

Fighting Shadows

Self-stigma and Mental Illness
Whawhai Atū te Whakamā Hihira



2008

Written for the Mental Health Foundation of New Zealand
by **Debbie Peterson, Alex Barnes, and Chloë Duncan**

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Mental Health Foundation of New Zealand

PO Box 10051, Dominion Road, Auckland 1446
81 New North Road, Eden Terrace, Auckland
Phone 09 300 7010 Fax 09 300 7020
www.mentalhealth.org.nz

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He Mihi

E ngā mana, e ngā reo, e ngā kārangaranga maha, tēnā koutou, tēnā koutou, tēnā rā tatou katoa.

Ko tēnei te taonga i whakatau atu i mua kia koutou i runga te kaupapa o ngā ‘Tangata Whakamā’. He ripoata ki te whakawhiti ngā kōrero pakiwaitara, he mauui hinengaro i roto ngā whatumanawa o te tangata.

Nō reira, whakapānuitia tēnei ripoata, ka ora tonu to mohiotanga mō tēnei kaupapa.

Tēnā koutou katoa.

Rawiri Wharemate

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Preface

The Board and staff of the Mental Health Foundation are proud to be part of a programme that challenges discrimination and promotes social justice. The Like Minds, Like Mine programme has achieved measurable attitude change in the New Zealand population and international recognition for its intentions and achievements.

There has been a research component since the early days of Like Minds and the first research report *Respect Costs Nothing* (2003) helped set the national agenda for all of us.

The research into employment experiences of service users, *I Haven't Told Them, They Haven't Asked* (2007) with its associated literature review, added depth and further defined those aspects needing change and action.

This research report into internalised stigma moves into further uncharted waters and is all the more significant because of that. The people who took part in the project, including the researchers, focus group participants, facilitators and advisory group are congratulated for the energy and determination they have applied to this work. Their efforts have produced not only a clear picture based on real lives but a model that can be used to explain cause and effect and plan actions that can make a difference.

Gratitude is due especially to those who have shared their personal stories, but they have a right to expect more – namely that the knowledge and understanding developed will be used in practical ways to reduce and eventually eliminate stigma and discrimination in all their manifestations.

Judi Clements

Chief Executive
Mental Health Foundation of New Zealand

Foreword

To my knowledge this report is an international first. The exploration of self-stigma presented through this publication provides a raft of new insights into this complex subject area. These insights are presented through a model and imagery that we can all easily relate to and work with. I am particularly looking forward to setting up some circuit breakers!

Being both a person who has discriminated against people with experience of mental illness and a person who has been discriminated against as a result of having a mental illness seems crazy. Yet, from reading this document, I now know that having both of these experiences is not at all unusual.

As someone who works on the Like Minds, Like Mine programme to counter the stigma and discrimination associated with mental illness, I am really excited by this piece of work. It provides us with comprehensive information and guidance that we can use to develop specific initiatives for addressing self-stigma in our own communities.

For some time we have been aware that stigma (including self-stigma) and discrimination are the biggest barriers to recovery. However, this publication goes further by confirming the significant role that recovery-oriented services can play in combating self-stigma.

Research of this nature is successful only when people give generously of their time and energy and share their experiences. I think that as Like Minds, Like Mine providers, we can best show our appreciation for the contributions that have been made to this work by putting the same effort into applying the findings of the research. By doing this I believe we will continue the high standard of the work and, ultimately, effect positive change for people with experience of mental illness.

Let's get to it!

Sarah Gordon

Managing Director
Case Consulting Ltd

Introduction

Purpose of this research

The purpose of the research that forms the basis of this report is to:

- explore the issue of self-stigma (often called internalised stigma) from the perspective of people with experience of mental illness
- investigate the causes and effects of self-stigma
- discuss means of combating self-stigma amongst people with experience of mental illness.

As a public health-funded piece of research for the Like Minds, Like Mine programme¹ to counter stigma and discrimination associated with mental illness, this work directly contributes to approach six² of the programme's national plan for 2007–2013 (Ministry of Health 2007). The findings of this work will help national and regional Like Minds, Like Mine providers to address self-stigma through resource development, education, and training initiatives.

New model of self-stigma and discrimination

Self-stigma is an issue that most people with experience of mental illness would recognise, seeing it either in themselves or in other people. It is generally believed that self-stigma arises from internalising the negative messages and behaviour that people with experience of mental illness receive from others. In other words, the concept of self-stigma seems fundamentally and inextricably linked to the concept of discrimination. This research looks specifically at this issue and explores whether this is the case. In doing this, we have developed a new model of stigma and discrimination directly from the findings of the research. This new model illustrates not only how discrimination and self-stigma are linked, but also how to combat self-stigma.

New Zealand and overseas research is limited

There has been little discussion in New Zealand about the concept of self-stigma and how it relates to mental illness, and little international research has been undertaken. This study is unique in that it purposefully asks people with experience of mental illness about their experiences of self-stigma and their suggestions for managing and combating it.

In undertaking this research, we realised that self-stigma associated with mental illness was a concept that had seldom been written about in non-European cultures. We wondered whether the experience of self-stigma differed, or even existed, in non-European cultures compared with European cultures. To find out more about this we decided to ensure that a range of people with experience of mental illness were represented in our research. This meant working with people with experience of mental illness from throughout New Zealand and from a variety of cultural backgrounds. It should be noted however that while we included a range of people the results cannot be generalised to whole population groups.

Other experiences of self-stigma

We recognise that other groups in society experience self-stigma related to causes other than the experience mental illness. For example, internalised racism is a type of self-stigma, and self-stigma can be associated with being positive for Human Immunodeficiency Virus (HIV) or having Acquired Immunodeficiency Syndrome (AIDS).

Some of the people in this study have experienced self-stigma from having experience of mental illness and from other causes. For them, the stigma of experiencing mental illness cannot be considered in isolation.

¹ For more information on the Like Minds, Like Mine programme to counter stigma and discrimination associated with mental illness see: www.likeminds.org.nz

² Approach six in the Like Minds, Like Mine National Plan 2007–2013 states the programme must “develop approaches to address the internalisation of stigma and discrimination associated with mental illness” (p. 15).



Recommendations

The development of a new model of stigma and discrimination offers important actions we can all take to combat self-stigma. We believe the actions identified in our eight recommendations that came out of this model can disrupt the cycle of stigma and discrimination at both personal and societal levels. The recommendations are:

- recognise the contribution of mental illness and foster leadership of people with experience of mental illness
- celebrate and accept difference
- affirm human rights
- encourage disclosure
- encourage recovery-oriented practices
- encourage empowerment
- support peer support services
- challenge attitudes and behaviour.

Content of this report

This report is divided into six chapters.

- Chapter 1 summarises the literature review the Mental Health Foundation undertook to discover how other researchers have defined self-stigma and what knowledge exists about this concept.
- Chapter 2 describes the methods used for the research – literature review and focus groups.
- Chapter 3 presents the findings of the research by addressing the questions asked of the focus groups. The facilitators of the focus groups wrote the end of this section, which illustrates the differences and similarities between the groups.
- Chapter 4 places the findings and literature review in context and presents a new model of stigma and discrimination.
- Chapter 5 presents the conclusions of the research.
- Chapter 6 proposes eight general recommendations on how to challenge self-stigma.

The report concludes with an appendix that contains the contents of the general focus group information pack, and a list of references.

Summary of literature Review



Introduction

Most research into stigma and mental illness examines stigmatising attitudes towards people with experience of mental illness, rather than what people with experience of mental illness think and feel about experiencing stigma (Wahl 1999; Schulze and Angermeyer 2003; Dinos et al 2004; Bagley and King 2005). This approach appears to be typical of research into stigma in various areas – stigma is usually investigated by focusing on the stigmatising majority groups, rather than on the stigmatised minority groups (Oyserman and Swim 2001). Consequently, little research has been conducted into self-stigma amongst people with experience of mental illness (Yen et al 2005). The majority of research that does investigate self-stigma amongst people with experience of mental illness takes the form of first-person accounts of experiencing stigma (Wahl 1999; Schulze and Angermeyer 2003).

Link and Phelan (2001) suggest that this failure to investigate the experience of stigma amongst people with experience of mental illness, and the consequent failure to investigate self-stigma, is because most researchers have not experienced mental illness, so do not pay adequate attention to the experiences of people with mental illness. It has been demonstrated that the meanings and weight given to different kinds of discrimination differ between people with experience of mental illness, their friends and family, and mental health professionals (Schulze and Angermeyer 2003). Accordingly, in order to gain an understanding of self-stigma amongst people with experience of mental illness, a direct study of the issue needed to be undertaken.



Definitions of stigma and self-stigma

Most definitions of stigma used in the literature are developed from Goffman's 1963 book *Stigma: Notes on the management of spoiled identity* (Wahl 1999; Dovidio et al 2001; Smith 2002; Caltraux 2003; Schulze and Angermeyer 2003; Bromley and Cunningham 2004; Dinos et al 2004; Stuart 2005). Other researchers have developed multi-component definitions of stigma, usually involving elements of labelling, stereotyping, social isolation, prejudice, and discrimination (Haghighat 2001; Link and Phelan 2001; Watson and Corrigan 2001; Corrigan and Rusch 2002; Corrigan and Watson 2002; Schumacher et al 2003; Corrigan 2004; White 2004; Angermeyer and Matschinger 2005; Corrigan and Kleinlein 2005).

One main definition developed by Link and Phelan (2001) is ultimately derived from Goffman's (1963) definition. It was developed in response to the argument that the use of the term 'stigma' results in blame devolving on the victims of stigma, and the term 'discrimination' should be used in preference to the term 'stigma' (Link et al 2004). The definition states that stigma exists where five conditions coincide. These conditions are:

- people identifying human differences and labelling them
- the linking, in dominant cultural beliefs, of labels with negative stereotypes
- the placing of labelled people in categories that isolate them from, and set them in opposition to, the majority
- the experiencing by labelled people of unfair status loss and discriminatory behaviour
- that labelling is contingent on the power differentials existing in society (Link and Phelan 2001).

A competing multi-component definition of stigma has been developed by Corrigan and colleagues (Watson and Corrigan 2001; Corrigan and Rusch 2002; Corrigan and Watson 2002; Schumacher et al 2003; Corrigan 2004; White 2004; Corrigan and Kleinlein 2005). In this definition, stigma is conceptualised as a construct comprising three "component social cognitive structures" (Corrigan and Rusch 2002, p 317): stereotypes, or negative beliefs held by most members of a social group about a minority group; prejudice, or agreement with such stereotypes,

usually incorporating a negative emotional reaction to the stereotype; and discrimination, or behaviour motivated by that prejudice.

Distinction between stigma and discrimination

In New Zealand we tend to use the term 'discrimination' instead of the term 'stigma'. Goffman's (1963) definition of 'stigma' did not include the idea of discrimination. Sayce (1998) has argued that Goffman's definition of stigma, and definitions derived from it, focus attention on the people who suffer in the course of stigmatisation, rather than on the stigmatisers. The term 'stigma', by focusing on a mark, attribute, or characteristic of the stigmatised can be stigmatising in itself (Sayce 1998; Maio 2004). Accordingly, it is argued that the term 'discrimination' should be used to refer to the concept and social phenomenon that has been referred to by the term 'stigma' (Sayce 1998; Maio 2004; Mental Health Media 2004). This puts the blame for any injustice and shame firmly on the discriminators. In addition, the strong moral connotations of the word 'discrimination' may be useful for activist work (Sayce 1998).

In view of the above argument, researchers have become more specific in their use of the term 'stigma'. They refer to public stigma (Corrigan and Kleinlein 2005) (what we in New Zealand would call discrimination), structural stigma or structural discrimination (used to refer to institutions that exist outside direct interpersonal interactions and that promote discrimination (Corrigan et al 2004; Corrigan et al 2005) and internalised stigma or self-stigma (the subject of this research). Even if researchers still prefer to use the word stigma over the word discrimination, they have in recent years tended to describe discrimination as a component of stigma or state that there is a close association between stigma and discrimination (Link and Phelan 2001; Watson and Corrigan 2001; Corrigan and Rusch 2002; Corrigan and Watson 2002; Ritscher et al 2003; Schumacher et al 2003; Ritscher and Phelan 2004; Corrigan 2004; Dinos et al 2004; White 2004; Corrigan and Kleinlein 2005; Pinfold et al 2005; Stuart 2005; Nimhe 2004).

In this study we use the term discrimination in the common New Zealand sense (often called public stigma or just stigma by researchers) and self-stigma (or internalised stigma) to mean a person's attitudes and behaviours towards themselves. (We address how researchers define self-stigma in the next section of the literature review and fully define self-stigma for

the purposes of this research later in the report.)

Definitions of self-stigma

As with the terms stigma and discrimination, the term 'self-stigma' has various definitions, with researchers' definitions usually based on their definition of stigma or discrimination. Most often, self-stigma is conceptualised as a form of 'internalised stigma' (Lee et al 2002; Ritscher et al 2003; Caltraux 2003; Corrigan 2004; Stuart 2005), where public stigma (or discrimination) must pre-date self-stigma. Stuart (2005, p22) claims that this definition of self-stigma can be traced back to Goffman (1963), and can be described as the "internalised feelings of guilt, shame, inferiority, and the wish for secrecy experienced by those who live with a mental illness".

Corrigan and colleagues describe self-stigma as a three-component social construct similar to their construct of stigma (Goffman 1963; Corrigan and Rusch 2002; Corrigan and Watson 2002; Schumacher et al 2003; White 2004; Corrigan and Kleinlein 2005). The three components of self-stigma are understood slightly differently to those of stigma: stereotypes are conceived as negative beliefs about the self; prejudice is understood as agreement with these negative beliefs and subsequent negative emotional reaction; and discrimination is conceived as (usually self-destructive) actions motivated by prejudice (Corrigan and Rusch 2002; Corrigan and Watson 2002; Schumacher et al 2003; White 2004; Corrigan and Kleinlein 2005). Self-stigma is a belief in negative stereotypes about a group to which one belongs and the application of those beliefs to oneself, thereby undermining one's self-efficacy (Watson and Corrigan 2001).

Difference between self-stigma and other concepts

The definitions of self-stigma used by researchers present a problem – what is the difference between self-stigma and low self-esteem? This problem is foregrounded by definitions such as those adopted by the Stigma-AIDS eForum where self-stigma is conceptualised as "a negative response by a person towards him or herself" including negative feelings towards the self and self-damaging behaviours performed because of those feelings (Health and Development Networks 2004, p 6).

Occasionally, authors who define self-stigma as a construct quite different from self-esteem slip, even if only implicitly, into equating the two concepts. For instance, Corrigan and Watson (2002) assert

that the fact some members of stigmatised groups do not internalise stigma may be demonstrated by these members having higher self-esteem than do the members of the majority. If all negative feelings directed towards the self can be considered to be self-stigma, then there must be some relationship between self-stigma and self-esteem.

Another concept raised in the literature is the difference between self-stigma and reactions to discrimination. Camp and colleagues (2002, p 825) argue that stigma may affect stigmatised individuals' self-esteem in diverse ways: not only through the internalisation of stigma, but also through such processes as "being affected by the response of others in the immediate environment". That is, not all reactions to discrimination – not even all negative reactions to discrimination – manifest as self-stigma, so a clearer theoretical distinction should be made between "the effects of internalising negative views of mental illness ... and the effects of experiencing rejection by others" (Camp et al 2002, p 831).

A related problem is suggested by Corrigan and Watson (2002), who note that studies into self-stigma among people with experience of mental illness sometimes define self-stigma by measuring behaviours that also comprise symptoms of depression or schizophrenia. This may lead to artificially high levels of self-stigma being found amongst people with experience of mental illness.



Causes and effects of self-stigma

The definitions of self-stigma used by most researchers directly follow from their definitions of stigma. This reflects that the internalisation of societal stigma (or discrimination) surrounding experience of mental illness, by whatever process, is generally seen to be the cause of self-stigma (Spennato 1997; Lee et al 2002; Boyd et al 2003; Caltraux 2003; Corrigan 2004). Usually, it is the adoption of negative majority attitudes or beliefs about experience of mental illness that is held to be the cause of self-stigma amongst people with experience of mental illness (Lee et al 2002; Ritsher et al 2003; Caltraux 2003). In one instance it is suggested that the attitudes of members of stigmatised groups simply "mirror" those of society in general, and it is because of this mirroring that self-stigma occurs (Health and Development Networks 2004, p 12).

Corrigan and Watson (2002), on the other hand, argue that it is by encountering discrimination, trying to make sense of discrimination, and believing that discrimination is legitimate, that people with experience of mental illness come to internalise stigma. Similarly, Spennato (1997) presents self-stigma as beliefs held about oneself caused by discriminatory social interactions, by discriminatory institutional experiences, and by encountering in the media negative stereotypes about a group to which one belongs. These models are undermined however, by findings from the work of Ritsher and Phelan (2004), Hansson and Bjorkman (2005), and Dinos and colleagues (2004), which suggest that there is no straightforward association between levels of experience of discrimination and levels of self-stigma.

Some people with experience of mental illness who experience discrimination are indifferent to it (Camp et al 2002; Corrigan and Watson 2002). Some participants in the Camp (2002) study were found to have tried passing as 'normal' – but this was not necessarily associated with self-stigma, and sometimes was done by individuals who identified and empathised with other people with experience of mental illness. Other participants expressed ambivalence about the stigmatic and generally pejorative nature of labels used to describe the experience of mental illness, but did believe that experience of mental illness was a mark of difference

and that some sort of label was useful (Camp et al 2002). Link and colleagues (2001) found that research into different groups' experiences of discrimination showed that lowered self-esteem was not an inevitable response to being discriminated against.

That different people with experience of mental illness respond differently to discrimination does not mean discrimination is not the cause of self-stigma. It does however, indicate that experiencing discrimination is not sufficient in itself to cause a person with experience of mental illness to internalise stigma (Corrigan and Watson 2002). In the literature, Corrigan and Watson (2002) go furthest in developing a model to explain why some people with experience of mental illness internalise stigma, while others resist it. Their model locates the cause of this distinction in the interpersonal situations in which people with experience of mental illness encounter, and make sense of, discrimination. If people with experience of mental illness encounter discrimination, interpret this discrimination as being due to stigmatising beliefs, and, crucially, perceive these beliefs to be legitimate, then it is highly likely that they will internalise those stigmatising beliefs. If, on the other hand, those stigmatising beliefs are not perceived to be legitimate, then individuals with experience of mental illness will not internalise them; should those individuals' sense of identification with people with experience of mental illness as a group be high, they will respond with righteous anger, and should it be low, they will respond with indifference (Corrigan and Watson 2002).

Prevalence of self-stigma

Findings as to the prevalence of self-stigma amongst people with experience of mental illness indicate that the majority experience self-stigma to some extent, with a substantial minority reporting high levels of internalised stigma (Ritsher and Phelan 2004; Dinos et al 2004; Yen et al 2005). Almost 90 percent of participants in Dinos and colleagues' (2004) study reported experiencing subjective feelings of stigma, and almost three-quarters of participants in Ritsher and Phelan's (2004) sample had self-stigma scores over the mean. Twenty-eight percent of participants in Ritsher and Phelan's survey, all of whom were diagnosed with mental illness, were found to endorse negative stereotypes about people with experience of mental illness. Further, Ritsher and Phelan found 33 percent of participants to have very high scores

of internalised stigma; the corresponding figure in Yen and colleagues' (2005) study was 25 percent. Dinos and colleagues found that subjective feelings of stigma occurred whether or not participants had experienced overt discrimination.

Role of diagnosis in triggering self-stigma

Research into self-stigma amongst people with experience of mental illness, and in the related area of research into self-stigma amongst people who are HIV-positive or have AIDS, indicates that self-stigma is especially common and intense immediately following diagnosis (Corrigan and Watson 2002; Lee et al 2002; Dinos et al 2004; Health and Development Networks 2004). One writer, on being diagnosed with schizophrenia, immediately began thinking he would never again hold a job and started considering suicide (Mind 2002). Further, it appears that intensity of feelings of self-stigma is directly and positively correlated with recentness of diagnosis (Corrigan and Watson 2002; Lee et al 2002). People report a dramatic and detrimental change in self-regard on being diagnosed as HIV-positive (Health and Development Networks 2004). It has been argued that diagnosis and treatment by mental health care professionals is the primary cause of self-stigma (Caras 2006). Dinos and colleagues (2004) report that positive responses to diagnosis were more often reported by people diagnosed as experiencing depression or anxiety than by people diagnosed with schizophrenia or bipolar disorder. This may be related to the finding that levels of discrimination towards people with experience of schizophrenia are higher than those towards people with experience of depression (Schulze and Angermeyer 2003; Mann and Himelein 2004).

Effects of self-stigma

Self-stigma has been found to have effects on members of stigmatised groups that are different from the effects of discrimination (Ritsher and Phelan 2004; Dinos et al 2004). Ritsher and Phelan (2004) argue that internalised stigma may have far more destructive consequences for people with experience of mental illness than does the experience of societal stigma alone.

One study argues that the primary effect of self-stigma amongst people with experience of mental illness is reduced self-esteem and self-efficacy (Watson and Corrigan 2001). Ritsher and Phelan (2004) found that, even when controlling for low baseline levels of self-esteem and depressive symptoms, internalised stigma strongly predicted

reduced levels of self-esteem amongst people with experience of mental illness. These findings are echoed by those of Corrigan and colleagues (2003), who argue that self-stigma leads to people with experience of mental illness suffering from low self-esteem and demoralisation. Both Hansson and Bjorkman (2005) and Bagley and King (2005) describe self-stigma as being negatively correlated with empowerment. However, several studies demonstrate that experiencing discrimination, rather than internalising stigma, can cause this sort of damage (Wahl 1999; Link et al 2001; Chung and Wong 2004). In fact, Chung and Wong (2004) found that reduced self-esteem, increased social isolation, the discontinuation of treatment, and worsened symptoms (all commonly associated with self-stigma) were associated with experience of discrimination.

Research has repeatedly found that people with experience of mental illness who self-stigmatise are more isolated, alienated, and socially withdrawn than are people with experience of mental illness who are not self-stigmatising (Caltraux 2003; Ritsher and Phelan 2004; Bromley and Cunningham 2004; Stuart 2005). This social isolation usually involves withdrawal from, and problems with, friendships and family relationships, and includes avoiding employment (Caltraux 2003). Because self-stigmatising people with experience of mental illness may have relatively limited social networks, they are less likely than the general public to receive support when they need it (Bromley and Cunningham 2004).

Another consequence of reduced self-esteem for people with experience of mental illness and self-stigma is that they are less likely to seek treatment for symptoms than are people without self-stigma (Watson and Corrigan 2001; Corrigan and Rusch 2002; Mind 2002; White 2004; Yen et al 2005). Watson and Corrigan (2001) argue that the failure to seek treatment amongst self-stigmatising people with experience of mental illness is likely to be the result of a hopeless, 'why try?' attitude. However, Corrigan and Rusch (2002) go on to argue that research still needs to determine the directionality of the relationship between self-stigma and failure to seek treatment. It has been shown, however, that perceptions amongst people with experience of mental illness of high levels of public stigma – whether or not this perceived stigma is internalised – predict low levels of adherence to a course of

treatment (Sirey et al 2001).

Self-stigma can also damage people with experience of mental illness by worsening symptoms and impeding recovery (Ritsher and Phelan 2004; Dinos et al 2004; Yen et al 2005). Yen and colleagues (2005) question the directionality between worsened symptoms and self-stigma, arguing that it is perhaps the fact that people with more severe symptoms of mental illness tend to be more socially isolated than people with milder symptoms that may lead to them rating themselves higher on measures of self-stigma. However, Ritsher and Phelan's (2004) findings demonstrate that high levels of self-stigma are predictive of worsened symptoms of depression.

Additionally, people with experience of mental illness who internalise stigma report a reluctance to disclose their experience (Bromley and Cunningham 2004; Dinos et al 2004). In Dinos and colleagues' (2004) study, all participants who reported subjective feelings of stigma also reported a fear of disclosure. Ritsher and Phelan (2004) argue that it is the very fact of the experience of being divided from society as a whole, and being part of a stigmatised group, that is the most damaging aspect of the experience of self-stigma.



Combating self-stigma

Corrigan and Rusch (2002) argue that the most effective means of combating self-stigma is by attacking societal stigma (discrimination). The Stigma-AIDS eForum concludes that attempts to eliminate self-stigma should support and extend existing programmes to eliminate societal stigma (Health and Development Networks 2004). Some authors, however, report that it is better to combat self-stigma directly rather than to attempt to eliminate self-stigma by combating discrimination (Ritsher et al 2003; Health and Development Networks 2004; Bagley and King 2005). In addition to the arguments above, the Stigma-AIDS eForum included arguments that self-stigma becomes so ingrained that it would persist even in the absence of societal stigma, and, because it is impossible to eradicate discrimination, advocates for stigmatised groups should focus on eradicating self-stigma (Health and Development Networks 2004). This last point is echoed by Bagley and King (2005), who argue that as stigma-busting campaigns only slightly reduce levels of public stigma, and given there is a core of stigma-resistant people with experience of mental illness, anti-stigma campaigns should focus on reducing self-stigma. It is also supported by Ritsher and colleagues' (2003) contention that self-stigma is one of the few aspects of stigma that mental health care workers could address directly.

One recommended method of combating self-stigma amongst people with experience of mental illness is education (Watson and Corrigan 2001; Bagley and King 2005). Bagley and King (2005) argue that, rather than focusing on public education, stigma-busting campaigns should focus on educating people with experience of mental illness to help them reject self-stigma and confront or constructively avoid public stigma. Education is argued to be helpful in reducing, as well as preventing, self-stigma (Watson and Corrigan 2001).

Authors suggest that an effective means of combating self-stigma amongst people with experience of mental illness is to take measures that increase people's understanding of the stereotypes directed towards them or directly confront the content of stereotypical beliefs (Corrigan and Watson 2002; Health and Development Networks 2004). Corrigan and Watson (2002) describe how members

of stigmatised groups tend not to internalise stigma if they can attribute stigmatising stereotypes to societal biases and structural inequalities; it has also been found that members of stigmatised groups who perceive a systemic social bias to discrimination report higher self-esteem. It is possible that if people with experience of mental illness had better information about the structural causes of stigma and discrimination, they might be less inclined to internalise stigma (Corrigan and Watson 2002). On the other hand, Yen and colleagues (2005) caution that the literature has repeatedly found no relationship between levels of self-stigma and levels of knowledge about experiencing mental illness, and suggest that education about self-stigma on its own might not help combat self-stigma. Other studies suggest caution in adopting this approach, at least without supplementing it with other means of combating self-stigma (Bagley and King 2005; Hansson and Bjorkman 2005).

It has been found that peer support groups are helpful to self-stigmatising people who are HIV-positive or have AIDS (Health and Development Networks 2004), and it may be that such groups could also help reduce self-stigma amongst people with experience of mental illness. Yen and colleagues (2005) note that length of hospitalisation for people with experience of mental illness is not associated with reduced self-stigma and, accordingly, argue that inpatient services could do more to take into account that many patients experience self-stigma. Corrigan and Rusch (2002) add that, as the current literature indicates a link between people with experience of mental illness reporting self-stigma and failing to seek treatment, anti-stigma programmes should be used to promote treatment programmes. These treatment programmes should, in turn, focus on combating societal stigma through protest and encouraging contact between people with experience of mental illness and people without that experience (Corrigan and Rusch 2002).

Caltraux (2003) points out that often self-stigmatising people with experience of mental illness are not aware that their actions are self-stigmatising. Consequently, should people with experience of mental illness exhibit self-stigmatising behaviours at work, employers, employment support services, and government agencies have a responsibility to encourage the development of a workplace culture

amenable to employees with experience of mental illness empowering themselves (Caltraux 2003). Employers in this situation should provide self-stigmatising employees with 'extrinsic' supports and educational resources, which employers manage until employees have recovered sufficiently to manage the supports themselves (Caltraux 2003).

Self-stigma and empowerment

Corrigan (2004) has defined self-stigma as the opposite, in social terms, of empowerment. Corrigan describes empowerment as a measure of the control people with experience of mental illness have over all areas of their lives. The measure comprises two superordinate components, one involving positive self-regard, and the other involving the desire to have a positive effect on one's community.

Enhancing empowerment is mentioned in the literature as a means of combating self-stigma (Watson and Corrigan 2001; Health and Development Networks 2004; Shih 2004; Bagley and King 2005). Following a review of the literature, Bagley and King (2005) conclude that many people with experience of mental illness might cope best with active problem solving, which involves people having control over their lives. The Stigma-AIDS eForum states that one of the best means of combating self-stigma is by facilitating empowerment, especially at the point of diagnosis (Health and Development Networks 2004). Shih (2004) argues that empowerment helps people with experience of mental illness to develop feelings of mastery and self-efficacy, and thereby helps them to combat discrimination and avoid internalising stigma.

The literature recommends a few specific techniques for facilitating empowerment amongst people with experience of mental illness. It is argued that disclosure helps empower members of stigmatised groups (Health and Development Networks 2004). Other means of enhancing empowerment include internalising the principles of recovery; using cognitive restructuring in order to challenge self-stigmatising thoughts; supporting consumer-operated health initiatives; supporting research into empowerment, especially consumer-conducted research; increasing mental health service accountability to consumers; and supporting clubhouses, lodges, supported employment

services, and supported education (Corrigan 2004). Specifically, cognitive reframing therapies may help build empowerment and reduce self-stigma (Watson and Corrigan 2001). Shih (2004) describes three techniques through which people with experience of mental illness can reduce their self-stigma: compensation, or developing skills that compensate for the disadvantages they experience; selectively interpreting the social environment in ways that protect one's sense of self-worth; and avoiding stigmatised identities by drawing resources from whatever other identities they can lay claim to.

Methods



Reference group members

A research reference group was formed towards the end of 2006 to offer suggestions regarding the research process and to assist with the analysis.

The group comprised Mary O'Hagan, Lynne Pere, Dean Manley, Vito Malo, and Sarah Gordon. Debbie Peterson and Alex Barnes from the Mental Health Foundation participated in and organised the meetings.

The group met five times from late 2006 to early 2008.

Primary research methods

Two primary research methods were used to collect information for the research project: a literature review and focus groups.

Literature review

The literature review focused on the definitions of, causes of, and methods for combating self-stigma.

Literature was sourced from research journals, books, bulletins, reviews, and websites.

Chloë Duncan and Debbie Peterson compiled a first draft of the literature review in October 2006. Later that year, the draft review was shared with the research project reference group, which commented on the draft. The group's comments were integrated into the literature review summary in this report (section 1).

Focus groups

Focus groups were used to gather information about self-stigma from different members of the community. Kitzinger (1995, p 299) defines focus groups as:

A form of group interview that capitalises on communication between research participants in order to generate data ... People are encouraged to talk to one another: asking questions, exchanging anecdotes and commenting on each others' experiences and points of view.

The focus group method was selected because it offered participants a peer environment, where people could explore their perceptions of self-stigma and engage in dialogue safely.

Each focus group ran for about two hours in a venue the participants knew and were comfortable with.

Participants received a light morning or afternoon tea, and were given gift vouchers to thank them for their time and participation.

Participants in the focus groups

Eleven focus groups were held nationally. Eight of the groups were regional providers of the Like Minds, Like Mine programme. Contact with these groups was made through regional Like Minds co-ordinators. Three groups that were not formally associated with the Like Minds programme also participated. These groups were made up of people using regional mental health services or working in the mental health field. Participants for these groups were contacted through existing working relationships and mental health networks.

A prerequisite for all people who participated in the focus groups was that they had experience of mental illness at some point in their lives.

In the interests of understanding how self-stigma affects people of different cultures and in different groups, the focus groups in different centres around the country comprised:

- five groups of Pākehā (non-Māori) (called the general focus group) (Auckland, Napier, Wellington, and Christchurch (two groups))
- two groups of Māori/tangata whaiora [people seeking wellness] (Porirua and Turanganui-a-Kiwa/Gisborne)
- one group of refugees (Wellington)
- one group of Chinese (Auckland)
- one group of young people (Wellington)
- one group of Pasifika (Lower Hutt).

By including diverse groups from different centres we could look at and use a variety of cultural understandings of self-stigma. This diversity also modelled an inclusive and participatory research approach.

Seventy-six people participated in the groups. Table 1 illustrates self-defined demographic characteristics of the participants.

Table 1: Self-defined demographic characteristics of focus group participants

Characteristic		Number
Gender	Female	34
	Male	42
Ethnicity	New Zealand European/Pākehā	30
	Māori	18
	Pasifika ^a	8
	Chinese ^b	6
	Other ^c	8
	Unknown	6
Age (years)	Under 25	8
	25–39	24
	40–59	26
	60+	10
	Unknown	8

Notes

^a"Pasifika" includes people who identified as Samoan, Niuean, Tongan, and Tokelauan.

^b"Chinese" includes people who identified as Chinese-Malaysian or as being from Hong Kong and mainland China.

^c"Other" includes people who identified as Somali and Iraqi.

Recording of focus group discussions

Facilitators were asked to facilitate and record the focus groups' discussion in the way that best suited the particular focus group. For example:

- the Māori/tangata whaiora group followed tikanga Māori (Māori culture and customs) in the form of mihi whakatau (welcome), karakia (blessings or prayers) mihimihi (formal speeches) and whakawhanaungatanga (the forming of relationships or connections)
- the refugee focus group used professional interpreting services in their focus group
- the Chinese and Pasifika groups used the English language but had facilitators who were also fluent in the first language of the participants.

Facilitator preparation

In May 2007, before the focus groups were conducted, a facilitator preparation session was held in Wellington. Debbie Peterson and Alex Barnes from the Mental Health Foundation delivered the preparation session, which six facilitators attended. A further two facilitators were given preparatory material for their respective groups.

The preparation session covered:

- the background to the project (a Like Minds, Like Mine research project)
- an introduction to focus groups (definitions, roles, and responsibilities)
- the structure of focus groups (duration, size, questions)
- ethical issues (consent and information forms, working with different groups)
- recording focus groups' discussions and analysis (flip charts, facilitator opportunities to provide feedback on the draft self-stigma report).

Facilitators were asked to participate based on their depth of experience in working with people who have experience of mental illness and/or their knowledge of the cultural backgrounds of the focus group participants. Because of the experience the facilitators had in working with the different communities of interest, it was agreed that the facilitator would have a degree of flexibility in how they facilitated, structured, and organised their particular focus group. In some cases this meant they co-facilitated with a person affiliated with that group, in other instances they worked as an individual facilitator. This enabled the facilitator to meet the different needs of participants to the best of the facilitator's ability and address the key research questions.

3

Findings

Role of the project team

The project team at the Mental Health Foundation supported the facilitators. It provided the relevant resources and ensured that the running of the focus groups went as smoothly as possible. The general focus group information pack for facilitators and organisers has been reproduced in the Appendix.

Facilitators' reflections after the focus groups

As the report authors we wrote up, analysed and discussed the general findings once we received the notes from each group. We worked with the facilitators to reflect critically on the process for their respective groups. We asked the facilitators to write their own reflections on the issue of self-stigma, because although we found many common themes, we also wanted to determine any differences between the groups. We believe these differences were important to include and discuss in this report.

Focus group questions and analysis

In the focus groups, the facilitators asked participants seven questions.

- What does internalised stigma mean to you?
- What are some examples of internalised stigma?
- How has internalised stigma affected your life?
- When did you first experience internalised stigma?
- Where do you think internalised stigma comes from?
- What makes internalised stigma worse?
- When you feel internalised stigma, what helps you deal with it and what advice would you give to others experiencing it?

We used the term 'internalised stigma' in our questions, but most people responded using the term 'self-stigma'. We then decided to use 'self-stigma' throughout this report. The questions were open-ended to explore participants' personal experiences of self-stigma and how people may have managed to overcome it.

Once the focus group had been completed, the facilitators were asked to write up the results and give them to the authors either in person or via email. All the

information gathered was kept in a secure location.

We then analysed answers to each question using the software package Nvivo and through thematic analysis. Themes were identified for each question and then differences and similarities between groups were sorted and analysed.

Uniqueness of this research

The inclusive and participatory nature of the research approach meant incorporating a flexible research process, which added complexity but ultimately strengthened the project. The unique dimensions of this research were:

- it was the first mental health research in Aotearoa/ New Zealand to focus on self-stigma
- all focus group participants had experience of mental illness, that is, they were current service users or people working in mental health services
- the focus group process for the refugee group included trained interpreters, which was vital in accurately recording their experiences.

Limitations of the research**Budget constraints**

While the research attempted to include a diverse range of people in a range of specific focus groups, budget constraints meant we could not include larger sample sizes for each group. Therefore, results of this research cannot be generalised to whole population groups.

Interdependence of the experience of mental illness with other factors

When we asked people about their experiences of self-stigma, it became apparent that their experience of mental illness was often mixed with other factors such as ethnicity or family background and upbringing. However, the research never aimed to separate experiences of self-stigma from other life experiences and realities – rather we acknowledge that these factors should be seen as interdependent.

This section is based on the answers to the seven questions asked of participants during the focus groups and concludes with the facilitators' reflections.

- What does internalised stigma mean to you?
- What are some examples of internalised stigma?
- How has internalised stigma affected your life?
- When did you first experience internalised stigma?
- Where do you think internalised stigma comes from?
- What makes internalised stigma worse?
- When you feel internalised stigma, what helps you deal with it and what advice would you give to others experiencing it?

Examples of what self-stigma means to people

When participants were asked how they defined self-stigma, they described more than 20 characteristics, with examples for each (although some participants did challenge whether self-stigma exists). Examples of the experience of self-stigma included not being 'normal', being discriminated against, and being isolated.

While there was a range of responses, the interdependence of themes and people's understanding and examples of self-stigma were clear. For example, participants' feelings about "not being normal" also related to their feelings of isolation, comparisons of themselves with other people, and a sense that their experience could never change. While each example and understanding is discussed separately in this report for the purposes of analysis, each aspect is related to the others.

Not feeling normal, feeling unusual

Some participants explained that for them self-stigma related to not feeling "normal". In this sense, they did not feel "equal to a normal person". One person described their feeling of abnormality this way:

It is like the ugly hat has been on the shelf all this time – a misconception about what mental illness is. But now, I have become the person who wears the ugly hat – being described as crazy, dangerous and someone

that others need to stay away from.

Other examples of "not being normal" included experiences of not being listened to and other people generally disregarding the participants' observations, feelings and needs.

Being withdrawn, isolated, lonely, vulnerable

For many participants, social isolation and a feeling of vulnerability typified their understanding and experience of self-stigma. One person commented that they felt "alone and isolated in my problem", while another person explained that they tended to withdraw from people they knew such as friends and social networks.

For other participants their examples of self-stigma stemmed from feeling as though they were on the margins of society and "not allowed to participate in life fully". Without the company of people with similar mental health experiences, some participants felt lonely and unaccepted.

Comparing oneself with others negatively

The act of comparison also defined people's understanding of self-stigma. Comparisons differed between participants. Some spoke about how in mental health peer groups some people compared their experiences by levels of "severity". These types of comparisons resulted in people saying things like, "You weren't as unwell as me". Subsequently, some people were acutely aware of a pecking order within peer groups, depending on how severe a person's experience was. Another participant simply described how they constantly compared themselves and their sense of worth to others.

Some participants commented that they did not want to disclose their experience of mental illness to others because of the comparisons that might result. One participant felt most comfortable relating to people in ways that did not involve an explicit recognition of his mental health experience:

Most people who know me don't know my experience of mental illness – which is cool. I'd rather they knew me as a fellow car mechanic or a fellow diver.

Not feeling good enough, feeling hopeless or useless

Feeling hopeless and not good enough had two aspects. Firstly, for some of the participants feeling "not good enough" pervaded all aspects of their

lives, including being a "good husband, wife, mother, and human being". Secondly, some believed their self-stigma was reinforced because they were often treated as "useless" and "worthless" by others. For example, one participant reflected that media messages about people with experience of mental illness made them think they were worthless and crazy:

[We're] worthless because he/she is crazy, and these stereotypes and perceptions are being portrayed by the media, so now I experience mental illness, I must be like that too.

Another participant shared that their understanding of self-stigma was reinforced by the roles he was given by whānau (family) members, explaining that "when I went to whānau hui [family gatherings] at the marae [meeting area of family or tribe] I was always the one sent to clean the whare paku [toilets] – and no one would help me". This participant felt these roles were reserved for him because, while his whakapapa [genealogical] line was of a high rank, he experienced mental illness, so he was deemed no longer worthy of respect.

Having a sense of inevitability that things will not change and recovery is not possible

Another manifestation of self-stigma revolved around participants' beliefs that their condition and experience would not change, and that there would be little or no recovery. At times, people explained this was quite subtle and projected on to them by others. For example, one person spoke about how, when she became upset or distressed, that people automatically believed she was becoming unwell again and that her distress was part of her "illness" as opposed to a normal emotional reaction.

Another person was more explicit about how the "things can't change" belief underpins their understanding of self-stigma. They described it as:

Believing I'll be sick forever and useless and never able to do what I want to do and will never amount to anything because I have a mental illness.

This was supported by others, saying that it felt for them as if "I am hopeless because I think I'll be mentally ill for the rest of my life". Another person described their experience of being diagnosed as a "death sentence":

When I was told I was a schizophrenic and would be on medication for the rest of my life, that killed me. It was a death sentence.

Feeling different or an outcast, not fitting in

Not feeling as though they "fitted in" and having a sense of difference contributed to people's definition of self-stigma. One participant explained that their unusual diagnosis made them feel "freakish and isolated" and reinforced that they were "unusual". Related to this, people also expressed that they were often "put down for being different". A refugee participant explained that they believed that they did not "fit in New Zealand society, I even smell bad, and I think people avoid me at all costs".

Another participant recalled a story of being at a marae and people talking negatively about him, then ostracising him. For this participant, this type of negative behaviour towards him from whānau was "normal". On one occasion he recalled hearing a kaumātua [elder] tell off one of the young children for doing this. The participant said he heard the kaumātua say, "Kaua e kōrero kino ki a ia! [Don't talk that way (badly) to him!]". At this point he felt that, for the first time, a sense of respect was being demonstrated towards him. However, this was followed by the kaumātua saying, "Kia tupato! E makutu ia koe! [Be careful! He will curse you!]". The implication was 'this guy's been cursed, that's why he's nuts'.

Challenging the notion of self-stigma, not buying into the label

Members of the Turanganui-a-Kiwa/Gisborne focus group challenged whether self-stigma related to the experience of mental illness existed. Participants explained that self-stigma existed only if people "bought into" (that is, accepted) the label and its effects. One person spoke about using a health continuum to understand people's well-being, noting that "regardless of people's mental state there are always positive aspects. People become what you call them, 'tangata whaiora', for example". It was noted that this has the same effect as if people only focused on the negative attributes of their mental health experience:

If you have an opinion of yourself that you're unlovable, people won't love you. By the same token, if you give people permission to put you down, they will.

Consequently, rather than exploring and defining the concept of 'self-stigma' these participants explained that they would rather focus energy on building pride in the mental health consumer/tangata whaiora movement. For them, this meant validating the positive characteristics and moving beyond "recovery" to being "out and proud" and future-focused on their strengths.

Other participants added to this, noting that the concept of 'self-stigma' was bound by the majority Pākehā culture, and did not represent Māori ways of understanding hauora [health] and wairua [spirituality].

Feeling less worthy than others or inadequate, having low self-esteem

Feeling inadequate and believing that people with experience of mental illness are less worthy than other people, was another example of what self-stigma meant to people. People spoke about their experience of hearing "all these negative and wrongful accusations about people with experience of mental illness, such as crazy, stupid and someone who is going to be laughed at". For these participants this was an example of public stigma directly creating their self-stigma. The experiences of diagnosis and institutional care were also identified as examples of how self-stigma can emerge, with people claiming that these encounters "don't increase self-esteem, [they do] more damage".

Another person shared that self-stigma emerged when they used their experience of mental illness as a way of explaining their inability to complete a certain task:

If I cannot do something, I am afraid that people will question me. So sometimes I say in advance that I am not well, that I have emotional problems or that I am very depressed.

Low self-esteem was linked to people's definition of self-stigma when they did not recognise or acknowledge any positive feedback they might receive. One person explained that "most of the time I do not believe it when people give good feedback to me or say something nice about me".

Being a burden to others, needing support

Not wanting to present themselves as in need of support and dependence, so not seeking help was

seen as an example of self-stigma. A participant gave an example of this in relation to family and travel:

[I] don't ask for help - [I] don't want to be seen not to cope ... with children or taking an international flight ... since [my] anxiety diagnosis.

Others believed that because of their experience they had become "a burden to others and society". This resulted in beliefs about a fundamental feeling of non-acceptance that others projected onto participants who then internalised it.

Limiting oneself

Some participants explained that limiting oneself was also a characteristic and lived experience of self-stigma. For some participants, their self-stigma was so strong they felt as if it was dragging them into such a low state of mood that they likened it to being dragged "under the water" and drowning.

Alternatively, others described how self-stigma helped them to "limit positions which could increase stress". In this instance, people believed that self-stigma could help them decrease anxiety and manage strenuous situations by allowing them to recognise their limitations.

Reflecting discrimination, believing what others say, accepting discrimination

A common meaning people ascribed to self-stigma was internalising the discriminatory attitudes that were directed towards them or the negative attitudes they had been exposed to in public:

Believing what other people told me ... all the time ... because I wasn't getting any positive stuff really [so I believed all the negative].

In these situations it was usual for people to stigmatise themselves to the point that where, on "being called an idiot, I believed them and I acted stupid". Some described how this internally focused discrimination was painful and a clear example of how a person can oppress themselves, which can lead to further alienation from oneself and society.

Reinforcing stereotypes

Often self-stigma resulted in people reinforcing the negative stereotypes of themselves and others with experience of mental illness. Many participants explained that "it's no use giving my viewpoint because it's not worth anything".

Another example of self-stigma that people discussed included "believing the diagnosis or saying you're a consumer is self-stigma". In this regard, subscribing to an identity based on one's experience of mental illness was potentially seen as a form of internalised stigma.

Engaging in negative self-dialogue

A constant negative internal dialogue was identified as a major feature of self-stigma. People explained that often their negative thoughts lowered their expectations of themselves, made them distrust others, and made them question their ability to have intimate relationships:

Questioning relationships - should I tell, will they stay, did they break up with me because of it?

Negative self-dialogue also affected people's friendships. They explained that it made them think they would "never amount to anything, don't deserve happiness [or] good things". In worst-case scenarios, the internal negative dialogue contributed to people becoming unwell again, not wanting to recover, and having suicidal thoughts.

Feeling rejected by family, letting one's family down, excluding oneself from family

For most participants, family-related experiences were often the essence of their self-stigma. People had numerous examples of family-related rejection, distrust, isolation, exclusion, and shame.

One person described being in a Māori mental health unit and ringing up his whānau while he was there. On receiving his call, his whānau responded, "We don't want to see you". He then explained that "the only person who came to see me in the whole year I was there was my coach because I play basketball. My whānau didn't want to know me because I had a mental illness". For some, the rejection from their family was the hardest rejection to deal with. One person explained that "I can block out what other people think of me, but the depth of what my whānau think of me hits in the heart".

Another family theme included the historical nature of people's experience. In this instance their self-stigma was related to a "family history of mental illness and institutionalisation". Conversely, it was shared by a Pasifika participant that in Pasifika communities "there is a stigma around one's family name and the

historical knowledge and use of that name".

Government interventions by organisations such as the Child, Youth and Family Service were also cited as sources of self-stigma, particularly for parents with experience of mental illness:

It kills your dreams. It killed my dreams of having children. It robbed me of time with my children. [The Child, Youth and Family Service] say I'm a bad influence. I couldn't understand they could say those things about me, read it back to me - am I really like that?

People acknowledged that because of their close relationships with those affected by mental illness, families were often the source of stigma, and the consequent self-stigma. As one person explained it, "familiarity breeds contempt; because it's whānau, it's easier to write off affected whānau members". It was also acknowledged that sometimes "whānau and family resources can become exhausted" by their experiences of dealing with mental illness, which can lead to a lack of family support. Another person noted that "often families don't have the tools [or information] to work with family members affected by a diagnosis". It was common for participants to explain that they felt they had to hide "diagnosis and medication from family as a way of self-care".

Having self-doubt

Some participants described self-stigma as "absolute doubt". One talked about "inner doubt all in his head" and his belief that "you've built yourself a house of cards and it will all come tumbling down". In a similar way, a person commented that self-stigma for them was:

That inner voice, that inner doubt. It's that repetitive skipping record that constantly reinforces your own inability and lack of worth.

These overwhelming feelings of self-doubt resulted in some people feeling and believing that they were not "reliable enough to be in a responsible position". It was obvious to one person how damaging self-doubt and the resulting self-stigma could be:

We screw ourselves with that sort of crap ... That's what stunts your growth. That's what kills you - the inner self-doubt.

Blaming oneself

Self-stigma in the form of negative self-talk and doubting one's own ability meant that people often blamed themselves for not reaching their potential. Self-blame meant people did not take offered employment positions, retrenched and isolated themselves from family and friends, and did not plan for the future. One participant explained that they did not want to plan or think ahead about their circumstances "because I don't know if I'll be alright and I don't want to let other people down or be unreliable at the last minute".

Feeling a failure or weak

People's sense of failure as a result of a perceived "inner weakness" permeated beliefs about self-stigma. Participants explained that often other people's expectations, particularly around achievement, or one's feelings of vulnerability when stepping up to a position of responsibility were linked to self-stigma. One participant described this dimension of self-stigma in this way:

[I] won't ask for help – sense of failure; don't want to expose self, want to be seen as coping, can see it as a weakness by self.

For some, a belief of failure and inner-weakness often became seen as a personal problem, an affliction others did not seem to suffer from. This resulted in some people becoming isolated in dealing with their mental health issues.

Feeling ashamed, losing face, feeling guilty or embarrassed

Some participants explained that their feelings of self-stigma started after their acute experience of mental illness. After reflecting on their mental health experiences and its effects, people expressed that they became vulnerable to feelings of shame, devastation, and guilt. One participant explained this situation through the following example:

When I was in the manic stage I refused to go to hospital, because I didn't think I had a problem. Once I was able to make sense of the whole event, and feel as myself again, the reality started to kick in. Knowing for a fact that I experience mental illness and that my family went through all this, really made me feel devastated, ashamed and guilty. You couldn't help but blame yourself and feel guilty.

The effects of people's shame and guilt were wide-ranging. Some explained that it manifested itself in the following negative ways. Participants said they did not:

- apply for a job because they thought they could not do it because they had a mental illness
- go out in public because they felt different from everyone else
- share their history with friends, family, and work colleagues because they feared retaliation and how they would then be seen or related to.

The effect of people's shame and guilt was an unwillingness or inability to do or be part of all those things that constitute being an active member of society.

Feeling insecure, lacking confidence, feeling anxious

Self-stigma had impeded and reduced people's confidence, and often resulted in feelings of insecurity and anxiety. For some participants, a lack of knowledge and information about their diagnosis combined with their not knowing how to combat discrimination contributed to a lack of confidence:

When you don't have enough information or knowledge about your illness, you have no defence. So when people say "You're just a schizo so you're stupid anyway", I can't refute that, because I don't know.

In these situations, one person explained that they "let arguments go" because "[I] don't feel that I have any power in an argument – we don't have the same power as other people even in our own families". This resulted in people being cautious and anxious about disclosing their experience of mental illness to family, friends, and prospective employers.

Feeling suicidal

Feelings of suicide were linked to self-stigma. These links included people thinking negatively about themselves and their life potential, being socially isolated, and the perceived negative impact a diagnosis would have on their life chances and ongoing well-being. People's feelings of suicide and self-harm impeded their visions of recovery, which contributed to them feeling as though they were unable to have and maintain a healthy future.

Fearing discrimination

People's concern and anxiety about being on the receiving end of discrimination increased the power of self-stigma. This fear increased the power of self-stigma and was identified as one of self-stigma's characteristics. One participant shared that she did not want to tell one of her husband's family members about her mental health experience because she feared discrimination from the wider family.

Apprehension about how people would react to one's experience of mental illness was very real for people. Being judged and looked down on because of their experience was a fear; the phrase "know me before you judge me"³ was often raised by participants:

You struggle to fight the discrimination in your own community among families, friends. You hear voices that are not positive and that drive you nuts or give you a headache. How annoying and ear-bashing it [can] be ... People can misjudge you 'cause of the illness you have, and not know you first before accepting you.

Trying hard

For some, self-stigma included putting forward a personal characteristic or side of themselves to "prove" a certain quality. Examples included projecting themselves as they thought others would want to see them, although it did not reflect what the participants really felt. A work example related to people striving "to prove [they] are well"; in some cases this meant people not taking their allocated annual leave. Another person shared that he tries "to be an asshole so people notice I'm here". At its base, people explained that they tried hard to impress others because of other people's, and their own, expectations surrounding self-worth and value.

Feeling angry and in despair

For some participants, self-stigma was linked to anger and despair, either about their own situation (internal) or how family and friends had reacted to their mental health experience (external). The internal anger and despair related to people's varying abilities, depending on how mentally well they were and their experience of being admitted to hospital.

External anger and despair related to negative family and community reactions to participants' experience of mental illness. Some participants explained that this anger arose when other people did not

understand their limitations. Another person said it was difficult to forgive wider family members for how they had treated them and their children:

Hard to forgive family, especially when they've worked with [the Child, Youth and Family Service] to take the children away from me. [I have] feelings of anger towards them.

Effect of self-stigma on people's lives

The effect of self-stigma on people's lives was diverse and far-reaching. Some people described the effects of self-stigma in a holistic way, commenting on its negative physical, mental, social, and spiritual effects. One person phrased its multi-dimensional effects in this way:

It's cost me jobs, career advancements, relationships and relationship growth. It's cost me time, money and energy. It's taken many years to overcome the bulk of my own self-stigma. I am still affected by it, but I'm working on changing that. Up until recently I was very 'in the closet' in regards to my whaiora status. Only a handful of close most trusted people knew. It's only been in the last few years that I've gone more public – and I still experience strong reservations about this. To me I am my own worst critic and my worst tormentor. I know that there is little to nothing that limits me in life but myself.

Being 'other' and socially excluded

As a result of its wide-ranging consequences, many people felt they had to "work harder than others" to prove their worth. This was linked to people's feelings of 'difference' from other people – a range of feelings and experiences that indicated to them that they were not 'normal' members of society. For example, some people believed that because they had experience of mental illness they were "a hindrance and a burden".

I was constantly worried people might be able to see I am different from them because I have mental illness when out in public. I don't know how people are going to look at me if they saw this crazy person. This happens even when I am having morning tea with my husband.

Another person articulated that they had to be twice as good because "everything is perceived as twice as bad". Others spoke about the obvious changes that occurred to their bodies and moods because

³This is a phrase from the Like Minds, Like Mine media campaign and advertisements.

of medication they were on. For them, this was an obvious marker of their difference:

When you see the side effect of the medication how could you not internalise the fact that you are different from other people such as feeling sleepy, drowsiness, gain or weight loss, issues like this.

Social exclusion was typified by people's fear of discrimination in their daily lives. At times, this fear had the effect of holding people back from possibilities and their life potential. People spoke about change being scary because "you convince yourself you can't handle it, so life just passes you by". This fear also related to people's expectations of themselves, in which case they avoided taking on responsibility at work because they were worried they would not do the work well enough. One person shared that the effect of discrimination on their lives scared them so much that they did not venture out into public:

You don't feel safe when you're out and about – people tend to have a go at you – they can see right away that you're different and you get abused for that, so I don't go out anywhere.

People also acknowledged that barriers to participation were based on the label of mental illness and its "oppressive power". For many, being "seen as an illness, not a person" underpinned people's fear and experience of social exclusion. One person observed that her medical case notes, which contained a misdiagnosis, continued to influence her life negatively. Another participant spoke about how some religious people viewed them as "a weak soul" because of their condition and experience. Generally, however, people returned to the theme of discrimination and its relationship to social exclusion:

The experience of mental illness is the only thing that can cause you to not have travel insurance, to have your licence removed, to have your passport removed, to not be allowed to have firearms, to not be allowed to stand on a Board, to not be able to stand for Parliament etc etc ... All based on an illness.

Being socially withdrawn and isolated

Responding to self-stigma by withdrawing socially was common amongst focus group participants. Often people isolated themselves out of fear of being judged by others or because they had an

overwhelming sense of hopelessness. This was exhausting for people and added to their sense of social loss:

After being told what you have, you begin to feel shame, fear, confusion ... You have a sense of loss. You don't know how this is going to impact on your life, afraid other people might find out. You start to isolate yourself from others and eventually from society.

For some, isolation was a by-product of the self-stigma relating to their condition, which, in turn, "controlled their lives". Others felt "confused and out of the circle; on the edge and out of anyone's interest".

Issues of withdrawal and isolation also affected friendships negatively. People explained that their friendships often changed because they were afraid of their friends' reactions to their experience of mental illness. These feelings of fear were often based on deep insecurities and beliefs about self-inadequacy, which resulted in withdrawal from friendship networks or an unwillingness to make new friends or relationships:

I'm afraid my friends might find out about my illness. I begin to avoid social events, because you are feeling insecure about what happens when they find out that you are crazy.

You start to withdraw from your friends because of lacking confidence, and you also have doubts about how people are going to react when they find out. Also sometimes you might have [a] fear of letting new friends know about your mental illness.

Having self-doubt

Not believing in their ability and worrying about whether they can "keep it together" was often how people described their self-doubt. Because of the self-stigma people experienced, they expressed that they were not capable of a variety of things, including studying, maintaining relationships, or finding employment. Once again, people questioned whether they were indeed 'normal' because of their anxiety about whether they would succeed:

This also has huge impacts on your marriage, your career, your job, because you are having severe self-doubt. Would you still be able to do things that you normally can?

Feelings of hopelessness and inadequacy affected people's beliefs about their ability to find employment. It was common for this to affect participants' behaviour, a type of self-discrimination, with participants explaining that their chances of gaining employment were minimal because of their mental illness experiences:

Someone told me that you've got to prove that you're the best person when you go for a job. And if you don't believe that, then it's not worth even trying.

Another person shared that sometimes people with experience of mental illness who work in the mental health area can also hinder recovery because of a power-related hierarchy:

People with experience of mental illness put other people with experience of mental illness down when they're in roles of responsibility within the system. There is a hierarchy of power that exists.

One participant talked about applying for a job and thinking, "Should I disclose or not disclose in the part where it asks if I have a condition that might affect my job?". It was at this point that the dynamics of self-stigma began to emerge, and the person started to think, "Maybe I'm not good enough for this job [because I have a condition that might affect my employment]". Other experiences echoed this example, where people did not apply for jobs because they thought "there's no point because I'll get turned away anyway", that is, they assumed discrimination would happen. Being out of employment had obvious effects on people's financial stability, which affected their sense of worth and ability to provide for their own financial needs.

Experiencing negative family relationships

Self-stigma had negative effects on people's family relationships. People spoke at length about how they often felt excluded from family, which damaged their trust of other family members and sometimes led to exclusion from the family:

Mum there, Dad there, aroha [love] from the cousins, manaakitanga [care and respect], whanaungatanga [kinship] ... until you get unwell. Whānau response when this happened was "sort your crap out, then give us a call". So who do I turn to now? When you're supposed to stand up on your traditional Māori culture and values.

Other family experiences included comparisons with other family member. People spoke about how they were often compared with members of the family who did not have experience of mental illness. For example, a person shared that problems within her family were always her fault "cause she's mental". Other forms of self-blame emerged regarding the care of children, particularly when parents became unwell. Participants felt they let their children and wider family down when they were hospitalised. For some, hospitalisation undermined their parental roles. Therefore, they were seen as not having the ability to parent.

In worst-case scenarios people's family relationships became so fractured that they lost all contact with their family and their assets such as their home. Correspondingly, when people reflected about their future role as a parent, some spoke about how this role was questioned and undermined because of self-stigma:

I won't even think about having kids now – I don't think I'd make a good parent. Before my illness I was really keen to be a father, but not now. I couldn't handle them.

Questioning entitlement to political and moral rights

In a broader context, forms of self-stigma were linked to people feeling less entitled to various rights than were those who did not experience mental illness. People explained that this negative belief about entitlement resulted in their feeling as though they had no political or moral rights. Examples included people feeling that they had no right to a relationship because they "may not cope", to employment or to maintain a family. One person expressed the dynamic in this way:

Self-stigma stops you reaching your dreams. Stops you having dreams. Dreams are what keep you going.

Other negative effects of self-stigma

Other comments about how self-stigma affects people included:

- constant negative internal dialogue
- missed opportunities
- increased use of alcohol and drugs
- an acknowledgement of the role trauma (experiences of abuse and violence) can play in compounding people's experiences of self-

stigma.

Positive effects of self-stigma

While common themes about how self-stigma affects people's lives included negative experiences related to social exclusion and isolation, self-doubt, negative family experiences, and questioning one's rights, people recounted some positive experiences. Positive experiences related to:

- becoming involved in peer services or groups and mental health advocacy
- sharing experiences with friends and family, hence strengthening understanding and relationships
- becoming more tolerant and accepting of others.

When people first experienced self-stigma

Using mental health services and being diagnosed

Most participants recalled that their first experience of self-stigma occurred when they began accessing mental health services and/or were given a diagnosis for the first time. This was important for people, because it signalled a new way of perceiving themselves and being perceived by others:

The first time I walked into the psych unit I thought, "What's happening to me. I'm going where the loonies go. I must be mad too".

Some had a poor understanding of what their diagnosis meant, while others expressed that the diagnosis gave them an understanding of their condition, in which case it was "good to have a label". However, the relief of a diagnosis or label soon turned to disbelief as the effect of people's varied reactions to their diagnosis set in:

A diagnosis made it feel official and I was terrified and frightened. I could feel myself gradually going down.

I first experienced the stigma when it was not private anymore, when I got [a] diagnosis and medication. I couldn't hide anymore.

Feeling different, being 'other'

People expressed that they felt "different" or not "normal" from a young age. Some perceived this difference from the beginning of primary school. One participant made sense of his feeling of difference by

exploring cultural dimensions and coming to a better understanding of his Māori cultural heritage:

The things I experience that have been diagnosed as 'psychosis' through to possible 'schizo-affective disorder' are things I have experienced as long as I can recall. Right from very early years. To me they are part of my whakapapa and constitute mate Māori [Māori sickness] as opposed to mate Pākehā/mate a hinengaro [non-Māori sickness/mental illness]. However, it was at a young age, I think about the time I started primary school and so was around many other children all day, that I realised I was 'different'.

Others spoke about "standing out" because of how they related to "normal people", or because they did not believe they functioned as "normal people". One person explained that what distinguished them from "normal people" was that they did not have "jobs, families, relationships", whereas people free from the experience of mental illness did. These perspectives indicated to them that they were unlike other members of the community:

In my 20s, I didn't feel confident committing to a relationship, something was wrong with me.

At age 11 - had to change schools - had a diagnosis - started to feel I could never make things work - it was 'me' - I was the problem.

The constant comparisons between themselves and others fuelled participants' beliefs about their difference:

Everywhere you go people make comparisons - you're not like your brother, or you should be doing this by now or having a job at your age - it makes it hard to compete.

Another participant explained that it was only when they saw an old friend in hospital that their self-stigma was triggered. The experience of seeing a friend in the acute ward contributed to them thinking "I am a nut case". In this instance, the feelings of difference that set them aside from general society arose through acknowledging their similarities - both had accessed mental health services.

Experiencing discrimination

The need for social acceptance was vital for people's sense of self-worth and community belonging. Consequently, experiencing discrimination or a fear of discrimination in the community were often the first

triggers for people's self-stigma.

I am confused because I want people to show [an]interest in me and at the same time I fear how I am going to be perceived, accepted or rejected.

Reaction of the community - they behave differently, can tell those who know or who don't.

People spoke about how, after their first episode, friends were no longer interested in maintaining friendships. Another person shared that at age 15 their employer used bullying and verbal intimidation towards them, which triggered their self-stigma. For migrants and refugees, arriving in New Zealand heightened their sense of self-stigma. Many had a sense that a mental health condition would be a shameful and negative thing in New Zealand:

I feel ashamed that I cannot fully participate in New Zealand society and show that I am useful and a good person.

I was, and am still, afraid that my depression will make this society fed up with me, as I need a lot of help and support.

Experiencing negative family experiences

Family were identified as having an important influence in people's first experience of self-stigma. It was also found that negative family experiences were stimulated by a lack of understanding and openness about family histories of mental health:

I first experienced it from my parents. My family experience of illness marginalised me, made me feel ugly.

One person shared that the loss of their partner and children triggered their sense of self-stigma. Another participant spoke about how his father treated him in the same way as his father treated his mother, who also had experience of mental illness. For some, family reactions (as a result of a sense of shame) often meant families attempted to control who knew and who did not know about their family's experiences of mental illness:

My parents would never tell a person about my mental illness, so I guess I internalise this as something that will bring shame to our family.

Although negative family-related experiences created the foundations for self-stigma for some people, refugee participants explained that it was when they

were separated from their families that their natural support system broke down:

I experienced stigma when I was separated from my family and when I had feeling of a lost future.

Without my family I feel weak, vulnerable and not complete.

Others spoke about how their diagnosis made them feel like they had let their families down. This perceived failure to meet family expectations heightened their thoughts of suicide.

Experiencing violence and other abuse

The relationship between family and partner violence and other abuse was also identified as influencing people's first experience of self-stigma. A group of people believed that their understanding and knowledge of self-stigma pre-dated their diagnosis. In particular, these participants believed that their self-stigma began because of other negative experiences such as abuse:

Self stigma can/does often pre-empt or be in place prior to the mental illness which further compounds the feelings, ie, due to childhood abuse/trauma.

I first experienced self-stigma when my partner used to beat me - and that was all I was good for I guess. You start losing your self-esteem and self-confidence.

Other experiences of self-stigma

Other contributing factors that one or two people noted in relation to their first experience of self-stigma included:

- beginning to feel overwhelmed and out of control, but not knowing why
- societal expectations
- general stigma associated with mental illness.



Where self-stigma comes from

Discrimination

When participants were asked where they thought self-stigma came from they explained that discrimination was the main source. The experience of being discriminated against contributed towards self-stigma. People said that self-stigma often came from ignorance, fear, and a lack of information and understanding. For some, there was a cultural component:

The culture elements play an important role in the perception of mental illness. However, this can be changed if the right information and support [are] given from the early stage when someone experiences mental illness.

People reported three types of discrimination (in its broadest sense): the treatment they received from mental health services; negative family experiences; and in employment.

Discrimination in the health system

For some participants, their institutional treatment “sowed the seeds of doubt”:

The mental health system is bad. The nurses are the worst. They hold you back – don't let you think about doing better things. Always tell you not to go for a job, or to think about something real hard before doing it in case you start it and can't finish. They sow the seeds of doubt.

People reflected that their source of self-stigma and subsequent self-discrimination often depended on how well informed their clinician or general practitioner was about their diagnosis. For example, people spoke about the power of being told they were “unwell” by their psychiatrist. For some, this experience made them “go inside” themselves, which resulted in a loss of hope for the future. Others spoke about how their clinician had little understanding and willingness to promote recovery plans. This added further to people’s experience of “oppression and alienation by the system of self and who we are”.

One person shared that when she was accessing treatment in a psychiatric unit nurses would ask “a real stupid question” like “how mental are we today?”. These forms of derogatory questions impeded people’s recovery and sense of self-worth and

contributed to self-stigma.

Another form of self-stigma related to how migrants were treated in their original country, which included being locked up, institutionalised, heavily medicated, and told they were not going to be cured:

Another one is how crazy people are being treated in your own country, being locked away, institutionalised and shunned away.

Some people believed that information included in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (American Psychiatric Association 1994) contributed to self-stigma. The point of diagnosis and how other people received it also significantly affected how participants understood their condition and its implications on their lives. People explained that the point of diagnosis was crucial because it was then that they felt most vulnerable to associated mental health stigma, and were at risk of internalising negative messages.

I guess you already have [a] certain wrong perception towards people who experience mental illness. ... All these negative terms and stereotypes were being internalised immediately after ... being diagnosed.

Discrimination by family

Family stigma about mental illness also contributed to people’s first experience of self-stigma. It was expressed that while families wanted to “make it better” participants often felt they were failures when recovery was slow or did not meet their family’s expectations. The understandings that families held in relation to mental illness were also important factors in influencing people’s understanding of their own condition.

Family put-downs and hierarchies all played roles in people’s understanding of where self-stigma comes from. For example, sibling rivalry, family comparisons, and judgements were all cited as contributing sources of self-stigma. How family and friends related to people with experience mental illness created the foundation on which beliefs about the self (negative or positive) were based.

Discrimination in employment

Employment-related sources of self-stigma included employers’ “lack of confidence” in the abilities of a person with experience of mental illness. Another person spoke about the issue of disclosure, and how

it was difficult to look for work because they did not feel comfortable disclosing their experience of mental illness:

Employment – difficulty in getting a job. I often don't feel comfortable disclosing my illness.

One participant associated her experiences of workplace bullying as reinforcing her internalised stigma. She described being ridiculed at work because of her experience of mental illness, referring to other staff members talking about her. She recalls her colleagues saying things like, “Here comes the dongie-psycho”. They also criticised the way she dressed, which made her believe her workmates and managers thought she was “funny”.

Public stereotypes

Participants spoke about the terminology used regarding mental illness. Some believed the term “illness” put people into a “helpless situation or mode”. Another participant said the Like Minds, Like Mine advertisements on television about mental illness were wrong, “I don't really relate to the word ‘illness’”. Another participant explained that she too did not relate to the word ‘illness’, so referred to her experience of mental illness as “waka wairua” [a spiritual journey], “ ‘cause I'm still on my waka [canoe] on this journey. I haven't fallen off the waka yet, even though some people say I have”. One kaumātua spoke about how “self-stigma is born of low self-esteem, and that’s emphasised by the way the public view tangata whaiora”.

For many, stereotypes about mental ill health were seen as a source of self-stigma. They connected to a lack of social and public understanding and reinforced mental illness myths. Participants based these comments on society, social systems, and the values they were taught from a young age about mental ill health. As one person said, “If there was no external stigma, self-stigma would not be there. It plants the seeds”.

Media

Many people blamed the media as contributors to self-stigma. People believed that the myths and stereotypes associated with mental illness were often the result of negative media coverage of mental health issues:

The movies and the newspaper are always going on about it. You're never portrayed as having a good thing.

Participants generally agreed that the media had little understanding of the complexity of mental illness and health. Therefore, the reporting of mental illness and health was often sensationalised, biased, and incorrect. Because of a lack of understanding, people expressed that these negative media stereotypes then become internalised:

If they [are] being treated negatively or being judged from others such as being told they are weak, crazy and dangerous ... they will internalise this as true.

Conforming and making comparisons, being ‘other’

One participant suggested that self-stigma comes from ‘conforming’ to other people’s stereotypes, stating that “conforming to all that stigma is bad. When you accept it and start conforming to it, it's bad. And you've got to stop it”. This participant added, “Plus everybody’s journey and remedies are different. I think psychiatrists think, ‘oh, you’re schizophrenic, so I’ll treat you this way’, but we’re all different”.

The complexity of mental health was a common finding amongst participants, as a result, conforming to or ‘fitting in’ with social and health norms was often seen as unrealistic and not inclusive.

Linked to conforming, people identified that comparison between oneself and others could also be a source of self-stigma. People explained that comparisons led to self-judgement and high expectations, “a desire to live up to expectation and not disappoint” as one person phrased it. Another person explained it this way:

It's taking on board what those around us show and say, about what society also does and says. Not just about ourselves but also just as importantly about others ... That's how we formulate our identity as human beings – by the comparison of the external, by seeing how this person compares to that person and how we ourselves compare to them. We define ourselves based on what we see others as, and also what others see themselves as. It's all a matter of 'normal' and 'the other'.

The perception of being “other” and the act of comparison deepened the self-stigma people experienced. People explained that this happened

primarily through negative self-talk such as self-put-downs, doubting one's capability, perspective, and intuition, self-blame, and not trusting other people's positive comments. Often these things led to insecurity, low self-esteem, disappointment, anger, and frustration.

Other sources of self-stigma

Other sources of self-stigma that individual participants highlighted included:

- experiences of sexual abuse and its contribution to people's mental health and stress
- God – a belief that a higher power created people's source of self-stigma
- childhood experiences
- the length of people's recovery
- discrimination from insurance companies
- not receiving access to decent housing
- negative experiences of government services, for example, from the Ministry of Social Development and the Child, Youth and Family Service.

What makes self-stigma worse

Discrimination

Discriminating attitudes and behaviour from other people were identified as making self-stigma worse. Discrimination was direct and indirect, and included judgemental behaviour by others and media coverage. For some participants, racism was particularly linked to making self-stigma worse:

It is difficult if you encounter racism and other forms of being disrespected. That makes internalised stigma worse and sometimes unbearable.

The connection between racist attitudes and the resulting inflation of self-stigma was especially true for people from refugee backgrounds. These participants spoke about the extra layer of stereotypes they faced because of the part of the world they came from:

If you are a refugee, if you are from countries that the rest of the world believes that terrorists come from, if you are alone without family or extended family, if you do not speak language then it is difficult to speak for yourself.

Indirect forms of discrimination commonly mentioned as making self-stigma worse included "hearing other people say horrible and discriminatory things about people who have the same issues or a similar situation to mine". These situations generated fear, anger, and confusion:

Because of self-stigma, you developed certain negative images about yourself, so when someone says something that might mean nothing ... you interpret in a way that match[es] your own self-stigma.

Others described indirect discrimination as a "lack of hope and faith within others towards you". People noted that this form of discrimination included support people being well meaning but overbearing and patronising, or demonstrating a lack of trust and confidence in people's ability, offering constant criticism and judgement, and reinforcing negative images:

If other people don't have faith/hope in you and simply accept that you are what you are where you are instead of encouraging you to be the very best you can be – then self-stigma will continue unabated.

We also look for those things that reinforce what we believe. If we believe we are bad then we will only look for the bad in what we do – as such we will (consciously or unconsciously) overlook the good we do as well, as it doesn't serve to feed our belief structure.

For some people, mental health services also made things worse. Because of existing self-stigma, one person mentioned that "if clinicians happen to make an insensitive remark to people like us, you can feel bad for the rest of the day because you begin to wonder if he sees us that way; what about the rest of the people?". Again, people explained that often psychiatrists were expected to cure all people with experience of mental illness. In reality, however, this was a false expectation and sometimes clinicians did not have "all the answers".

The media was cited as a medium that often misrepresented and promoted negative stereotypes of people with experience of mental illness. One person commented that the media did this by endorsing "'can't cope' messages and a focus on 'dependence' and 'support' as opposed to 'independence'".

People's attitudes and behaviour

Self-doubt and giving power to negative thoughts also made self-stigma worse for people. This was summarised by people talking about a loss of hope in their lives and relationships. Some talked of suicidal thoughts, which were often the effect of keeping negative thoughts to themselves and allowing these to build up.

When people personally subscribe or "buy into" the negative stigma associated with mental illness they found the internalised stigma became more oppressive in their lives. This resulted in people focusing on their faults, being defensive, constantly justifying their positions, and becoming "illogical". One person described how they caught themselves stereotyping a friend with mental illness:

I have a friend who also experiences mental illness. We were in the same class at [university]. On one Christmas, after a long night of partying she came over to my house drunk. She sat [on] the kitchen floor ... looking drunk, I remember I was feeling very nervous when I left a chopping knife sitting on the kitchen bench. I couldn't believe my own thoughts, because we both actually experience [the] same mental illness, yet I was having this stereotyped view about my friend.

Medication

Taking medication also contributed to increasing self-stigma for two reasons. The first was the side effects of drugs, which made it difficult for people to stay motivated and dulled people's senses. People spoke about how taking medication made them unaware of their living environments, "medication, blankets, what's really going on". The second reason related to being reminded about mental illness every time they took medication. One person called this "the stigma of use, especially when others know you're taking it".

Other contributions to worsening self-stigma

For refugees in particular, political crises and war in their home lands made the self-stigma worse. These events created a sense of hopelessness that significantly and negatively affected their recovery:

Ongoing war, political problems and bad news from country of origin makes it worse. It brings terror, fears, worries, shame, hopelessness and helplessness. That is when I lose hope that I or the world will be better.

Additional contributors to self-stigma that individuals emphasised included:

- unsupportive family
- people's ignorance or lack of knowledge about mental illness
- isolation
- failing to achieve something
- experiencing the symptoms of mental illness
- trying too hard to be "normal".

Dealing with self-stigma

Participants dealt with self-stigma in a variety of ways. They offered diverse insights into what helps them, while also identifying strategies for helping others.

Transforming self-dialogue from negative to positive

When asked what helps people manage and overcome self-stigma, the majority of people commented that noticing and transforming negative internal dialogue into affirming positive self-talk was very helpful. In this case it was important for people to be mindful of and celebrate the small achievements in their daily lives. This included noticing the negative thoughts, then changing them.

Value the things you do well, even if it's 'only' having a shower, or getting the mail. It's significant to you, so it matters.

Recognise its happening; don't buy into other people's reactions – you have the power of choice!

People also spoke about recognising that stigma results from a judgement not fact, this helped them keep perspective on the negative self-talk and shift to a more positive state of mind. A conscious acknowledgement and reflection of one's strengths and talents helped combat people's negative thinking.

Look after yourself, be groomed. Try not to focus on bad things. Avoid thinking that everyone is arrogant and doesn't show interest. Some people are great, remember that when feeling down.

Using affirmations

Some people talked about using affirmations to change patterns of negative thought and self-discrimination. For many, affirmations helped them

reframe things in a positive light:

Affirmations. Those sayings such as “I am a good person” etc. They can work wonders if you work with them. The benefit of things like affirmations is that they are effective self-programming. The reason we tend to believe what we believe is that it’s been constantly reinforced and repeated to us over and over again – and so those messages sink in and seed themselves within our internal belief structure, which once again is on a subconscious level. Affirmations have the reverse effect – they are still based on repetitive messages with the aim of seeding those messages within our subconscious – however, the messages this time are (or should be) of a positive nature.

People offered various examples of affirmations they had used in their lives that helped them manage self-stigma effectively. Affirmations were based on people believing they were loved for who they were (that is, being one’s own best friend), reading about recovery and people’s recovery stories, and being with others who were positive and offered inspiration. Changing the pattern from negative self-thought into a realistic appraisal, was key in the use of affirmations:

Basically it’s about creating a pattern – and one that is sustainable. Initially people may find it helpful to write the affirmation – or even just the word ‘affirmation’ on a Post-it and place it beside their bed or on the mirror or on the fridge to remind them to say their affirmations to themselves.

Being self-accepting and disclosing experiences

Several participants explained that for them to challenge their negative dialogue of self-stigma it was necessary to accept themselves and their experience of illness. Some spoke about valuing their experience as a “survivor” of mental ill health, for them this offered a unique understanding of themselves and the world. In some instances, people expressed that their experience of mental ill health did not result in self-stigma. This form of self-acceptance opened up doors for seeking support when needed, and helped people integrate their experience into different parts of their lives:

I think that one of the important things is to say you’re a survivor. If you can face the trauma it gives you well-being to feel what you’ve got is unique to you.

[I] remind myself that there are people who do care about me or others in a similar situation. I remind myself that others can learn from me about coping skills. I will go and ask for help from services that care.

Right now I am studying [a] psychology degree at [university], this has helped me to reflect on my own personal experience of mental illness when I am writing some of the essay[s]. The response has been very positive from my tutor, and they also encourage me to carry on my reflection when it is relevant to the topics.

The act of verbalising their experience with others, “seeing my words spoken” as one person put it, helped people stay positive through sharing their experience. It enabled those affected to be honest about themselves while asking questions about their experience. Such practices helped people to disclose their experience to others in ways that did not make them feel vulnerable.

I believe I am a better person – not so self-centred, more patient, more empathetic, [more caring] about others.

Having peer support

The role of peer support groups and working with people who have had similar experiences was vital in challenging self-stigma. People spoke at length about the strengths of peer support groups as important in paving the pathway to recovery. Supportive collectives such as peer and advocacy groups offered people a space to connect and reflect, be positive role models, and recover with others:

Meet others with experience of mental illness, you can support and inspire each other.

It’s about mana [integrity] – enhancing that person ... Mana enhancing a person or self-preservation and maintaining one’s self in the positive things.

The support from people who share a culture, an identity, or other experiences is also important:

Feeling a sense of belonging within Māori health consumers like this group, gives me compassion for my peers, listening to their stories and them listening to me.

For me is it to know that I can still do things that I enjoy and am good at, helping others and sharing my

experience has enabled me to believe [in] myself.

Often the act of helping others gave people an opportunity to reclaim their sense of self-worth. This in turn increased self-confidence and people’s sense of control and power over their lives. Peer groups helped people to see themselves as ‘normal’; they offered a means of participation, interaction, and learning. It was in groups of peers that people began to develop strategies and tools of self-care and preservation, which they used for themselves and shared with other members of the group:

I’m involved in a Bo Ai She, a Chinese consumer self-help group. I’m able to be part of the group to share my own experience ... Learning to help other people who have gone through the same things has been a blessing in my life.

Able to be part of the group to share my own experience of mental illness was extremely helpful, especially when you are surround[ed] by a group of people who understand how you feel and without being judged.

Developing strategies for well-being

Creating and maintaining tools for well-being were seen as essential parts to people’s recovery. They helped people “learn what to do when ... unwell”, while also giving people a way to enhance their moods:

Every time I started feeling upset or self-doubt I would go back to see my wellness tool-box to find things that I enjoyed to lift my mood.

Several participants also mentioned the Wellness Recovery Action Plan (WRAP) as another helpful and practical tool for people dealing with self-stigma and recovery generally. Another participant spoke about developing a unique “self-stigma action plan”, which would help people regain control over their well-being:

Action plans. We are – at least at some level – consciously aware of our own self-stigma and how it makes us feel/act. As such we can become more aware of when we are feeling those limitations of ourselves, when we are engaging in negative self-talk and the like – so we can also, therefore, create some form of action plan around those times. It can be beneficial to construct a self-stigma action plan with various activities that we enjoy, which we can do whenever we identify we are engaged in self-stigma. They could be something like “Go ... for a walk”, or

“Say my affirmations”, or “Give someone I trust a call”. The benefit of these – and following these – is that it allows us to take some assertive control upon how we are processing both the external inputs and our own internal thought processes.

Developing strength through identity and action

The supportive culture created by peer and advocacy groups also differed, depending on the type of group, its members, and their beliefs about practical recovery. For example, people’s culture and identity were important to them and their recovery. In the case of Māori/tangata whāiora, they explained that re-affirming themselves culturally, by learning waiata [songs] and te reo me ōna tikanga [Māori language and culture] for example, had a hugely positive effect on their sense of well-being and belonging:

What I found healing was listening to waiata, listening to my language ... Gave me a bit of grounding. Gaining that identity, I felt much stronger.

I find that wairua health helps me – [as does] knowledge of whakapapa.

Some people acknowledged that at times family and whānau experiences of mental illness took a toll on the wider family and drained people’s resources. Therefore, it was important to build strong and supportive families and whānau, as they are crucial to developing people’s resiliency and sense of belonging and identity.

Positive actions that use a person’s strengths helped to combine positive (affirming) thoughts with concrete actions or hobbies. This combination of positive thoughts followed with practical action (or vice versa), helped shift people’s attention from negative behaviour and thinking into a positive frame. Such actions were deliberate and in some cases small to begin with, but ultimately created a sense of worth and fulfilment:

I believe everybody is good at something that is unique to you ... and when you feel good at that thing that you do, when it shows, it will benefit.

You need someone to give you a chance, a break to achieve a small goal so you can go on to achieve bigger and better ones.

Other approaches to dealing with self-stigma

Other strategies for dealing with self-stigma that one or two people drew attention to included:

- having an understanding general practitioner and a supportive network of family, friends, and peers
- taking medication
- exploring alternative and complementary therapies
- seeking and receiving spiritual support
- having a sense of humour
- exercising regularly and eating well
- finding employment
- being self-reflective (for example, keeping a diary and “an eye on the big picture”).

Facilitators’ reflections

The facilitators of the focus groups wrote this section. It illustrates the differences and similarities between the groups that participated in this research. We asked the facilitators to write their own reflections on the issue of self-stigma, because while many common themes emerged, there were also cultural and background differences between the groups. For the purpose of future research and work related to self-stigma, it is important to record these group differences as part of the findings of this research. These unique reflections illustrate the different and similar issues that a variety of people face when dealing with self-stigma and discrimination.



Chinese focus group: Facilitator Ivan Yeo (Mental Health Foundation of New Zealand)

The discussion with the Chinese focus group began with understanding the meaning of terms like self-stigma, self-discrimination, stigma, and discrimination. The aim of the discussion was to reach a group consensus on the meanings of these key terms from a Chinese cultural and linguistic perspective.

Each participant then briefly introduced themselves, explaining where they came from (that is, Hong Kong, China, Chinese-Malaysian), their name, and anything they wanted to share with the group. This was followed by a discussion on the meaning and language of self-stigma in Chinese. Smaller groups then formed to discuss the research questions and provide feedback to the group as a whole.

The participants would have liked to have spent more time discussing self-stigma and discrimination, as they are things they know and experience, and yet have never been encouraged to talk about openly or amongst their peers. Chinese people are inclined to raise their voices when a topic is close to their hearts or they are passionate about it. Unfortunately, the space in which the focus group met limited their self-expression, because participants needed to be aware of the volume of their discussion, because of its potential effect on others in nearby office spaces. This proved difficult for me as a facilitator, because it is considered inappropriate to constantly remind someone to lower their voice.

The participants wrote their responses to each question on large sheets of paper in the Chinese language. I then translated these responses when I wrote up the notes for the report. During the facilitation, I used the whiteboard to collate the definition of self-stigma. I also wrote notes during our discussion. Translation is challenging, as I needed to constantly relate responses back to the context within which the participants spoke.

Although we had diverse backgrounds – different countries of origin, ages, levels of formal education, and social and political backgrounds – we all shared a common view on self-stigma. The group believed that it originated as a result of society and the media’s influence. Many expressed that when they were young they were greatly influenced by what they saw and heard through the media and other people’s

negative descriptions of people with experience of mental illness. As a result, the negative messages were internalised after diagnosis. Chinese people, especially migrants, who experience mental illness, also experience self-stigma to some degree in terms of their skin colour and English language abilities.

As a Chinese person who has experience of mental illness, I am also interested in finding out how Western notions of self-stigma relate to Chinese culture and Chinese experiences in New Zealand. I believe it is important that we discuss this issue in more depth. From my experience and through the experiences shared within the group I facilitated, I believe the process of internalisation is a vicious cycle and has many different layers.

Several issues arose for our focus group. On reflection, ideally, it would have been beneficial to have two people facilitating: one recording the discussion, another facilitating the workshop. It was difficult conducting the workshop in a language that no one from my own organisation could speak.

The participants from the Chinese communities were hard to find. This was due to issues of trust. The focus group would not have been possible if the existing Chinese Like Minds, Like Mine network had not been established and I had not formed personal relationships with its members. I believe a Chinese person with experience of mental illness would not be open to addressing such important and personal issues in front of a stranger. However, through the establishment of trusting relationships between me and the participants, the focus group was possible.

Pasifika focus group: Facilitators Mailigi Hetutu and Sokopeti Sina (Vakaola Pacific Community Health)

To begin the session, people were welcomed into the group and an opening prayer was given. People were asked to introduce themselves in a way that felt most comfortable for them. After the opening prayer and group introductions, the topic of self-stigma was introduced. This was followed by a discussion about the purpose of the focus group and the research project.

There was a lot of initial discussion about the definition of self-stigma. Some participants understood its meanings, but a few did not. People explained that they found it hard to relate to the English definition as their first languages were

Niuean, Tongan, Samoan, or Tokelauan. Once people found ways of relating to the English meaning of self-stigma, we addressed the six questions in order. We closed the focus group with a prayer and thanked everyone for their contributions.

We recorded the group using whiteboards and big blocks of paper. This was so everyone could see what was being written and recorded. To keep the discussion focused, we wrote up the definitions of self-stigma, so people could see them clearly and keep coming back them.

Because self-stigma was so personally sensitive, we did not force people to speak. We allowed people to speak at their own pace and in their own time. This meant everybody was given a chance to speak, and we encouraged people to listen and not talk over one another.

For the Pasifika people involved, family roles were a big issue. Most people spoke about how they developed self-stigma from believing they were worthless. These messages were given to them by other family members – mothers, fathers, uncles, aunties, brothers, and sisters. Family also controlled people’s money and finances, which were often used to control people.

Another issue was the care of children. At times, concerned family members tried to take control of people’s children, which undermined their abilities and belief in themselves.

Those involved in the church explained how they were often not allowed to participate, which increased their sense of worthlessness and self-stigma. People spoke about how they became suicidal because they did not believe they were good enough. Again, these messages were learnt through family, friends, the church, and, at times, included family violence.

Being on medication was a big issue for people. It changed people’s behaviour – some of it good (mood stabilisation), some of it bad (weight gain, feeling spaced out). People explained that medication contributed to their different behaviour, and therefore their beliefs about themselves.

Since facilitating the group, people have told us that the focus group allowed them to speak up, feel valued, participate, and find strength. Some still expressed thoughts of suicide, however, which we have been

careful to follow up on.

This research provided a tool for connection, strength, and value for people. By participating in the focus group, people felt more self-confident. They were able to express their inner sadness and anger in a safe way. It has inspired people to write stories and journals about their experiences of mental ill health. Through our involvement, we were able to gain insights into the whole well-being of a person. Those who participated were also able to foster insights into their own experiences, and how these were similar to those of others.

However, it is important to note that language differences were a barrier. It would have been easier if each Pasifika group held their own focus group in their own language, as opposed to English. There is a need to continue doing research for Pasifika people in this area, using their own languages and cultures as a foundation. This would allow people to feel more comfortable, while also developing more key messages for Pasifika people.

Further research is needed to look into how Pasifika families relate to family members with experience of mental illness.

Young people's focus group: Facilitators Bernie DeLord (Mental Health Foundation of New Zealand) and Jessica Senior (Wellink Trust)

The group started with a welcome, introductions, and we stated the purpose of the session.

We talked through all the forms regarding confidentiality, and answered questions group members had about confidentiality and what happened to the information afterwards. Once this was established, people signed their forms. We then looked at the definitions of self-stigma for the session and talked through what they meant to people. The definitions were written up on a board so everyone could see and refer to them. All the questions were written on a piece of flip-chart paper.

It soon became evident the amount of experience that people were willing and wanting to share around self-stigma, so instead of going through the questions in order, we facilitated a discussion around the questions. There was a huge amount of enthusiasm for the topic, with people giving several examples of how self-stigma has affected them. With their permission, we wrote down the key points and reflected them

back to check we had recorded them accurately.

The discussion continued for about one hour, then we invited people to write something on the individual flip-chart sheets relating to each question. This worked well, with participants able to record key comments that they then added to as the session progressed.

Despite the heaviness and intensity of the content, the aspects that shone through were people's resilience and sense of humour and their willingness to carry on in their lives challenging stigma. For all, stigma and discrimination from family and friends were hurtful and undermining. People explained that it was very common among young people to feel self-stigma in the form of guilt or shame related to family. This was despite the fact that not all feelings seemed to be realistic, for example, not all families are ashamed of a person's mental health experience. In addition, some people explained that they were ashamed of the effect that their experience of mental illness had on their family, but that other people should not feel this way.

The group discussed how stigma restrained them. Examples included not being able to say they were having a bad day or feeling fed up, pretending they were feeling okay when they were not, feeling scrutinised, and having any behaviour changes seen as negative. It also affected how they felt about key issues such as having children and settling down with someone, or trusting enough in friends to tell them what exactly was happening.

Participants explained that, as young people, being labelled by professionals (with diagnoses) and by non-clinical people (family, friends, and peers) can be extremely unpleasant and often seemed to do more harm than good. Arising out of the group, it became clear that particular words have an enormous impact on young people, and on the way they view themselves. It is hard not to self-stigmatise when words used to describe you include "urgent", "severe", and "chronic".

Hope was a key factor – it was important to have people in their lives who gave them hope and believed in them, and were hopeful and encouraging. Not all people in the group had this, but they said that was what would be helpful.

Another main point for most was that while they

had contact with services, few had specific talking therapies or an opportunity to discuss coping strategies and ways of moving forward in their lives. Therefore, they were dealing with having mental health issues as well as dealing with the stigma and feelings of isolation. This was in addition to having few resources or little knowledge about recovery models. Considering this, all of the individuals displayed a strong sense of resilience and an ability to keep moving forward.

Other key issues were the responsibility of the media and society's influence and the messages that had been internalised by them. These were made worse by racial prejudice.

A few people said the session had made them think about themselves. Some said they believed they felt so bad due to having a mental illness but that after the session they realised that it was not the illness that made them doubt themselves – it was the stigma and discrimination from others and the self-stigma they felt towards themselves. Some said they had little belief in themselves and now realised how stigma, discrimination, and self-stigma had directly affected them and held them back from realising their potential.

This group highlighted the gaps in recovery models being taught and the lack of talking therapies accessible to young people. Participants indicated that discussing the topic of self-stigma was a very important aspect of helping them to understand why they felt the way they did about themselves. Once this understanding occurred, self-stigma could be addressed and barriers removed.

We were interested in taking part in this session as we have worked extensively with young people within a mental health context. It was a privilege to be offered the opportunity to work with a group of amazing individuals.

The only thing we would have changed would have been to involve a larger range of people, for example, older people and people with gay, lesbian, bisexual, transgender and inter-sex experiences. Other suggestions from members of the group included focusing more on mental health anti-discrimination work within schools, families, and the media. People also pointed out that this research reinforces the importance of changing the language used in relation

to people's mental health experience.

Refugee focus group: Facilitator Ranka Margetic-Sosa (Refugees as Survivors, Wellington)

I was suggested as a facilitator for this group by ChangeMakers Refugee Forum, a Wellington-based pan-refugee community advocacy organisation. My experience at Refugees as Survivors, a mental health service for refugees and migrants, has allowed me to know the refugee community in Wellington and offer insights about their mental health issues and how these affect individuals and communities.

Lots of ground work was done before we convened the group. This included informing all potential participants about what the Mental Health Foundation is, and the type of work its staff do. The purpose of the research also had to be explained in detail before people consented to participate. This was important, as it gave people an opportunity to ask questions and make comments. Seeing previous Mental Health Foundation research (for example, Respect Costs Nothing (Peterson et al 2004)) was also an important part of the process, as it gave participants a feel for the type of research being done.

Initially the definitions of self-stigma were explained one on one, then collectively when the group met. People were invited to share their own understandings of self-stigma during these discussions. This helped create a common knowledge about the topic. It was vital that potential participants made an informed decision about their participation.

As a facilitator, I also had to devote time to the project, to understand the concepts and become familiar with the research focus. Having the project management team available to discuss these issues with me helped a lot.

Other preparations for the group included contacting professional interpreting agencies in the area and ensuring their involvement. Two trained interpreters were used, using Somali and Arabic languages. They played an important role in explaining the participation information sheets, consent forms, and gift vouchers. They helped prepare the group generally for the session. The act of formalising people's participation via the consent forms and the vouchers helped to cement people's motivation and participation in the group.

From the beginning of the process, it was crucial that people were treated with respect, and that they understood they were being invited to participate. It was important that we avoided pressuring people by using words like “should” or “ought” throughout the process. It was vital that people felt some ownership for the process, which was done by creating a climate of invitation, encouragement, respect, and comfort for all involved. This was especially important because of the very personal aspects of the research.

Ground rules were explained at the beginning of the group, and opportunities were given for people to add to the rules or suggest changes. Issues of confidentiality and a general outline of the session were then discussed. As a member of a refugee mental health service, I explained that support could be offered to people if they felt they needed it after the focus group. I also explained that project managers of the research were happy to speak to people about the research, its process, and any issues people might have.

The written material (such as consent forms and information sheets) did not help the refugee participants because they are still learning how to read and write in the English language. They needed time to comprehend what was being asked of them. Therefore, the group was not recorded on a whiteboard or large pieces of paper. I recorded the participants following the basis of oral tradition, using a small note book to make notes without identifying people. Before moving on to each question I read back people’s responses to the group via an interpreter. This was to ensure I had recorded people’s comments correctly. This also meant trusting people’s words and lived experiences by sitting, listening, talking, asking questions, offering answers, placing challenges, welcoming agreements and disagreements. People were very patient with each other.

To begin with people were cautious, but their enthusiasm increased as they saw and heard similarities between themselves and others. I encouraged people to share their diverse perspectives because I did not want people to just ‘fit in’ with others or the existing definitions. Sometimes participants showed their agreement or otherwise through body language rather than spoken words. The process provided different ways of being open with one another.

Age and gender differences within the group had to be dealt with sensitively. It was important to acknowledge people’s integrity and standing in their respective communities. Having both genders represented meant I had to be mindful of gender differences across cultures and belief systems. This was a unique aspect of the group.

We changed the order of the last two questions, so that people focused on the positive ways they managed and overcame self-stigma after discussing what made self-stigma worse.

For people with refugee backgrounds self-stigma is amplified by the complex process of resettlement in New Zealand. People face challenges of integration, while also lacking traditional supports. People deal with a constant “feed-in effect” from the wider world. Depending on where people are originally from, they often feel as though they are of less value than other New Zealanders, perhaps because they come from a country that may be in the middle of an ongoing war or conflict. Being from a place that ‘terrorists come from’ makes it difficult to challenge self-stigma, because the negative messages are constant within the media. This is compounded by the discrimination and prejudice refugees experience in New Zealand communities.

Since holding the focus group, two participants have approached me about the project. The first person explained to me that the group had a really positive impact on their life and mental health condition. This participant said they often reminded themselves of the advice given by the group about how to overcome self-stigma. The suggestions provided them with strategies to help themselves. This person also spoke about how before the group they did not feel as though they had the right to offer suggestions to others. However, the focus group provided a new way of gaining confidence in themselves.

The second person expressed anxiety about the representation of the group. They explained that they did not have the “right” to represent others from refugee backgrounds. This participant asked whether their experience of self-stigma was good enough to represent other refugees’ experiences.

To my knowledge this is the first time that refugees have been invited to participate in research into self-stigma. I would like to see further research

and work done around how to build and integrate more traditional supports – family, friends, spiritual support, traditional medicines – into general services.

Tangata whaiora/Māori focus groups: Facilitator Lynne Pere (Health Services Research Centre, Victoria University of Wellington)

Two focus groups were facilitated with tangata whaiora: the first in Porirua and the second in Turanganui-a-Kiwa/Gisborne. Both involved established tangata whaiora networks meaning that, in general, participants in each group knew each other, which meant they already had group rapport.

Each group began with karakia, offered by the kaumātua of the group. Then, in keeping with tikanga Māori, mihi whakatau followed. This gave all participants the opportunity to identify themselves through both whakapapa and mental health experience.

As part of this process, I introduced myself or was formally welcomed by the kaumātua. I explained that I would be a co-facilitator alongside one of the group’s team members, and gave a brief explanation of the day’s kaupapa (programme/outline). I then explained the background to the research, including that it was being undertaken by the Mental Health Foundation’s Wellington office on behalf of the national Like Minds, Like Mine programme. I explained who the members of the foundation were and that their role was to promote mental health, and provided background to the Like Minds programme. I then explained how the self-stigma research had come about, through the 2004 *Respect Costs Nothing* research (Peterson et al 2004), and displayed the two definitions of self-stigma provided. These were written on large sheets of paper and hung on the wall for easy reference.

The first focus group followed a planned and agreed format that began with the group setting ground rules for the day. These ground rules were made clearly visible as a reminder of the need to respect each other’s contributions.

Participants were given time to reread the information sheets and questions and had the opportunity to ask any questions. Once satisfied that everyone was well informed, participants were asked to sign consent forms to participate. They were advised that the discussion of the day might raise issues for them that they might want to talk to

someone about afterwards, and were provided with options for follow-up if needed. Participants were informed of a koha (gift) they would receive at the group’s conclusion.

An uninitiated, lively discussion began about the definition of self-stigma. As people began to share aspects of their experiences, I felt we were in danger of going off track. However, we managed this and the participants began to answer the research questions.

My co-facilitator led most of the remainder of the first focus group while I took notes. I prompted participants and sought clarification only when necessary, whilst my co-facilitator systematically led the group through each question. The last two research questions were asked in a different order to ensure the focus group ended on a positive note. Participants added written comments, phrases, and words they felt were relevant as they came to mind. These contributions were collected at the end of the focus group as contributing data alongside my notes.

The discussion generated throughout this focus group was enthusiastic, often emotional, and honest. Despite planning to run the focus group for two hours, it ran for four. Participants were reluctant to stop for kai [food] when it arrived, so it was agreed that following a brief break, the kai would be put on the table we were seated around, blessed, and shared as we continued with the discussion.

Because the focus group ran over time, one participant had to leave before the group formally ended. This participant asked if they could email the rest of their thoughts to me. I agreed and the participant did so the following week.

The progression of the second focus group was very different than the first. It began with a discussion about the concept of self-stigma. This led to discussion about whether self-stigma in fact existed. My co-facilitator suggested the implication of the research, which asked people with experience of mental illness about their experience of internalised stigma, was that the two went hand in hand – if you experienced mental illness, you experienced self-stigma. He vigorously disputed this, and suggested that some people did not experience self-stigma.

Based on this perspective, my co-facilitator and others deemed the research questions inappropriate, because, as they stood, they all implied that

participants would have experienced self-stigma. He challenged other factors associated with the research process, including whether participants should remain anonymous in their contribution, and the cultural appropriateness of the Mental Health Foundation's written material that was provided to him as a co-facilitator. For example, several participants indicated that they did not want their participation to be anonymous, insisting instead that they be named if quoted or referred to in any reports. With regards to tikanga Māori, the setting of ground rules at the beginning of any discussion is implicit through the pōwhiri [welcome] and mihimihi processes, which are governed by concepts of tapu [sacredness] and noa [familiarity], rather than stated rules. The information also did not mention karakia, mihi whakatau, or any other processes Māori expect in a gathering of this sort. Additionally, the terminology used in the second of the definitions of internalised stigma (for example, 'negative stereotypes') was not understood by all participants.

It was suggested that no notes be written, but rather the kōrero [discussion] from the focus group be listened to. However, I requested and was granted permission from the participants to take notes during the focus group discussion. I explained my inability to retain information without written notes.

Despite these criticisms, the participants decided that the focus group would proceed. Consent was gained through participation in mihi whakatau, and through processes associated with tapu and noa. My co-facilitator asked each participant their thoughts on self-stigma and whether they felt they had experienced it. The Mental Health Foundation's definitions were put up in front of the group for participants to read, and the terminology 'negative stereotypes' was discussed and explained.

Following a refreshing, sometimes challenging, but always inclusive discussion, the focus group ended with gratitude being expressed both by and to the participants and the facilitators for their respective input. The group was closed by the kaumātua with karakia. Kai followed.

As a facilitator, I enjoyed the opportunity to listen again to the experiences of tangata whaiora. What was driven home for me through this research, however, were the raw learnings from the Turanganui-a-Kiwa/Gisborne group. I was remiss in my initial

involvement with this research in not checking the suitability of the information sheet for Māori. This is not my usual practise, and I do not know how this occurred, but I was made aware of my mistake by my co-facilitator's challenge. His reasoning for not formally setting ground rules in the same manner as the Porirua focus group, and for not requesting written consent to participate from focus group members, also brought home for me the importance of adhering to local tikanga, and of its absolute place within Māori research. This learning curve was steep but, I suspect, lifelong.

General focus groups: Facilitator Sonja Goldsack (mental health consultant)

I facilitated four focus groups in Auckland, Napier, Christchurch, and Wellington. For each group I used a different process, as the participants in each centre differed. Some of the significant differences between each group included gender (one group consisted of only men, while the others were mixed), and different socio-economic elements between groups (some people were in employment, while others were not). In another instance, all of the participants were working in mental health services or in mental health generally at the time the group met. Combined, all of these elements and experiences appeared to impact on the ideas and themes that emerged through the group discussions.

I recorded each group's discussion on large pieces of paper or an electronic whiteboard if this was available. I paraphrased the points people made or used direct quotations and then put them under the relevant question. When themes emerged, I often kept the discussion on that theme for a while, exploring it within the group. Examples of central themes included the impact on and influences of family, relationships, and employment. In terms of accuracy, it was important that everyone could see and understand the notes I was making. I asked probing questions such as "Can you explain that a bit more?" to help generate more information about a certain theme or issue. Apart from some people wanting to learn more about self-stigma, there was little feedback from participants after the groups had been completed.

Each group of participants held different understandings and awareness of what self-stigma was and how it affected them. For example, the majority of one group had a high level of

understanding regarding the external stigma and discrimination they faced from friends, within intimate relationships, from family, and in employment. However, this group had not given much thought to how this affected their own sense of self. In this instance, while they were caught-up in daily external stigma, they showed very few signs of how recovery processes could help them personally combat this situation or how to look inside themselves for solutions.

Conversely, other participants appeared to have moved beyond explaining how discrimination was a barrier for them, and were focused on the concept of internalised stigma, where it came from, and how to overcome it through positive self-talk and affirmation. These participants spoke about how they could internalise stigma, but equally, how they could also externalise the experience and find strategies to overcome it. On reflection I believe the different perspectives people held about self-stigma and public stigma often depended on a variety of factors, such as people's local community and support networks, levels of employment in those communities, and people's peers.

Many of the participants talked about their families. This theme usually included how their experience of mental illness had changed their family relationships, or how this experience had impacted on their roles as a parent. Both elements were generally perceived negatively, and ranged from negative messages from family ("You're not able to cope"), to people self-blaming because of their experience of mental illness ("I'm not able to be a parent").

Another theme that arose included whether or not people self-stigmatise before a diagnosis. For example, some people's experience of childhood trauma and/or abuse appeared to have greatly influenced their negative self-perceptions. This situation often generated a sense of self-stigma early on in life. This was usually compounded further after they were first diagnosed.

On reflection, I would be interested in exploring how the recovery process may or may not affect people's understanding and awareness of self-stigma. Are people who are recovery focused better able to understand self-stigma than those who are not as recovery focused (or vice versa)? I would also be interested in understanding how people's experience of abuse affects their self-stigma.

4

Making meaning of things



Introduction

This discussion is in four sections. The first looks at different aspects of self-stigma and the implications of the findings of the research. The second section looks at existing models of self-stigma, while the third section presents a new model of stigma and discrimination that directly evolves from this research. The fourth section seeks to answer some of the questions raised in the literature, both from the findings of the research and the new model that has been created.

Aspects of self-stigma

Diagnosis

For many people in this study, being told their diagnosis for the first time was also the first time they felt self-stigma. This finding was also reflected in the literature. They internalised the beliefs and myths surrounding mental illness that they had grown up experiencing, realising that all of these now applied to them. The time of diagnosis seems to be an especially vulnerable time for self-stigma. Mental health staff need to be sensitive to this, as it is their handling of the situation that may make all the difference for someone being diagnosed for the first time.

Diagnosis can be positive and does not necessarily, of itself, cause self-stigma. Some people talked about the relief of finally having a label that described what was happening to them. This was short-lived, however, when they experienced the reactions of other people to that label, thus leaving them vulnerable to internalising negative attitudes and developing self-stigma.

Mental health services

Many people described the attitudes and behaviour from the mental health services they accessed as contributing to self-stigma. Insensitive comments, the doubting of people's abilities, and an unwillingness to use recovery-focused plans and techniques were some of the attitudes and behaviours reported. Some people mentioned that mental health services' attitudes towards them were discriminatory, given the comments made about them and the treatment they received. It seems obvious that if the mental health services that people rely on for treatment do not reinforce that mental illness is something that can

be recovered from, then the person themselves will believe this, which contributes to self-stigma.

Some participants criticised the entire medical model of mental illness (diagnosis and treatment systems), especially the use of DSM-IV, as contributing to self-stigma. This may be because it is seen as not being recovery focused and is interested only in symptoms, not in wellness.

For those who had first received poor treatment for mental illness in their country of origin, these experiences had left them wary of New Zealand mental health services, as well as contributing to their feelings of self-stigma.

Another issue mentioned by some participants as contributing to self-stigma was a perceived hierarchy of experience of mental illness among consumers working in the mental health area. In other words, some experiences of mental illness were deemed to be 'worse' than other experiences. Some people believe that the worse the experience of mental illness the more value the person was perceived to be able to add to a peer support group. Those whose experience was perceived as less valuable, experienced an increase in self-stigma. Is the experience of depression any less important or life affecting than the experience of schizophrenia? Or is it just different?

Medication

The literature mentions that self-stigma is associated with a reluctance to adhere to treatment. Two aspects of taking medication were identified as contributing to self-stigma by the focus group participants. The first was that the very act of having to take medication every day was a constant reminder of a person's mental illness – this reminder added to the self-stigma that people experienced. The second was having to deal with the side effects of medication. Psychiatric medications may have side effects that are noticeable to other people such as sleepiness, weight gain, sexual dysfunction, a dry mouth, sensitivity to sunlight, and muscle contractions. These act as visible reminders about mental illness, making people feel different from people who do not have to take medication.

Utilising a holistic approach to recovery, whereby medication is balanced alongside eating and exercising regularly, keeping to routines, and

connecting with others, is one way that the negative aspects of medication can be diminished. Reinforcing that medication is just one part of a person's mental, emotional, and physical well-being is important and was recognised as such by the participants in this study.

Feelings of difference and social exclusion

Some people said that their feelings of self-stigma occurred before they were diagnosed as having a mental illness. They reported feeling “different” from an early age, and that the roots of self-stigma for them were these feelings of not being “normal”. That self-stigma can pre-date any recognised mental illness is an interesting finding that does not seem to be mentioned in the literature.

People reported that feelings of difference persisted after experiencing mental illness and contributed to self-stigma. People compared themselves with others without experience of mental illness and realised that they were not “normal” because they were not in employment, not in a relationship, or not experiencing other things that people without mental illness experienced. The reality is, however, that people with experience of mental illness are capable of working, being in relationships, and participating fully in society. We should recognise this and encourage people with experience of mental illness to recognise this in themselves.

Another aspect of self-stigma that stops people with experience of mental illness from participating in society is a fear of failure. Some people believe they should not work because they fear they will not be able to do the job properly. Some people fear relationships because they fear rejection. Encouraging people to face their fears through self-care, role modelling, and advocacy may be another way to combat self-stigma.

Fear of failure is different to another concept that is commonly linked to self-stigma in the literature – a fear of discrimination. A fear of discrimination may exist without self-stigma. Just because a person does not do something through fear of discrimination does not mean that they are experiencing self-stigma. The fear of others' behaviours and attitudes may be justified. Respect Costs Nothing (Peterson et al 2004) illustrates this, with large numbers of people with experience of mental illness experiencing

discrimination. In some cases, however, this fear of discrimination may not be justified. Someone with experience of mental illness may not know this, however, until after they have disclosed, and then not experienced the discrimination they were expecting.

One result of self-stigma is that people with experience of mental illness often work harder to try and show others that they are just as capable (or even more capable) as those without mental illness. This can result in excessive expectations for themselves, and may lead to emotional and physical burn out. It also means that if a person does not meet their high expectations, they may feel as if they have failed, which contributes to self-stigma. This self-judgement may be harsher than any judgement from others.

Unlike in the literature, only one person in the focus groups identified low self-esteem as a component of stigma. The literature mentions low self-esteem specifically, and almost equates self-stigma to low self-esteem. Can self-stigma exist without low self-esteem? In our model discussed later in this chapter we show how the two can relate to each other.

Discrimination

Society's beliefs and myths about mental illness can lead to discrimination against people with experience of mental illness. Just as in the literature, most of the focus group participants identified discrimination as a major trigger and component of self-stigma. This included discrimination from all sources, including mental health services and friends and family. As one group of participants said, self-stigma comes from ignorance, fear, and a lack of information and understanding – all aspects of discrimination.

Another form of discrimination included support people being overbearing or patronising, lacking trust and confidence in the person with experience of mental illness, and being critical and judgemental. Not allowing people to take their own risks and to be themselves contributes to self-stigma.

A lack of confidence from employers also led to self-stigma, making people wonder whether they would be good enough for the job and if they would be able to cope.

Links with other types of discrimination

People's experience of mental health discrimination was also linked to other forms of discrimination,

predominantly that stemming from racism.

People from refugee backgrounds were particularly at risk of being treated in an inequitable way within mainstream mental health services because of their ethnic or geographic origin. In this sense, some people's experience of mental health discrimination cannot be isolated from their cultural, religious, or ethnic identity.

Specific mental health services such as kaupapa Māori, Pasifika, Chinese, and refugee programmes may be the most effective ways of helping people to deal with the discrimination associated with mental illness and ethnicity. These services are successful in supporting people because they offer spaces of connection and security through cultural practice, responsiveness, and understanding.

Family

Many people said that their experience of self-stigma had been triggered, often from an early age, by the attitudes and behaviour of family members. Some cited a lack of understanding and openness in the family environment towards issues of mental illness, as well as unhelpful beliefs about the nature of mental illness. These beliefs often resulted in people with experience of mental illness facing discrimination from their family members. Participants felt that this discrimination was not necessarily intentional, with family members not always realising the effect that their attitudes and behaviour had on their family member with experience of mental illness. However, the effect of this on the individual with experience of mental illness may be great, with some participants saying they had lost contact with other family members because they did not want to experience discriminatory behaviour. This had a devastating effect for some, and contributed to them feeling bad about themselves, losing financial assets, and becoming isolated from friends and social networks.

People also talked about how they saw their family treat other family members with experience of mental illness, so were afraid that they would be treated in the same way. This created a fear of discrimination that participants associated with self-stigma.

Outright discrimination and subtle discriminatory attitudes and behaviour can trigger self-stigma. Feeling different from family or being excluded from family social situations can contribute to self-stigma,

as can not meeting family expectations or being compared with other family members, or even sibling rivalry. All of these contributed to the feeling of ‘difference’ associated with self-stigma.

Having others question one's parenting ability was also seen as contributing to self-stigma. Some felt this so intensely that they had decided not to have children. Participants also worried that their mental illness might be passed on to their children, which also triggered guilt and self-stigma. For participants with children, becoming unwell was sometimes seen as letting their children down, somehow failing them. In general, people with experience of mental illness are able to parent effectively, but sometimes they need support from others, as do most parents, yet many of the participants mentioned their ability to parent as a concern.

Growing up in a climate of violence and abuse was also seen as contributing to self-stigma. At times people were victims of violence because of their experience of mental illness, or they believed their exposure to abusive and violent environments added another layer to their mental distress and self-stigma. Experiences of violence and abuse compounded people's sense of hopelessness and created further barriers to realising their potential.

Refugee participants talked about another aspect of family relationships as contributing to self-stigma – being forcibly separated from family. They lacked the usual supports that others might have available to them, and felt excluded from New Zealand society. This feeling of isolation contributed to self-stigma.

Media

Many people blamed the media for its role in increasing self-stigma. Coverage of mental health issues that was biased, negative, sensationalised, or incorrect was seen as contributing to the negative stereotypes that surround mental illness. These in turn influence the attitudes and behaviour of the people who believe them, including people with experience of mental illness. One particular stereotype the media was seen as contributing to was that people with experience of mental illness cannot cope with life, are dependent, and need support. It is easy to see how self-stigma can develop if people believe this stereotype.

People's attitudes and behaviour

People's attitudes and behaviour towards themselves were seen as contributing to self-stigma. Not believing in one's own ability and buying into the various negative stereotypes surrounding mental illness led to participants experiencing a loss of hope, a fear of being judged, a sense of being inadequate, and an inability to dream about their future. One outcome was social withdrawal and isolation, which impacted negatively on people's relationships.

Another outcome of self-stigma was a feeling that participants, because of their experience of mental illness, were not as deserving of the rights, responsibilities, and privileges that other people enjoyed. This has implications for people with experience of mental illness who are unfairly treated or discriminated against, and may explain why some people are reluctant to complain when they find themselves in this sort of situation. This belief of being less entitled may also be the fundamental reason why people with experience of mental illness may not apply for jobs or study or otherwise participate fully in society.

Treating people with experience of mental illness as full members of society, with the same rights, responsibilities, and privileges as any other members is the only way to overcome the discrimination associated with mental illness. It will also help to combat self-stigma. After all, if people with experience of mental illness are held in the same regard as the rest of society, they will also learn to perceive themselves that way. It should be acknowledged that while discrimination is prevalent, additional support for people to overcome it and the effects of self-stigma is also necessary.

Dealing with self-stigma

People identified many strategies for combating self-stigma. Many of these were activities that people with experience of mental illness could do by themselves, such as the positive thinking and affirmations mentioned in the findings. Some, like self-acceptance, required a change in attitude. Other people can also play a role, including using recovery-oriented practices such as Wellness Recovery Action Plans (WRAPs) plans, reducing the discrimination associated with mental illness, and challenging discriminatory practices, as well as creating supportive environments where it is safe for people

to disclose their experience of mental illness.

People also talked about the importance of culture and identity in their lives, as well as having a strong and supportive family or whānau environment. These aspects helped to build resiliency and a positive knowledge of oneself. A focus on creating supportive and positive cultural identities and family environments is vital to the recovery process. These environments instil hope, fun, and meaningful connections in people's lives, which helps them relate to themselves and the wider world more positively. The Mental Health Commission's *Our Lives in 2014* (2004) defines recovery as envisaged by people with experience of mental illness. This vision includes having personal power, a valued place in whānau and communities, and services that support a person and lead their recovery (p 10). For those involved in this research, each of these elements plays an important role in their path to recovery and helps to challenge self-stigma.

Positive aspects of self-stigma

The fact the Turanganui-a-Kiwa/Gisborne focus group challenged whether self-stigma existed is also unique to this project, and is not reflected in the literature. Despite so many negative aspects of self-stigma mentioned by the participants, some participants were clear that validating one's positive characteristics and moving beyond 'recovery' to being 'out and proud' and strengths-focused had real benefits for people.

Overcoming self-stigma had led to a strengthening in relationships and an increasing tolerance of difference and acceptance of others. Importantly, one 'side effect' of learning to deal with self-stigma for some, was an involvement in peer support and mental health advocacy. Having to find ways of overcoming self-stigma may lead to a desire to help others in their journeys, and an involvement in the mental health consumer movement.

Facilitators' reflections: Culture, service access, and recovery processes

The facilitators' reflections raised three major issues in relation to self-stigma:

- how notions and approaches exploring self-stigma may differ across cultures
- a need for more services addressing self-stigma
- how recovery processes address self-stigma.

Cultural differences

Cultural differences such as language and its use, community organisation, family relationships, and differences in religious and ethnic backgrounds all influenced how people related to self-stigma as part of their experience of mental illness. It was clear that individual cultural communities – Māori, Samoan, Chinese, Tongan, Niuean, Tokelauan, Somali, Iraqi and Pākehā – all referenced self-stigma in different cultural ways. This means they all have different ways of addressing, understanding, and challenging it within their own world view. Exploring this diversity further is essential, particularly in culturally relevant and accessible ways.

Working with and across cultures also means having a flexible and open research approach – one that meets and respects the cultural needs of the participants. From our research experience, this was particularly important when discussing such a complex and personal issue as self-stigma.

Services

Unfortunately for some, access to mental health services that utilised talking therapies and were recovery oriented was limited. Addressing this gap in services, particularly for young people using services for the first time, is important, because they enable people to understand their experience in a holistic way that helps build resiliency.

Recovery processes

The role and effectiveness of recovery processes in breaking the cycle of self-stigma was another area highlighted for further exploration. What recovery projects and programmes are most effective in challenging self-stigma, and how do they do this? Similarly, the observation and finding that people's experiences of abuse also had a large bearing on their experience of self-stigma needs to be investigated.

Existing models of self-stigma

Two existing models of stigma and discrimination came to prominence in the literature review: Link and Phelan's (2001) definition of stigma (equivalent to discrimination in a New Zealand sense) and Corrigan and Kleinlein's (2005) model of self-stigma and public stigma (discrimination).

Link and Phelan's model

Link and Phelan (2001) define stigma (in the all-inclusive sense) in terms of five components. Stigma exists, they say, when the five components coincide. The components are:

- people identifying human differences and labelling them
- the linking, in dominant cultural beliefs, of labels with negative stereotypes
- the placing of labelled people in categories that isolate them from, and set them in opposition to, the majority
- the experiencing by labelled people of unfair status, loss and discriminatory behaviour
- that labelling is contingent on the power differentials existing in society.

In summary, the first four components are labelling, stereotyping, separation, and status loss and discrimination, with the overarching fifth component being power.

The advantages of Link and Phelan's model are that it incorporates power issues, talks about the power of labelling, and is not specific to mental illness. The disadvantages are that it does not explicitly explain self-stigma, and does not show how the different components of the model or how stigma and discrimination are linked. There is also no explanation of how recovery can affect stigma.



Table 2: Components of public stigma and self-stigma

Component	Public stigma	Self-stigma
Stereotype	Negative belief about a group For example, dangerous, incompetent, and weak of character.	Negative belief about self For example, weak of character and incompetent.
Prejudice	Agreement with belief and/or negative emotional reaction For example, anger and fear.	Agreement with belief Negative emotional reaction For example, low self-esteem and low self-efficacy.
Discrimination	Behavioural response to prejudice For example. Avoidance of work and housing opportunities and withholding help.	Behavioural response to prejudice For example, a failure to pursue work and housing opportunities.

Source: Based on Corrigan and Kleinlein (2005, p 16).

Corrigan and associates’ model

Corrigan and associates’ model includes two types of stigma: self-stigma and public stigma (which equates to our use of the term ‘discrimination’). Each type has three components: stereotype, prejudice, and discrimination (see Table 2).

The advantages of this model are that it explains how stereotypes, prejudice, and discrimination are linked, and offers an explanation of self-stigma. It is also not specific to mental illness. The disadvantages are that it is a linear model, there are no obvious actions that can be taken to arrest the processes, and there is no link between self-stigma and public stigma. The concept of power is not addressed.

New model of self-stigma and discrimination

A model has been developed from the findings of this research to explain discrimination and self-stigma and how the two are linked. It was developed in three stages. First, a definition of self-stigma was derived, then an analysis was undertaken of how the elements of self-stigma related to each other, and then ‘circuit breakers’ were identified to show how self-stigma could be combated.

New definition of self-stigma

The model starts with the definition of self-stigma that comes directly from the focus group responses:

Something is wrong with me that won't change, which means I'm less worthy than other people and less entitled than other people. Therefore, I ...

Table 3 shows the different concepts mentioned by the focus group participants in response to the first question: What does self-stigma mean to you? These responses are listed under the different components of the definition we came up with in response to these concepts. This illustrates how the definition was made to fit the aspects of self-stigma identified by the participants.



Table 3: Focus group participants’ responses to “What does self-stigma mean to you?” in the context of the components of self-stigma

Component	Response
Something is wrong with me ...	Feeling not normal or being unusual Feeling different, an outcast, not fitting in Reflecting discrimination, believing what others say, accepting discrimination
... that won't change ...	Having a sense of inevitability, that things can't change and recovery is not possible Fearing discrimination
... which means I'm less worthy than other people ...	Comparing oneself to others Feeling not good enough, hopeless, useless Reinforcing stereotypes Feeling shame, a loss of face, guilt and embarrassment Being insecure, lacking confidence and being anxious
... and less entitled than other people.	Feeling less worthy and inadequate, having low self-esteem Feeling a burden to others, needing support Beating oneself up, having negative thoughts
Therefore, I ...	Feeling withdrawn, isolated, lonely, vulnerable Having limitations Engaging in negative self-dialogue Family – rejection, letting them down, self-exclusion Experiencing self-doubt Blaming oneself Feeling a failure and weak Curtailing dreams Feeling suicidal Needing to work harder Feeling anger and despair

Something is wrong with me ...

We deliberately did not refer to the something ‘wrong’ as being mental illness, as many of the participants mentioned that self-stigma for them began before they were diagnosed as having a mental illness. For others, however, the thing that was ‘wrong’ was specifically mental illness. This part of the definition makes it clear that self-stigma is intimate and personal.

something that was with you for life and could not be recovered from. There was a sense of inevitability that they would be like this for the rest of their lives. There was also a realisation that having a mental illness meant they were changed forever.

... that won't change ...

Many of the participants in the focus groups talked about how they perceived mental illness as being

... which means I'm less than other people ...

The message that the person with experience of mental illness is “less than other people” comes both from within and from other people. The belief that a person is less than other people is part of a cycle. The person is treated as less worthy than others, so they believe and act as though they were less worthy, so

others perceive them as less worthy, and so the cycle continues.

Who is telling people with experience of mental illness that they are less than other people? This is where the stereotypes surrounding mental illness come in. If society believes that people with experience of mental illness are different in a negative way to other members of society, then this is also a message the person with experience of mental illness hears. Internalising these stereotypes contributes to self-stigma.

... and less entitled than other people ...

People may believe that because they have experience of mental illness they have fewer rights, responsibilities, and privileges than other people have. Again, this is a self-replicating cycle – if people are treated as if they have no rights and responsibilities, then they may believe this and act accordingly.

Therefore, I ...

The last part of our definition is an action. Intrinsic to the definition of self-stigma is that the person is affected by it in some way, changing their behaviour as a result of it. For example, the person may think, “I will not apply for that job because I have a mental illness”. The action is associated with the feelings and attitudes that form the first parts of the definition.

New definition of discrimination

In examining the new definition of self-stigma, we realised we had also developed a new definition for discrimination:

Something is wrong with you that won't change, which means you're less worthy than other people and less entitled than other people. Therefore, we will treat you differently

Comparing the different components of the new definitions

The second stage of developing the model was to examine the different components of our new definitions, identifying the 'essence' of each component and how these related to each other.

Table 4: Comparison of the different components of the new definitions of self-stigma and discrimination

Component of self-stigma and discrimination definitions	Element
Something is wrong with me/you	Difference
That won't change	Inevitability or unchangeability
Which means I'm/you're less worthy than other people	Comparison
And less entitled than other people	Devaluation
Therefore, I/we ...	Discrimination

Because our research identified that discrimination can lead to self-stigma, the components were clearly not in a linear relationship. Further analysis showed us a model that is circular. We also realised that the path can be in either direction, and can start at any point (see Figure 1, p. 101).

The model shown in Figure 1 shows how self-stigma and discrimination are intrinsically linked, with each component able to be applied to oneself or to other people. By changing factors at any point you can exacerbate or relieve other factors in the cycle.

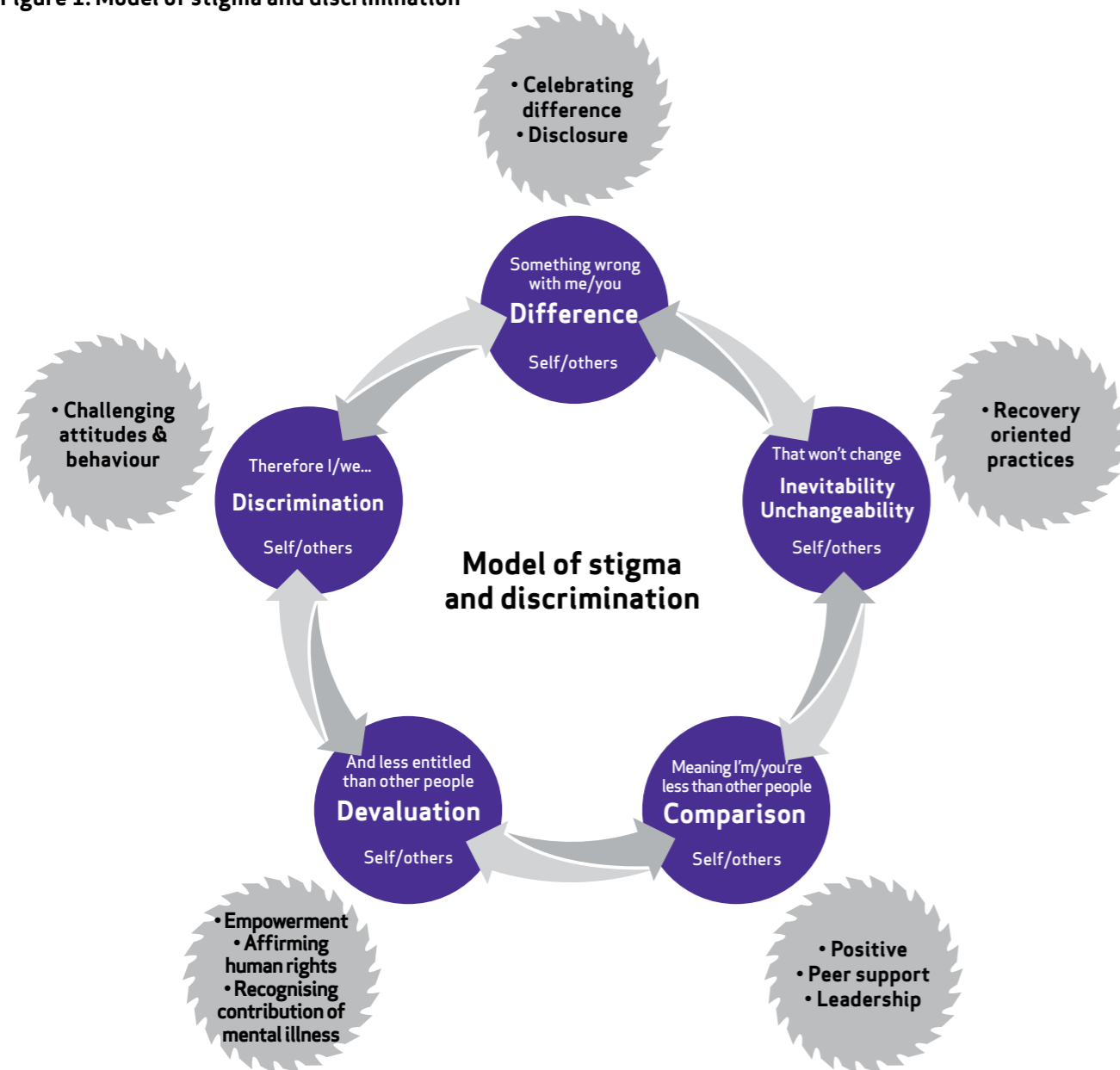
Identifying actions to interrupt the cycle of self-stigma

The third stage of developing the model was to identify the actions, or circuit breakers, that can happen at each stage to interrupt the cycle of self-stigma. Each point in the cycle has its own circuit breakers. The examples given are only illustrative, so are not comprehensive or exclusive.

Table 5: Circuit breakers (actions) that can interrupt the cycle of self-stigma

Element	Circuit breaker	Explanation
Difference	Celebrate and accepting difference	If society celebrates and accepts difference, rather than rejecting it, people with experience of mental illness will feel more 'normal'.
	Disclosure	Disclosure helps normalise mental illness.
Inevitability or unchangeability	Recovery-oriented practices	If mental health services instilled hope and if people with experience of mental illness knew they could recover, then self-stigma would be reduced.
Comparison	Positive role models	If people compare themselves with successful people with experience of mental illness, then self-stigma will be reduced. People can also learn from each other how to combat self-stigma. Having visible consumer leaders is vital.
	Leadership	
Devaluation	Empowerment	If people with experience of mental illness are encouraged to empower themselves, their self efficacy and self-esteem will increase, thus combating self-stigma. Recognising the human rights and valuing the contribution to society of people with experience of mental illness will also combat self-stigma.
	Affirmation of human rights Recognition of the contribution of people with experience of mental illness	
Discrimination	Challenging attitudes and behaviour	If people are encouraged to challenge discrimination when they are discriminated against, anti-stigma and discrimination programmes are implemented, and people with experience of mental illness challenge their own attitudes and behaviour, self-stigma will be reduced.
		Emphasis must continue to be eliminating the societal and public discrimination associated with mental illness.

Figure 1: Model of stigma and discrimination



Questions raised by the literature and our findings

Many questions were raised in the course of this research by the findings of the literature review, the research reference group, and in talking to other people about this project. Many of these can be answered by focusing on the model we developed. The following section of the report addresses some of these questions.

Is discrimination a source of self-stigma? Do you have to experience discrimination to develop self-stigma, or is the fear of discrimination enough? Does discrimination trigger self-stigma?

Our model shows that discrimination and self-stigma are inextricably linked. Discrimination (either towards oneself or other people) is a necessary part of self-stigma but may not necessarily trigger self-stigma. For some people, the trigger is feeling different or less worthy than other people. However, discrimination or at least a fear of discrimination is necessary for self-stigma to continue.

Is addressing self-stigma fundamentally linked to recovery from mental illness?

Recovery-oriented practices are those that uphold the philosophy of recovery; namely, they inspire hope, and give service users personal power, a valued place in their family, whānau, and communities, and support service users to lead their own recovery. Practices that adhere to these values are one of the examples given in addressing the inevitability or unchangeability element in our model. The belief that mental illness is not a life sentence, but a life-changing experience that can be learnt from, would seriously reduce the negative impacts of illness on the individual. It is not just treatment for mental illness that is important here, what is necessary is for this treatment to be hope-based, that is for all parties to believe that mental illness can be recovered from. If people do not view mental illness as permanent, this will help to break the cycle of self-stigma.

What is the difference between self-stigma and the symptoms of mental illness?

It may be difficult to distinguish between symptoms of mental illness and feelings of self-stigma. Is the person feeling bad about themselves because they are depressed or because they feel that their mental illness means they cannot work? The distinction can be made, however, because the feelings caused by self-stigma often linger long after the symptoms of mental illness subside. It is important for mental health professionals to recognise the role that self-stigma may play in worsening people's mental illness, and work with the person and their family/whānau in challenging it.

Is there a link between self-stigma and suicide or suicidal thoughts and behaviour?

Suicide was discussed by some of the focus groups as being related to self-stigma. There is a possibility that by addressing self-stigma we may reduce the incidence of suicidal thoughts and behaviour amongst people with experience of mental illness.

Does self-stigma come from within or without?

Is self-stigma caused by internal or external factors? The model clearly shows that the cause can be either set (or both sets) of factors; for example, an internal feeling of difference or an external experience of discrimination.

Does talking about self-stigma make it real? Does self-stigma exist?

When planning and carrying out the focus groups, we spoke to many people with experience of mental illness about our plans. Some could immediately identify with experiencing self-stigma. Others, including many of the focus group participants, said that they had not thought about the issue of self-stigma before, but after thinking about it realised how many of their attitudes and behaviour were shaped by it. For those people, naming the experience of self-stigma meant they could do something about it.

What is the relationship between culture and ethnicity and the experience of self-stigma?

Self-stigma was a concept recognised by almost all the focus group participants, despite their different cultural backgrounds. It manifested itself differently, depending on culture. For example, in the Chinese focus group people talked about losing face, while people in other focus groups talked about the impact their family name had on their personal identity because of its past associations with mental illness. Conversely, people from refugee backgrounds explained that because their countries of origin might be associated with terrorism, they were also fearful of being discriminated against socially and within the health sector.

Knowledge and expression of one's own culture and identity was also seen as an important way of combating self-stigma, especially for the Māori participants.

Can self-stigma pre-date diagnosis?

Many of the group participants said that they first started experiencing self-stigma when they were first diagnosed with mental illness. They realised they were different, which triggered self-stigma. Others, however, said that they had felt self-stigma before they were diagnosed, even before they had experienced mental illness. They recounted feeling different, often from a very young age – being diagnosed just confirmed the difference. In other words, they knew there was something wrong with them – one of the steps identified in the model.

What makes some people resist or not experience self-stigma?

Only one person in the focus groups said that they had not experienced self-stigma. However, in discussions

with others about this study, some said that they had not or seldom experienced self-stigma. The literature also indicates that some people do not appear to experience self-stigma, using the term empowerment as the opposite of self-stigma. Using our model it becomes clearer how some people avoid or overcome self-stigma. At each step in the model are circuit breakers, which, if applied, will disrupt the cycle of self-stigma, and empowerment is one of these circuit breakers.

What is the role of the mental health consumer movement in addressing self-stigma?

The mental health consumer movement has an important role to play in helping people with experience of mental illness combat self-stigma. The movement has a role in all of the circuit breakers identified in the model. Members can encourage people to celebrate difference, lobby for, and participate in recovery-oriented practices, provide positive role models and peer support, encourage self-respect, and challenge others' attitudes and behaviours.

How does self-stigma affect development (for example, of relationships, employment, education, and parenting)?

Mental illness often first appears when a person is reaching adulthood and making crucial decisions about their future. If they are experiencing self-stigma when trying to make these decisions, their judgement can be clouded by unhelpful attitudes. Thinking that they could not possibly study or undertake a job because of their experience of mental illness can have a major impact on their career decisions. So can thinking that they cannot have a relationship or be a parent.

Does disclosure help combat self-stigma?

Disclosure can help combat self-stigma. Talking to others about an experience of mental illness can help place things into context and create opportunities for peer support. Research has shown that contact with people with experience of mental illness is one of the most effective ways of combating discrimination (Gordon 2005). If more people were open about their experiences, we would expect to see less discrimination against people with experience of mental illness, more acceptance, and ultimately less self-stigma.

5

Conclusion

The aim of this research was to:

- explore the issue of self-stigma from the perspective of people with experience of mental illness
- investigate the causes and effects of self-stigma
- discuss ways to combat self-stigma amongst people with experience of mental illness.

The findings of this research show that self-stigma is an issue that many people with experience of mental illness face. It is closely associated with the discrimination that people experience, and can lead to a variety of consequences, including low self-esteem and self-doubt, and generally making life worse for the people who experience it. It can also result in people working harder to prove themselves, and overcoming it can lead to a sense of empowerment in people's lives.

The model we developed in the course of this research shows how inter-related self-stigma is with discrimination, the cyclical nature of self-stigma, and how this cycle can be broken at any stage. For the first time we can see the role that recovery-oriented practices can play in combating self-stigma, as well as the important role that the mental health consumer movement, peer support and anti-discrimination campaigns can play in interrupting the cycle.

One of the important circuit breakers identified in the model is disclosure. Encouraging people with experience of mental illness to disclose their experiences may expose them to discrimination, but is necessary to enable people to gain support from others, seek treatment for their symptoms, and challenge other's attitudes and behaviour. The more people disclose their experiences, the more 'normal' mental illness becomes in society, thus eventually reducing discrimination and self-stigma.

One of the hesitations we had in undertaking this research was about the role of people with experience of mental illness in creating and perpetuating self-stigma. We were worried that the findings of the research would focus on their own attitudes and behaviour at the expense of others in society. It is clear from the model that we developed however, that while people with experience of mental illness have an important role to play in reducing self-stigma, everyone in society has just as important a role.

This means that mental health services, friends and family, and others in society need to recognise the effect that self-stigma and discrimination can have on the lives of people with experience of mental illness, learn to celebrate difference, challenge others' and their own behaviour and attitudes, and most of all instil hope, knowing that mental illness is a unique experience that can be learnt and recovered from.

6 Recommendations



Examination of the findings of this study suggests that self-stigma is inter-related with discrimination. The development of the model of stigma and discrimination that arose directly out of this research offers important actions we can all take to combat self-stigma. The eight general recommendations below are based on the model's circuit breakers, which help to disrupt the cycle of stigma and discrimination on personal and societal levels.

Recognise the contribution of mental illness and foster leadership among people with experience of mental illness

We need to continue to publicly recognise the contributions of people with experience of mental illness. They are capable of working, being in relationships, having families, and participating fully in society. Encouraging visible consumer leaders is vital as they offer innovative ways of developing relevant services, being positive role-models and mentors, and advocating for and with people with experience of mental illness. If people compare themselves with successful people with experience of mental illness then self-stigma will be reduced.

Celebrate and accept difference

As a society we need to celebrate and accept difference, rather than reject it. We will know when we have reached this point when people with experience of mental illness feel 'normal' and included, and are actively involved in decision-making regarding issues that affect their lives.

Affirm human rights

Treating people with experience of mental illness as full members of society, with the same rights, responsibilities, and privileges as other members of society is the only way to overcome the discrimination associated with mental illness. It will also help to combat self-stigma, particularly by advocating for access to high-quality mental health services, rights to freedom of discrimination and access to justice, and promoting economic, social and cultural rights of people with experience of mental illness.

Encourage disclosure

Disclosure helps normalise mental illness. Talking to others about an experience of mental illness can help place things into context and create opportunities for peer support. Therefore, it is also necessary to enable people to gain support from others, seek treatment for their symptoms, and challenge others' attitudes and behaviour. Addressing self-stigma through resource development, education, and training initiatives at national and grass-roots levels will contribute to an environment where disclosure is encouraged and safe.

Encourage recovery-oriented practices

Recovery-oriented practices that inspire hope, give service users personal power and a valued place in their communities, family, and whānau, while also supporting them to lead their own recovery, is essential. If mental health services instilled hope and if people with experience of mental illness knew they could recover, then self-stigma would be reduced. Utilising a holistic approach to recovery, whereby medication is balanced alongside eating and exercising regularly, keeping to routines, and connecting with others is one way that self-stigma can be challenged.



Encourage empowerment

Encouraging people with experience of mental illness to empower themselves will increase self-efficacy and self-esteem thus combating self-stigma. All services should be successful in supporting people if they offer spaces of connection and security through appropriate cultural practices, responsiveness, and understanding. Evidence from this research suggests that specific mental health services such as kaupapa Māori, Pasifika, Chinese, and refugee-oriented programmes are some of the most effective ways of helping people to deal with the stigma and discrimination associated with mental illness and ethnicity. Therefore, services that work in partnership with people with experience of mental illness will help to overcome self-stigma.

Support peer support services

Encouraging and developing peer support services in the community will help to combat self-stigma. Peer services play a crucial role in building people's resilience by helping people to understand and learn from each other. Creating peer environments where common experience and mutual respect are built, enables people to feel a sense of belonging and connection, which undermines social isolation and feelings of inadequacy and self-doubt.

Challenge attitudes and behaviour

Encouraging people to complain when they are discriminated against, progressing anti-stigma and discrimination campaigns, as well as challenging some of the attitudes and behaviours of people with experience of mental illness will all contribute to reducing self-stigma. However, emphasis must continue to be on eliminating the societal and public discrimination associated with mental illness, as this is a main trigger of self-stigma.

Appendix



Appendix: General Focus Group Information Pack

Introduction

The information pack for the general focus group for the Internalised Stigma Research Project is reproduced in this appendix. The pack contained:

- a covering letter to the focus group organiser about the Internalised Stigma Research Project
- information about the facilitator's role in the Internalised Stigma Research Project
- an outline for the internalised stigma focus group
- a participant information sheet
- a consent form
- a short questionnaire to collect demographic information.

Focus Group Organiser: The Internalised Stigma Research Project

This research is being undertaken by the Mental Health Foundation's Wellington office on behalf of the national Like Minds, Like Mine project to counter stigma and discrimination associated with mental illness.

We will be running a series of focus groups around the country asking people with experience of mental illness about their experiences of internalised stigma and the best ways to combat it. We are aiming to have approximately six to eight people for each focus group, and each group will last for two hours. We will be asking questions about people's experience of internalised stigma and how people deal with it when it arises as an issue.

We will arrange the facilitation of each group, and notes will be taken. Each participant will also receive a gift voucher in recognition of their participation in the group.

We ask that you approach people to participate, and arrange for their participation in the focus group. Anyone with experience of mental illness is eligible to take part. We will provide an information sheet and consent form for you to distribute to potential participants. We also request that you arrange the catering and the venue. We will cover the cost of morning or afternoon tea, and the cost of hire for the venue (or pay a koha for the use of your own venue).

Thank you for helping us organise these groups. The research will make an important contribution to our knowledge about internalised stigma and how to deal with it. If you have any queries please contact Debbie Peterson or Alex Barnes:

Debbie Peterson⁴	Alex Barnes
Senior Policy Analyst/Researcher Mental Health Foundation 04 801 0353 debbiep@mentalhealth.org.nz	Senior Policy Analyst Mental Health Foundation 04 801 0354 alex.barnes@mentalhealth.org.nz

Some one will be in contact with you shortly to make arrangements for undertaking the focus group in your area.

Debbie Peterson and Alex Barnes
Mental Health Foundation of New Zealand

⁴Please note that Debbie is no longer with the Mental Health Foundation.

Facilitator's Role: Internalised Stigma Research Project

This research is being undertaken by the Mental Health Foundation's Wellington office on behalf of the national Like Minds, Like Mine project to counter stigma and discrimination associated with mental illness.

We will be running a series of focus groups around the country asking people with experience of mental illness about their experiences of internalised stigma and the best ways to combat it. We are aiming to have approximately six to eight people for each focus group, and each group will last for two hours. We will be asking questions about people's experience of internalised stigma and how people deal with it when it arises as an issue.

You have agreed to facilitate one of these focus groups.

What we expect:

- if you have responsibility for organising the focus group, that you will do that (see the information sheet for focus group organisers)
- you prepare for the focus group by becoming familiar with the definitions of internalised stigma and the set questions
- you ensure that the participants are aware of the purpose of the group, they have an opportunity to ask questions about the group, and they are given and understand a copy of the participant information sheet
- all participants must fill in and sign a consent form, including their name and address, and indicate whether they wish to receive copies of the final report
- the focus group starts and finishes at the agreed time
- you introduce yourself to the group and the participants also introduce themselves
- you allow the participants to express the views, experiences and opinions
- you set ground rules for the group at the beginning (confidentiality, respect for others etc), and you ensure that all participants are aware of these
- you take adequate notes of the discussion
- you ensure that participants are given vouchers for their participation, and that they sign for these
- contact Debbie or Alex after the group to debrief
- you will return the completed consent forms, questionnaires, focus group notes and voucher receipts to the Mental Health Foundation as soon as possible after the focus group

What you can expect from us:

- if you are not organising the group, we will arrange with the focus group organiser to organise the group, including the venue and catering
- we will provide training for the focus group facilitation
- we will be available to answer questions and to talk through what happened in the group
- we will provide stationery for you to take notes
- we will provide participant information sheets, consent forms, and focus group outlines

Outline of internalised stigma focus group

Introductions

Ground rules

Information sheet

Consent form

Questionnaire

Definitions of internalised stigma

We are using two definitions:

1. Negative thought or feelings towards yourself based in the fact that you have a mental illness
2. Self belief in negative stereotypes that have become linked to the experience of mental illness
 - What does internalised stigma mean to you?
 - What are some examples of it?
 - How has it affected your life?
 - When did you first experience it?
 - Where do you think it comes from?
 - When you feel internalised stigma, what helps you deal with it and what advice would you give to others experiencing it?
 - What make internalised stigma worse?

Participant Information Sheet: The Internalised Stigma Research Project

Background to the project

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 looking at the issues of internalised stigma and self-discrimination for people with experience of mental illness. The research team consists of the focus group facilitators, and Debbie Peterson, Alex Barnes, Bernie DeLord and Jane Norman from the Mental Health Foundation.

The aim of this research is to understand more about how internalised stigma affects people with experience of mental illness and what can be done to reduce its effects on people's lives. We are interested in both negative and positive experiences.

Who can participate?

We would like to involve people who have had experience of mental illness.

What does participation involve?

For this research you are being asked to take part in a focus group that will ask you about your experiences and thoughts about the issue of internalised stigma associated with your experience of mental illness. It is expected that there will be approximately six to eight people in the focus group and the group will last two hours. Notes will be taken during the group, and the group may also be recorded. The research team will be the only people with access to the recording and notes. No material which could personally identify you will be used in any reports on this study.

Focus group questions

We will be using two definitions of internalised stigma for this project:

1. Negative thoughts or feelings towards yourself based on the fact that you have a mental illness
2. Self belief in negative stereotypes that have become linked to the experience of mental illness – 'self-discrimination' is acting on those beliefs

Following this definition, each focus group will be asked to explore and answer the following questions:

- What does internalised stigma mean to you?
- What are some examples of it?
- How has it affected your life?
- When did you first experience it?

- Where do you think it comes from?
- When you feel internalised stigma, what helps you deal with it and what advice would you give to others experiencing it?
- What make internalised stigma worse?

In recognition of the time involved in this study, you will receive a Warehouse gift voucher. A full report on the study is expected to be released at the end of the research by the Mental Health Foundation for the Like Minds project, and this will also be made available to you 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.

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 the facilitator of your group or contact:

Debbie Peterson⁵	Alex Barnes
Senior Policy Analyst/Researcher Mental Health Foundation 04 801 0353 debbiep@mentalhealth.org.nzalex.	Senior Policy Analyst Mental Health Foundation 04 801 0354 barnes@mentalhealth.org.nz

⁵Please note that Debbie is no longer with the Mental Health Foundation.

Thank you for offering to participate in this research!

Debbie Peterson and Alex Barnes
Mental Health Foundation of New Zealand

Consent to Participate in Research

Issues of Internalised Stigma for People with Experience of Mental Illness

I have been given and understand an explanation of this research project, and have read the information sheet. I have had an opportunity to ask questions and have them answered to my satisfaction.

I understand that taking part in this study is voluntary and that I may withdraw from this study at any time, without reason. I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports of this study.

- I would like to receive a summary of the results of this research when it is completed.

Signed: _____

Name of participant: _____

Address: _____

Date: _____

Name of facilitator(s): _____

Signed: _____

Internalised Stigma Focus Groups

Questions about you:

Are you:

Male

Female

What ethnic group do you identify with?

.....

How old are you?

Under 25

25-39

40-59

60+

Who was the facilitator(s) for your focus group?

.....

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