can, just because I have a mental illness and I might be erratic and I might not be able to deal with the emotional stress of it all.

Another mentioned that her doctor was concerned that a polytech course might be too stressful:

I sort of opened her eyes that I could go to polytech and work all day. She just needed to know that I could. Well, she thought it was too stressful to do those hours, but I told her about work experience and everything, and it opened her eyes a bit.

One person, working in a mental health service, said that the assistance she had received changed over time, from not being supportive at first, to being more supportive.

At the beginning, they probably weren't that supportive, maybe they thought I would be better off not working there, or at all, but generally I've had a lot of support.

Another person received a lot of help from her doctor in returning to work.

I trust her, and I'm able to ask her any questions and she gives me information. She supported me going back to work, and we've talked about that, what it would entail and how I would keep myself safe and all those sorts of things.

Mental health staff had also been helpful about people working.

They have always been quite, sort of supportive and proud, like proud of you to go out and do that for yourself, or that's the way they seem to be to me.

They said I was probably able to work eventually, but I didn't believe them a lot of the time, but, you know, it's been a slow process.

One person had received a lot of encouragement from mental health staff to set up her own business, and in helping find grants.

In summary, a variety of support mechanisms were used by people when applying for jobs. These included supported employment agencies, mental health organisations, training courses, and help from Work and Income and friends and family. Mostly, people found supported employment agencies useful, although some participants sensed reluctance from agencies to work with people with experience of mental illness. Participants reported that mental health services were generally supportive of them working.

Reasonable accommodations

People were asked if any special arrangements had been made for them in their work, for example, flexible hours, time off for appointments, increased sick leave. If reasonable accommodations had been made, did they consider them to be helpful?

The most common accommodation made by employers was flexibility in the hours worked. People worked less than full-time, started later than usual, or had flexible hours. Some were also able to take time off for appointments when needed, and had flexible sick leave arrangements.

I only work 30 [hours per week] and that's an accommodation made for me, and I start at 10 o'clock most mornings, because I've negotiated that I'm not a morning person, and it's really hard for me to get going in the mornings, and I take an hour for my lunch break and work four days, I've had time off for my appointments.

One person said that the organisation he worked for was very flexible with regard to hours and sick leave, and had counselling available to all employees. This had meant that he had not required additional accommodations.

The organisation's got quite good policies anyway, not just for me, but for everybody, and that's actually been quite good. I've got flexible working hours... they don't call it unlimited sick leave, but I've got a designated 10-day sick leave per annum, but I can extend that if I ever need to, and there's also counselling sessions available for staff as well, so it's not specifically for me, it just so happens that actually works out quite well, and they didn't need to go outside of that format.

Another person also reported finding flexibility, as well as regular meetings with his manager and extra training, helpful.

My hours have been slightly flexible since I've had some reorganisation of my hours... there's been some leeway in terms of when I start work... meeting with my manager each week is the main thing, and that's been the most beneficial, where we discuss the work, and she helps me with my work, she's put a lot of effort into a lot of training, I mean just talking me through things has been invaluable.

One person mentioned that having her hours fixed, instead of working different shifts each week, was helpful.

[The supported employment worker] said maybe you need an advocate, and she said she would do that, so she went and talked to them and said... they were supposed to make reasonable accommodations and things, so... we normally work three weeks 8 till 6 and then one 8 till 5 and then one week 9 till 6, and they changed it so I always work 9 till 6.

Another person talked about how she had arranged her hours to suit, but then had found that she was missing out on certain work activities that were culturally important to her, so she was considering changing them back.

I've been used to working later because... I'm not too good in the morning... and I was required to work 8 to 4.30pm. I tried it ...but... it wasn't working out for me, so they readjusted my hours, so... I do 8.30 to 5, but I'm actually going to work towards going back to the 8 because I am missing out on that morning karakia and the waiata practice.

One person talked about the advantages of being self-employed, which allowed her to have a greater amount of flexibility in her job than she would have had otherwise.

If I was working for the government or in private industry... how would I ask... to take time off for counselling, I would find that quite hard... that's probably why I work part-time, so that I can go to my appointments... these appointments are... vital for my wellness.

For some people, the accommodations had been helpful, and meant that they could continue working.

Well, it just enables the workload to be a bit more... friendly for me, you know, it's like I can't put myself into a round hole because I'm square... so they are actually making allowances for me being a square.

It basically allows me to do my job, but also allows me to look after my health, and while I'm looking after my health I can actually do my job much, much better so, for me, coming in at 11 o'clock, because I'm still quite drowsy in the morning, and finishing maybe 6, 7 o'clock is actually better for me.

Some people had to negotiate in order to get accommodations, and one person used a supported employment agency to help settle this for her. The agency and employer looked at ways to do the work successfully. One person who had effectively negotiated flexible working conditions found that, when the management changed, so did her working conditions.

... but then another manager who took over, just completely squashed my reasonable accommodation and told me I had to start at 9, even though it had been negotiated.

Another person said that her employers “*tried to make it look like they were being flexible, but they weren’t really at all*”.

Three people tried to negotiate reasonable accommodations with their employers, but without success. They ended up resigning from their positions because of this. One person had asked for certain accommodations, but was offered a specific period of time off, instead.

I’d told them what I needed, and they said ‘no, you can’t have what you need, this is what we’re giving you’, and that was that. So to me it felt like, my needs which I thought were quite reasonable ...were unreasonable.

The second person had applied for, and got, a job, but did not disclose her experience of mental illness, she then became unwell and took time off work. When she returned, she requested a reduction in work hours. She was told that, because she had not disclosed the information of her illness in the interview form, the employer didn’t have any part-time hours, the job was for full-time hours, and that they couldn’t negotiate part-time. The employer also said they couldn’t offer any other part-time work that they saw as being appropriate for her to take on, and the best they could do was offer four weeks’ pay, instead of her giving notice. She was told they would relinquish her from the position right there and then, and would give her a letter to say that she was unable to continue her employment there. She was told to go back to the sickness benefit.

I explained to them that I was just in the process of going back onto medication, so therefore it was going to take a little while for it to all kick in, and for my chemical levels to adjust to the medication and, you know, it would be good if they could just give me the reduced hours for a little while, so I could still continue to work at a level that I could manage. That was basically a definite no – they weren’t prepared to do that at all.

The third person also took time off work after becoming unwell, and tried to negotiate with his employer, but, instead, his employer demanded his resignation.

I started getting letters that demanded my resignation... I could see where they were coming from [but], on the other hand, because it was an organisation that had quite a bit to do with mental health I actually thought, I was hoping that they’d actually be a bit more understanding, and it turned out they weren’t.

Eventually, he did resign.

I was actually so angry at them that, after a while, I just ended up resigning, and part of me was quite tempted to take a suit against the organisation because of it, but in the end, I just couldn’t be bothered, I just wanted to move on.

One person said that the need for accommodations wasn’t universally recognised.

Some of the people don't really understand why people have got these accommodations, some people who work in mental health think we are just the same as everyone else, and they are actually quite appalling at offering... reasonable accommodations.

In summary, participants reported a variety of accommodations that they had negotiated with their employers, including flexible hours and sick leave. These accommodations meant that, for some, they were able to continue working. For others, though, they were unable to negotiate the accommodations they needed, and ended up leaving their employment because of this.

Other comments

Several people commented about the *Like Minds, Like Mine* campaign to counter stigma and discrimination associated with mental illness. The remarks supported the focus on mental illness as being something that can affect anyone, including well-known, and well-respected people, and that *"its not something to be fearful of"*.

One person said the campaign highlighted the lack of knowledge and understanding around mental illness, and added:

Show them that people with mental illnesses are still people, and can still work and perform and have relationships and be a member of the community.

Another person said:

I think the Like Minds project has had a real impact, people have commented to me about that when I've told them, so that's really positive, and I think, yeah, there's more to do... And I'd like to be a part of it.

One person suggested that the *Like Minds, Like Mine* campaign could focus on *"places where mental health consumers are actually doing a full-time job, and talk about those"*.

Some commented on the positive aspects of working, with one person saying that gaining full-time employment may need to be a gradual process, but it was worthwhile in the end, and another noted how employment had helped improve her health.

Participants challenged the current attitudes of society and the discrimination that takes place against people with experience of mental illness. One person suggested recovery-focused, anti-discrimination training should be compulsory for people working in mental health services, and used as a way of filtering out those who do not have an understanding of stigma and discrimination in the recruitment process. One person was surprised his security clearance had not picked up his experience of mental illness.

Another person said that they thought mental illness should not be used as an excuse to perform poorly in a job, and people with experience of mental illness should be treated no differently than other employees, while someone else appealed for more understanding and flexibility from employers.

My quest would be that employers just recognise that, hey, I'm not a mass murder or going to do anything crazy or anything like that, and if I'm needing time out I don't need to be questioned about it, but also allowing, having that time available to work reduced hours or at different times, you know, I'm not in that state of mind for long periods of time, like with the [previous employer]; they lost out on a very competent and energetic person on their customer service team because of their lack of understanding knowledge and empathy.

One person hoped things would improve for others in the future.

The reason why I've taken up this interview, I'd just like to say, is because of, it's some understanding [of what] I've gone through because of my most recent job, and I'm hoping that this, this will come to allowing people like me to get work more easily.

Participants made comments about the place of supported employment services for people with experience of mental illness. One person suggested further publicity should be given to the Mainstream programme, and another felt there should be more help available to assist people to stay in employment.

... if there could be some assistance for people that are operating on a fairly high level, some assistance to continue with staying in employment, so rather than letting people fall out of it and crash and burn, yeah, it would be good if there were people, if there was a system that actually assisted you in not letting that happen.

Another person reported feeling grateful that he had not been discriminated against.

I think why I haven't been discriminated, I haven't sort of got the heart. You know my heart is what it is, but no one wants to discriminate me, and... I'm grateful, I haven't been discriminated.

And one person commented on how the role of people with experience of mental illness within the mental health sector had been changing, for the better.

... when I was very unwell I never thought I'd ever get back into this type of work again... I'm really quite amazed in the mental health field, how far we've actually come, 'cause I think 15 years ago this wouldn't be happening, 10 years ago even... Yes, and in the mental health sector, we are really looking at tangata whai ora being part of the services that they're receiving, you know, that the focus is there.

Summary

The findings from this research address the role of work, how a person's ability to work was affected by mental illness, the considerations surrounding a person's disclosure of their experience of mental illness to their employers and colleagues, and, where people experienced discrimination in employment, how this had affected them.

The findings also considered the effects of support in employment, including supported employment programmes, assistance from mental health services, and the help that comes from employers making reasonable accommodations.

The next section of this report discusses these findings in relation to the literature review undertaken alongside the research.

Introduction

For most participants in this study, working was an important aspect of their lives, enabling them to participate in society as full, contributing citizens. This finding is also reflected in the literature review (section 2 of the separate report) which focuses on the benefits of work in improving social inclusion, mental health and recovery

Most people reported that working was a positive experience, with many benefits. These included learning new things, receiving training, monetary benefits, having something to do during the day and making social contacts. Those working in the mental health sector said that they felt like they were making a difference in the lives of people with experience of mental illness.

The negative aspects of work that were experienced were largely the same as those faced by most workers – office politics, not being challenged by the job, balancing work and home commitments. The literature review (section 2) suggests that, in some cases, work may place additional stress on people with experience of mental illness, increasing the likelihood of them becoming unwell. However, there was no indication from the participants that this was so, except maybe in relation to discrimination. People reported that, even when they became unwell, they tried to remain in employment as much as possible. Lennan and Wyllie (2005) report that when an employee becomes unwell, their employer is also likely to want them to stay in employment. These findings indicate that the discouragement of people with experience of mental illness from working is not the best action. Efforts to fight discrimination, and to support people with experience of mental illness and their employers if people become ill while employed, will be more profitable and contribute further to recovery.

According to the literature review (section 4.2), people with experience of mental illness may pursue low-paid jobs because they perceive these as having lower stress levels than other jobs. In this study, this was not the case for many participants who were working in demanding jobs and enjoying them.

How does discrimination manifest itself, and what effect does it have on people's employment?

Many people in this study reported being discriminated against, either when looking for work or while working. Examples of this discrimination included being turned down for jobs because of their experience of mental illness, being teased by employers and colleagues and being treated differently from other employees. These examples confirm the findings of *Respect Costs Nothing* (Peterson, Pere et al, 2004), which indicated that discrimination was a major problem for people with experience of mental illness who were in employment or looking for work.

Being asked questions about their health was also a common occurrence for the participants in this study. What we do not know is whether the questions were asked in a way that was lawful (to determine whether a health problem may affect job performance), or if they were being asked in order to negatively discriminate against people, which was unlawful. Over one-third of the participants reported answering these questions by saying, no, they did not have a health issue. While this might be true if the problem did not impact on their work, even where their health problem could affect their work, the employee might choose to answer in this way if they feared opening themselves up to discrimination.

Given that employers consider themselves to be supportive of employees with experience of mental illness (section 7.0 of the literature review), it may be that many are discriminating against their employees without realising it. They may not be aware that their behaviour is causing problems. If few people with experience of mental illness are willing to lay complaints, the discrimination that many experience may never be drawn to their employer's attention. It may only be when the employee is on the verge of leaving because of this ill-treatment, that the employer becomes aware. Even then, an employer may dismiss the issue as a product of their employee's mental illness, rather than because of discrimination.

There are two avenues for people with experience of mental illness to lay complaints about discrimination. One is using the Human Rights Act 1993, the other is laying a personal grievance under existing employment legislation. This study confirms the findings of *Respect Costs Nothing* (Peterson, Pere et al, 2004) that few people with experience of mental illness lay official complaints about employment discrimination. The reasons that complaints were not laid varied. For some, the situation they found themselves in resolved itself, so they decided not to lay a complaint. For others, although they had the grounds to lodge a complaint, they decided against doing so. The two main reasons given were fear of repercussions, in terms of gaining further employment, and being too affected by mental illness to be able to go through a complaints process.

The fear of repercussions goes to the heart of the complaints process. Participants were concerned they would not be believed, or would be treated as 'crazy', or labelled a trouble-maker and mentally ill. They feared that subsequent employment would be impossible to find. One person described how the process of making a complaint in the organisation she worked for made her reluctant to complain. The literature review (section 4.1) also suggests that people with experience of mental illness meet with discrimination when utilising complaints processes.

The laying of complaints is an important way of reducing discriminatory practice. Not only is the behaviour of the person or organisation challenged, but publicising the complaint and its resolution means that employers can learn from others' mistakes. This may lead to a general change in behaviour. If the complaints process is not working, however, the message that discrimination is unacceptable may be lost. There is a need for further research into why people with experience of mental illness do not lay complaints, despite having just cause to do so, and into making the complaints process safer.



One way to help fight discrimination in the workplace is to provide employers and colleagues with information regarding mental illness and discrimination. One person reported that he was giving information to others in the workplace about mental illness because people knew he had experience with using mental health services.

Some of the participants in this study had been discriminated against on the basis of gender, ethnicity or sexual orientation, as well as their experience of mental illness. It seemed that the pressing issue for most people was discrimination because of their experience of mental illness, although that impression may be because people were responding to the topic of this research.

Do people stay in jobs where they are being discriminated against? It appears not. Most of the discriminatory practices reported by the participants occurred in previous employment, and were cited as a reason for leaving these jobs. It seems that, rather than trying to deal with the discrimination, people are likely to seek employment in a more supportive environment. Previous experiences of discrimination left people feeling wary of being discriminated against again. This can lead to two reactions – refusing to disclose their experience of mental illness until they have to, to reduce the chances of discrimination happening – or being upfront and open about their experiences, and choosing not to work for an organisation that may discriminate against them.

What effect does mental illness have on employment?

The greatest effect that mental illness had on people's ability to look for work was interference with their confidence and motivation to apply for jobs. Fear of becoming unwell, symptoms of their illness and side-effects of medication were also mentioned as barriers to employment. These factors were also reflected in the literature, but the main barrier to finding work mentioned in the literature review (section 4.3) was the fear of losing welfare benefits. Fear of loss of social security benefits was not a factor reported in this study, however, which may be because the sample group consisted of people who were working, as opposed to people who were on benefits.

The outcomes of these barriers were varied. Some people applied for jobs that were less demanding, some were wary of disclosing their experience of mental illness, and others applied for jobs that were deemed to be more supportive towards people with experience of mental illness. Organisations that were perceived to be supportive by the participants included those in the mental health sector, and certain non-governmental organisations with a community focus. The reason that organisations were perceived as supportive was not stated explicitly, but the implication was that organisations that understand mental illness would be more supportive of employees with experience of mental illness (see section 2.0 of the literature review). Six participants had worked in the mental health sector, and opinions were equally divided between those who felt the organisation they worked for was supportive and those who felt the organisation was not.

Research participants responded to the barriers in different ways. Several people received support from others as a way of overcoming the difficulties associated with applying for jobs. People struggle not only with their mental illness, but also with the treatments for it. One person chose to stop taking a medication because its side-effects interfered with his ability to work. When prescribing treatment, mental health professionals may need to consider how to help people balance medication and work.

Participants identified that, even when they were not feeling particularly unwell, concentration was a problem that sometimes made work a struggle. This was so bad that some people gave up their jobs. For those for whom this is an issue, reasonable accommodations may need to be negotiated that target concentration difficulties, in order for people to be successful in employment.

Most people in this research reported becoming unwell at some stage in their working lives. One response to this included leaving the job when symptoms, or the side-effects of medication, meant they could no longer perform at their best. Other people took time off work, and some received a negative reaction from their colleagues or employers when they returned.

Research with employers (see section 7.0 of the literature review) found that those interviewed reported being supportive of their employees' periods of unwellness. Lennan and Wyllie (2005) noted that employers sometimes attributed negative outcomes to lack of support from caregivers or mental health services. None of the employees in this study, however, cited lack of support from caregivers or mental health services, and some reported that employers did not provide the reasonable accommodations they needed to be able to stay working.

Some people found that on returning to work, their working environment had become quite hostile. There may be a need for some type of support that employers and employees can access if mental illness starts to interfere with employment, which provides both advocacy and information. Occasionally people become unwell to the point where they can no longer continue working for a period of time. Others may be able to continue working, with a bit of assistance.

According to the literature review, flexible working arrangements appear to be useful in helping people to remain or return to work (section 7.2). One person in this study noted that the flexible arrangements available to him were provided for all staff in the organisation he worked for, which meant he did not feel singled out.

People reported trying to hide the effect that mental illness was having on their work. The main reason for this was fear of discrimination – they did not want to be treated differently by their colleagues or employer because of their experience of mental illness. Another reason was fear of failure – they did not want their employer or colleagues to think they could not perform their job successfully. For some people, trying to hide their mental illness required a lot of effort, and was



not always successful. Some were so concerned about others finding out about their illness that they left their jobs rather than disclose. The support received by another person, when her colleagues found out, was excellent, however, and this finding was mirrored by other participants.

Because of the effects that mental illness has on employment, specific help is sometimes available to people with experience of mental illness by way of support to find, or continue in, employment (for example supported employment agencies). Several participants in this study had taken advantage of such assistance. Many received help from a variety of sources when applying for jobs. The most commonly mentioned source of help was from supported employment agencies. These agencies gave people access to subsidised employment schemes such as Mainstream, which is run by the State Services Commission.

Most of the people who had received assistance said that it was useful – helping them to access work and increase their confidence. Others, though, reported difficulties with supported employment services. Sometimes their supported employment worker did not know enough about the type of job the participant was seeking, so their help was limited. Participants who had used supported employment agencies that did not specifically target people with experience of mental illness found these agencies reluctant to help and not sufficiently knowledgeable about issues for people with experience of mental illness.

The literature review describes several traditional models of support in employment (section 8.1). Most of the people in this study, who had accessed supported employment services, used the ‘individual placement and support’ model, receiving ongoing assistance from their employment service. Supported employment services gave people an advocate who was available to help them if difficulties arose at work. This was particularly useful for those trying to access reasonable accommodations.

The literature review (section 4.3) indicates that fear of losing social security benefits is a barrier to employment, however, the people interviewed found the financial support available from Work and Income was valuable in enabling them to return to work. One person mentioned that access to a sickness benefit gave her a feeling of independence and self-reliance, allowing her the flexibility of working when she was able. Flexibility to move on and off social security benefits would assist people who periodically became unwell.

Section 8.6 of the literature review suggests it is preferable for employment services and mental health services to be integrated. While many participants found mental health services to be supportive, most said that these services had played a limited role in finding, or maintaining, their employment, except for providing medical certificates when people became unwell. Some said the support they received from mental health services changed over time, depending on the participant’s mental health.

The literature review (section 8.6) also suggests that many mental health staff are unaware of the value of employment, and do not support paid work for their clients. In this study, however, while some doctors were concerned about the stress people were under from studying or working, their attitudes changed when the participants proved they were capable of working or undertaking their courses.

Because health, and not employment, is the focus of mental health services, close liaison is needed between mental health services and those agencies that are expert in finding and supporting people in employment.

Do people with experience of mental illness disclose their experiences to employers, and what effect does this have on their employment?

Many people said that their employers knew about their experience of mental illness. The main reasons they knew were: the participant had disclosed the information when they had applied for the job, there was a requirement for the position to have experience of mental illness, there were health questions on the application form, or the participant had been employed through a supported employment service. Others said their employer did not know, and they had no intention of telling them. Some were not sure whether their employer knew or not.

Fewer people said that their colleagues knew about their experience of mental illness. Many preferred not to disclose this information, either because they felt their colleagues had no right to know, or because of a fear of discrimination and becoming the subject of office gossip. It seems that, when it came to colleagues, people wanted to have control over who they told, a point raised in the literature review (section 6.5). People using supported employment schemes, however, lacked this control, and one person noted feeling uncomfortable about telling more of her colleagues about her experience of mental illness.

Most of the participants had, at some stage, felt pressure to disclose their experience of mental illness to either employers or colleagues. People talked about what could be described as an ethical pressure to disclose (also a finding in section 6.2 of the literature review). They felt an obligation to tell others, especially if they needed time off. This need to explain absences to others is present in most workplaces, since nearly everyone has to take time off for things like dentist appointments, but a person with experience of mental illness may feel the pressure intensely because the consequences of explaining are greater. They may become subject to discrimination if they tell the truth.

The pressure to disclose may also be a response to internalised stigma. There was a sense from some of the participants that they believed that people with experience of mental illness are poor workers and their employer is doing them a favour by employing them. Given these beliefs, they felt a need to disclose their experiences in order to be fair to their employer.



People may have felt pressure to disclose, but this does not mean they actually did so. All but one person said they had felt some pressure, but few chose to disclose, or only told their employer, not their colleagues.

Some people thought that disclosure was morally the right thing to do. One person advised people with experience of mental illness to think very hard before disclosing, because once a disclosure was made it could not be taken back. The main reason given for not disclosing was fear of discrimination. Legally, there is an obligation to disclose only if a person poses a risk to themselves or others in the workplace, or if they are unable to perform the job, even with reasonable accommodations (section 7.1 of the literature review). As one person put it, if their work was okay, it was not necessary to tell. Many said that disclosure depended on the work – some jobs were seen to be more supportive than others, and advice was given to check out the organisation's reputation first before disclosing. Others thought that it would be safe to disclose if the organisation was in the mental health sector, but the experiences of some suggested that this might not always be the case.

Disclosure is usually necessary if reasonable accommodations are required, or if the person is using supported employment services (see section 6.2 of the literature review). Participants noted that if a person disclosed to a potential employer and then experienced discrimination that organisation was not one they would want to work for. The Like Minds Employment Agency Project (LEAP) booklet (2005) also notes that if a person discloses and then gains the job they are after, this can be especially empowering. This was the case for at least some of the participants who had disclosed in the job application process.

From an individual perspective, disclosure can place people with experience of mental illness in situations where they may be discriminated against, which can have negative consequences. In looking at the bigger picture, however, it is only through disclosure that discrimination may be challenged, and people's attitudes and behaviour changed. Therefore, people with experience of mental illness should be encouraged to disclose, and to complain if they are discriminated against.

There was no real sense from the participants about the best time to disclose experience of mental illness during the employment process. As stated earlier, some had no choice but to disclose at the beginning because they were part of a supported employment programme, others were upfront from the start, some only told once they became unwell. It appears from the experiences of these latter people, that this may not be the best approach. Two people were asked to leave their jobs when they became unwell while working and then told their employers.

A person may choose not to disclose because their experience of mental illness was some time in the past and was not a current issue. How should an employee handle the situation if they then become unwell? As mentioned below, in the reasonable accommodations section, if this situation arises, the person with experience of mental illness should consider using the services of an advocate.

The literature review (section 6.3) found that employers want to know as early on in the process as possible about their employee's experience of mental illness, though admit that this may expose people to discrimination. An employee who disclosed immediately after accepting a job offer would be perceived as dishonest (Lennan and Wyllie, 2005). One participant said that, from their experience, disclosure immediately after accepting a job was not a good idea.

There was also no real consensus from the participants on how to disclose. One person suggested being upfront from the beginning by putting their experience of mental illness in their application letter or curriculum vitae. Another suggested producing a letter from their psychiatrist stating they could work. The LEAP booklet (2005) recommends people should be honest, positive and specific. The experiences of the participants also suggest that it is best to plan disclosure carefully, rather than succumbing on the spot to pressure, or having others disclose unexpectedly for them.

There was no sense from the participants in this study as to whether disclosing their experiences of mental illness had any effect on their future career options. One person did mention that working in her particular role for a mental health organisation meant people may realise she had experience of mental illness. There was a sense from participants that making formal complaints about discrimination would have an effect on the ability to find further employment.

What (if any) reasonable accommodations are made in the workplace, and do these help people with experience of mental illness?

This research demonstrates the benefits of reasonable accommodations in employment for people with experience of mental illness. These allow people to work, and remain in work, despite having experience of mental illness. When this flexibility in employment does not occur, people find it harder to stay working.

The most common accommodation made by employers for the people in this study was flexibility in working hours. Being able to start later, or work part-time, helped many of the participants to remain in employment. This flexibility may be regarded as good employment practice and beneficial to all employees, not just people with experience of mental illness. Often, the requirement for accommodations wasn't immediate, with some people not needing them when first employed, but doing so later on, after becoming unwell.

Many people found it difficult to negotiate accommodations. Some successfully used a supported employment agency for this task, either as part of the process of starting work or later, when they realised that they needed changes to their employment conditions to remain working.



The literature review (section 7.5) reports that people often do not ask for reasonable accommodations because they do not wish to disclose their experience of mental illness. This was the case for some of the participants in this study, who requested accommodations only when they had to, after becoming unwell.

Unfortunately, for some, trying to negotiate accommodations after they became unwell was not successful. In three instances where this happened, the participants tried to negotiate without the use of an advocate. They were denied the accommodations by employers, who indicated that they did not believe the requested accommodations were reasonable, and so these participants left their jobs. This contrasted with the employers in Lennan and Wyllie's (2005) research, who said they had gone out of their way to provide accommodations to their employees so that they could keep working.

The Human Rights Act 1993 says that accommodations have to be provided unless it is "not reasonable" to do so. A question for employers is how to decide whether an accommodation is reasonable or not. It may be that, what is reasonable for a large employer is not so for a smaller one. In one of the cases where accommodations were denied, the employer was a large one, so some flexibility could have been expected. Where accommodations were refused, the participant may have had a case for laying a complaint under the Human Rights Act, yet none of them did, and in each instance was forced to leave their job.

Given the experiences of the participants of this study, the best approach for people with experience of mental illness, who need to negotiate accommodations, may be to enlist the help of an advocate who is familiar with the Human Rights Act and employment legislation. It certainly seems that those who had an advocate fared better than those who did not.

One of the issues raised from this study is the level of discretion that individual managers have about whether to grant accommodations. For one person, a previous manager had agreed to a later starting time, but when that manager changed the accommodation was withdrawn, and the person felt unable to renegotiate it. Where there are existing equal employment opportunities policies, it may be easier to negotiate accommodations, because policies such as flexibility in hours are already in place and managers do not have to use much discretion.

Reasonable accommodations need to be tailored to the requirements of the individual. In this research, some people needed to start later, others to work part-time, others to have fixed hours, some needed extra supervision, and for some accommodations were not necessary at all. None of the solutions mentioned by participants appeared to be very costly or difficult to implement.



Conclusion

In any 12 month period, it is expected that over 20 percent of people in New Zealand will have experienced some form of mental illness (Wells, Oakley Brown et al. 2006). The implications for their employment are great. People with experience of mental illness are over-represented in social security statistics – they make up 35 percent of those on the Sickness Benefit, and 27 percent of those on the Invalids Benefit (Beynon and Tucker 2006) – and only 44 percent of people with a psychiatric disability are in employment compared to 74 percent of the total working age population (Jensen, Sathiyandra et al. 2005). This is a substantial cost to the economy.

This study confirmed that people with experience of mental illness are capable of working. While some participants were employed in less demanding jobs, many were working in highly skilled, demanding occupations. It can be argued that, just like the rest of society, people with experience of mental illness should be encouraged to work. Employment is such a fundamental part of our well-being that every effort is needed to enable anyone who can, to find, and remain in, work. Employment gives people a focus in their lives, enables independence, fills in time, and helps them integrate into, and feel included in, the community.

Lack of confidence, lack of concentration and living in supported accommodation were three of the barriers to employment that people in the study identified. The greatest barrier, however, was discrimination. Discrimination came from potential employers, current employers and colleagues. It included being turned down for work, teasing and abuse, and being treated differently from others. It affected people's confidence, motivation and enjoyment of the work that they did.

Despite the prevalence of discrimination, however, few people complained. None of the participants in this research had made a formal complaint using human rights or employment legislation. The people interviewed, who had grounds to complain, either did not have the energy to do so because they were unwell at the time, or decided not to because of the fear of repercussions.

If formal complaints are not made, those responsible for discrimination are not challenged. They may not even be aware that their behaviour is unacceptable. Employers may feel that they are being supportive of employees with experience of mental illness, when the way they provide that support may be, or may appear to be, discriminatory. If people with experience of mental illness do not complain, the employer may never know.

One of the major findings from this research is that none of the participants put up with discrimination. In addition to the adverse effect on their motivation as an employee, they usually left their jobs and went on to other employment, often without giving employers the real reason they were choosing to leave. An employer who does not provide a safe environment will lose the contribution of affected employees.

Making formal complaints is one way of fighting discrimination in the workplace. Another is when people with experience of mental illness, who are open about their experiences, are present in the workplace. These ambassadors are able to provide living proof that people with experience of mental illness are just as able to contribute as everyone else in society. Once their experiences are known, as illustrated in this research, they can become sources of information for others wanting to know more about mental illness.

Experience of discrimination did have an effect on people's subsequent employment choices. People either made a conscious decision to hide their experience of mental illness, so they would not be discriminated against again, or chose to be upfront about it, so they would have more of an idea about how discriminatory a place of work was, right from the start, and could then choose whether or not to work there. Being discriminated against does not necessarily leave people feeling bad about themselves. It can, in fact, make people stronger and more determined to fight discrimination.

Not everyone in this study experienced discrimination, however. Some people said that their employer and colleagues had been very supportive of them.

There are arguments for and against disclosure of experience of mental illness. Disclosure may expose people to discrimination, but it also enables them to claim reasonable accommodations and means they do not need to lie in order to gain time off for mental health appointments, or if they become unwell. From the experiences of the people in this study, disclosure may be a better option than not disclosing. However, choosing the right time to disclose, who to disclose to, and maintaining control over who is told, is important. Better outcomes were achieved when the person disclosed to their employer before becoming unwell, though the literature (and the experience of one participant) suggests that employers may become angry if an employee discloses immediately after being offered a job.

Having someone to advocate on their behalf was also particularly effective for people with experience of mental illness, especially in negotiating reasonable accommodations. Those who had experienced difficulties at work and had used an advocate (usually from a supported employment agency) fared better than those who did not. An advocate can remind employers that they have obligations under the Human Rights Act and employment legislation. Such advice from an employee may appear to be too confrontational. An employer may also be reluctant to discriminate against a person with experience of mental illness if a third person is present.

Not disclosing their experience of mental illness was an option chosen by some participants in this study. This was either because their experience of mental illness did not impact on their work at all, or they were afraid of discrimination or other repercussions. Not disclosing for fear of discrimination meant that people were wary of others finding out. They reported this as adding to the stress that they were under at work.



One of the key findings from this study is that reasonable accommodations do work. They enable people to gain, and stay longer in, employment, often only requiring some flexibility from the employer. To gain reasonable accommodations from an employer usually requires disclosure. The person disclosing needs to weigh up the usefulness of the accommodations versus the risk of discrimination.

Where accommodations were requested, but not granted, participants in this research felt they could no longer work for the organisation concerned, because they were having too many difficulties related to their mental illness to cope with working full-time. This lack of flexibility from their employers was interpreted by the participants to be discrimination. It also meant that the employer lost the investment they had made in hiring and training the employee.

Employment in the mental health sector is common for people with experience of mental illness, and mental health services are often perceived as being more supportive than other organisations. The findings from this research suggest, however, that there are mental health organisations that are not free from discrimination. For some of the participants employed in this sector, their place of employment felt decidedly unsafe.

To answer the research question, this study and the literature review findings, against which the results were compared, clearly indicate that mental illness does have an effect on employment. Perception and discrimination are the key issues. The effect of the mental illness can be reflected in a person's lack of confidence when applying for jobs, might be seen in concentration difficulties when a person is working, or as giving someone valuable life experience, which they can use to do their job more effectively.

This research indicates that, where employers do not discriminate, are well-informed, and make adequate accommodations, the effect of mental illness on a person's employment can be minimal.

A counter question, and one that is just as important, is what effect does employment have on mental illness? This research indicates that the well-being and productivity of people with experience of mental illness is enhanced by employment, with the potential to have happier, more fulfilled people, and, maybe, less cost in the use of mental health services.

Recommendations

Many important issues have been identified by this study of employment experiences of people with experience of mental illness, particularly in the area of making it possible for people to contribute fully, without discrimination. Examination of the findings suggests that there are actions that can be taken to reduce discrimination. While these actions are listed below by the main people or organisations that can make that difference, we believe that it is everyone's responsibility to improve the situation for people with experience of mental illness.

Government Agencies (Ministry of Health, Mental Health Commission, Department of Labour, Human Rights Commission, Ministry of Social Development, etc)

- 1.** Promote good practice in employment and mental health services in relation to assisting people with experience of mental illness to enter, and stay, in employment.
- 2.** Promote the development of services that can provide advice to employers and employees if a person's experience of mental illness starts to interfere with their employment
- 3.** Encourage cooperation between agencies that work with people with experience of mental illness to support and facilitate the retention of people with experience of mental illness in the workplace.
- 4.** Promote awareness about the rights to protection against discrimination in the workplace amongst employers and employees.
- 5.** Undertake research into why so few complaints about employment discrimination are lodged under the Human Rights Act 1993 by people with experience of mental illness.
- 6.** Educate employers about their responsibilities under the Human Rights Act 1993, especially in the provision of reasonable accommodations, as well as the benefits of providing these accommodations.
- 7.** Promote the use of support people or advocates for people with experience of mental illness when negotiating reasonable accommodations with employers.
- 8.** Develop further programmes to target employers' attitudes and preconceptions about employing people with experience of mental illness. This may be through existing programmes (such as *Like Minds, Like Mine*, or the Mental Health Foundation's Working Well programme) or other initiatives that target employer or industry groups.
- 9.** Encourage government agencies to implement Objective 4 of the New Zealand Disability Strategy.

Non-government organisations (e.g. Like Minds Providers)

- 10.** Encourage the Human Rights Commission to undertake research into why so few complaints about employment discrimination are lodged under the Human Rights Act 1993 by people with experience of mental illness.
- 11.** Promote the development of a specific resource for people with experience of mental illness that provides advice on employment issues, including issues of disclosure.

Employer and employee organisations (e.g. Trade Unions)

- 12.** Challenge employers' attitudes and preconceptions about employing people with experience of mental illness.
- 13.** Promote practical steps that employers can take to combat discrimination in the workplace, such as:
 - providing information which raises awareness of the experience of mental illness in the workplace
 - promoting equal employment opportunities (EEO) policies that enable flexible working practices
 - training managers and supervisors to help them work with employees with experience of mental illness, improve workplace awareness, and develop good working environments
 - introducing or building upon existing anti-discrimination workplace resources and programmes
 - providing reasonable accommodations for their employees.

Everyone

- 14.** Encourage people with experience of mental illness to enter and stay in employment.
- 15.** Encourage people in the workplace to safely disclose their experiences of mental illness, and to complain if they are discriminated against.
- 16.** Undertake to not discriminate against people with experience of mental illness.

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Questions for the Like Minds/Mental Health Foundation Employment Research

- **Were you working before you were diagnosed with a mental illness?**
- **Have you worked since? Approximately how many jobs have you had since?** (*including full-time, part-time, seasonal, voluntary work*)
- **What has been the most recent job you have had?** (*including type of job, type and size of organisation*) How long did/have you had that job for? How many hours a week did/do you work?
- **Do you enjoy your work – positives and negatives?**

These next questions are about looking for work:

- **Have you ever been discriminated against or treated unfairly when looking for a job because of your experience of mental illness?** Please describe.
- **Due to other factors?** (*gender, ethnicity, being a parent etc*) Please describe.
- **Have you ever been specifically asked if you have mental health problems, or health problems in general, when applying for jobs?**
- **Has your experience of mental illness affected you when applying for jobs?** (*for example, fear of discrimination, difficulty being motivated, fear of not succeeding, side-effects of medication*) How did you overcome this?
- **Have you ever had any help with applying for jobs?** (*for example, supported employment, training, benefits from Work and Income*) How did you find out about this help? Was it useful? If it was, can you explain how it was useful? If it wasn't, can you explain why it wasn't useful?

These next questions are about your current employment, or your most recent job:

- **Are your employers aware about your experience of mental illness?**
- **Why/why not? What has that been like for you? If they know, how and when did they find out?** (*Did you tell them or did someone else?*) What was their reaction? Did they treat you differently after they found out? If so, please explain.
- **Have any special arrangements been made?** (*for example, flexible hours, time off for appointments, increased sick leave*) If yes, were these helpful/unhelpful? Why/why not? Have you given your employer any information or resources? What sort? Did they want more information?

- **Are your workmates aware of your experience of mental illness?** Why/why not? What has that been like for you? If they know, how and when did they find out? What was their reaction? Did they treat you differently after they found out? Have you given your workmates any information or resources? What sort? Did they want more information?
- **If you haven't told people at work about your experience of mental illness, how does that feel?** Has there been any pressure to tell them? Where has that pressure come from?
- **What advice would you give to others with experience of mental illness as to whether to tell your employer or other people in the workplace?**
- **Have you been discriminated against or treated unfairly in your job because of your experience of mental illness? Please describe. Have you been treated unfairly because of other factors?** (*gender, ethnicity etc*)
- **Have you ever had any other difficulties in your job related to your experience of mental illness?** (*for example, difficulty performing the job, difficulty concentrating, being easily distracted, lack of motivation, taking time off sick or for appointments, side-effects of medication*)
- **Have you ever become unwell while working?**
If **yes**:
 - How did the people around you react? Did you need to take time off? Did you return to work?
 - If you returned to work, what made you decide to do so? (*for example, right time, employer insisted, run out of sick leave*) How were you treated by your employer and colleagues? Were any special arrangements put in place? (*for example, flexible hours, time off for appointments*) If yes, were these helpful/ unhelpful? Why/why not?
 - Did your employer ask to talk to the health professionals helping you with your experience of mental illness? If yes, did this happen, and how was that for you?
- **Have mental health services played any role in your employment?** (*for example, talking to employers, supplying sick notes*) How was that for you? Were they supportive of you looking for work/being in a job?
- **Have you ever made a complaint about discrimination in looking for a job or being in a job due to your experience of mental illness?** (*for example, Human Rights Commission, personal grievance, Employment Relations Service*)

These next questions are about you:

- **What age group you belong to?** (under 25, 25–39, 40–59, 60+)
- **What ethnic group do you identify with?**
- **Do you have any other comments regarding your experience of mental illness and your employment situation?**

Information sheet on purpose of research

The Employment Experiences of People with Experience of Mental Illness

The Mental Health Foundation of New Zealand, as part of the Like Minds, Like Mine Project to Counter Stigma and Discrimination Associated with Mental Illness, is undertaking research in the Wellington region looking at employment issues for people with experience of mental illness. The research team consists of three interviewers, and Debbie Peterson, Catherine Williams and Marika Park from the Mental Health Foundation.

The aim of this research is to identify specific issues that affect people with experience of mental illness in employment. The focus will be on discrimination, disclosure of mental illness to employers and colleagues, and any special arrangements that have been put in place in the workplace, due to an employee's experience of mental illness. We are interested in both positive and negative experiences.

Who can participate?

Any person with experience of mental illness living in the Wellington region is welcome to take part in this research. We particularly want to talk to you if you are in employment, have recently been in employment, or are looking for employment. The employment experience may be full-time, part-time, self-employment, casual or contracting.

What does participation involve?

For this research, you will be asked to take part in a face-to-face interview that will ask you about your employment experiences. It is expected that the interview will last for approximately 60–90 minutes, and can take place at a mutually agreed time and location. If you would like to, you are welcome to bring a support person to the interview. The interviews will be recorded if you agree, and notes may also be taken. The interview will then be transcribed. The research team will be the only people with access to the recording and the transcript. No material that could personally identify you will be used in any reports on this study.

As recognition of the time involved in this study, you will receive a Warehouse gift voucher, and a summary of the research results will be available if you would like us to send it to you. A full report on the study is expected to be released at the end of the research by the Like Minds project, and this will also be made available if you wish.

Participation in this research is voluntary, and you may withdraw from the research at any stage without having to give a reason, including after you have completed the interview.

You will be asked to sign a consent form saying that you have read this information and have had an opportunity to ask any questions about the research. If you do have any questions feel free to ask your interviewer, or contact:

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*[please note Catherine is no longer
with the Mental Health Foundation]*



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