

Walk a Mile in Our Shoes

He tuara, ngā tapuwae tuku iho o ngā Mātua Tūpuna

Exploring Discrimination Within and Towards Families and Whānau
of People Diagnosed with 'Mental Illness'



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Executive Summary

1. Introduction

The Like Minds, Like Mine programme, funded by the Ministry of Health, is designed to counter stigma and discrimination associated with mental illness. This research explores discrimination within and towards families and whānau of people diagnosed with mental illness. It also seeks to identify strategies to overcome these forms of discrimination.

The New Zealand Human Rights Commission states that discrimination occurs 'when a person is treated unfairly or less favourably than another person in the same or similar circumstances' and includes both direct and indirect processes (Human Rights Commission, 1993 cited Mental Health Commission, 2004:3). In accordance with the Like Minds, Like Mine National Plan 2007-2013, this research is grounded in a human rights approach and informed by a social model of disability. The Treaty of Waitangi provides a foundational framework for relationships with tāngata whenua and has informed the values that underpin the research.

This project emerged from previous research undertaken by the Mental Health Foundation of New Zealand titled Respect Costs Nothing (Peterson, Pere et al, 2004). In this research 59% of people with experience of mental illness reported being discriminated against by families and friends. International research also suggests that families are a key source of discrimination. However, families themselves can be subject to discrimination which may impede the family's ability to provide support and enhance recovery.

The presence and meaning of discrimination within families is compounded by the unique nature of families and whānau, family perceptions of the causes of mental illness, issues associated with the family or whānau support role, and a background of childhood adversity and/or family dysfunction.

Discrimination towards families reflects a society wide tendency to view mental illness as a source of shame, embarrassment and/or fear. This view is often fuelled by a lack of appropriate information about mental illness and recovery. Mental health services have also been identified as a key source of discrimination towards families.

Strategies to reduce discrimination are diverse. However,

strategies tailored to the unique nature of families and whānau, and the particular nature of families' relationships and roles have rarely been explored. This research is based on the premise that discrimination towards families and whānau can impact on discrimination within families and whānau.

1b. Methodology

Grounded in a qualitative methodology, this research involved nine focus groups and one multi-region discussion forum. Separate focus groups were held with consumers, tāngata whai ora, families and whānau. One focus group included Pacific families and consumers together. There were also specific focus groups for Māori, Chinese, two general (non-specific ethnicity) focus groups and young adults. Participants were recruited through a range of organisations and networks connected to the mental health sector. The discussion forum, based on a dialogue approach, brought together a sub-group of families, whānau, consumers and tāngata whai ora. A total of 85 adults participated in the focus groups, and 19 adults participated in the discussion forum.

2. Meanings of Discrimination

Participants generally agreed about the meaning of discrimination as it relates to mental illness. Participants identified derogatory language used to talk about mental illness. They also identified the biomedical model, an imbalance of power, clinician's negative attitudes and limited knowledge base, and mental health service practices as a key source of discrimination. Multi-dimensional discrimination was also identified.

While there was general consensus about the meaning of discrimination at an abstract level, participants varied in their interpretation of the meaning of discrimination as it related to their own families or whānau.

3. Discrimination Within Families and Whānau: Consumer and Tāngata Whai Ora Perspectives

Consumers and tāngata whai ora spoke of the diverse nature of discrimination within their families and whānau. Discrimination was often associated with shame. Many families hid or denied mental illness,



refuted environmental causation, and used derogatory language and/or called the family member offensive names. Families' were perceived as having significantly reduced expectations of the consumer or tāngata whai ora, pathologising 'ordinary' emotions and behaviours, and appraising realistic needs (e.g. the need for time out, rest, quietness) in a negative way. Only one participant reported that there was no discrimination within their family or whānau. Many of the tāngata whai ora reported that overt discrimination and adverse relationships had resulted in alienation or estrangement from whānau of origin.

Some consumers noted that attitudes and behaviours within their families had improved with increased knowledge and awareness. Many consumers, and especially tāngata whai ora, held hope that their families or whānau would gain greater awareness of mental illness, be better able to understand consumer or tāngata whai ora needs and experiences, and increase their capacity to engage in more healthy and respectful relationships.

4. Discrimination Within Families and Whānau: Family and Whānau Perspectives

Pacific and Chinese families reported the presence of discrimination within their families. The general focus groups, whānau and young adults groups initially reported that there was little if any discrimination within their families or whānau. Subsequent discussions revealed that discrimination was present within the general and young adults' families. The whānau families' group spoke of the presence of discrimination in others' whānau.

Families and whānau responded in diverse ways to the presence of mental illness within the family and often experienced an array of conflicting feelings. Families often reported fear and blame. Some treated the consumer or tāngata whai ora differently from others in the family. Some wanted the family member to change their behaviour or ways of living. Families were often keen to differentiate negative behaviours they associated with mental illness from negative behaviours associated with a family member's 'personality'. Difficulties associated with recreational drug taking were addressed. Many families spoke of communication and relationship difficulties.

Families also reported challenges associated with adapting to a family member's progress and recovery. A minority spoke of calling the family member derogatory names and some assumed decision making authority irrespective of the family member's consent. Stress and pressure associated with providing primary support sometimes resulted in frustration and aggression towards the family member. Sometimes families excluded a family member from social events, or distanced themselves, to avoid embarrassment or potential disruption. A minority sought legal or compulsory medical intervention when the behaviour of a family member became too harmful or difficult for the family to manage.

5. Discrimination Towards Families and Whānau

Participants identified three key sources of discrimination. These included: a) mental health services; b) extended family and whānau; and c) societal norms, media stereotypes and the general social milieu. Other less common sources of discrimination were also identified.

Participants across all focus groups (except the Chinese group) identified mental health services as the most prominent source of discrimination towards families and whānau. The dominance of a biomedical approach, the absence of a holistic conceptual framework and lack of endorsement of cultural worldviews was regarded as discriminatory. Discrimination also reflected negative staff attitudes and behaviours such as not providing information, not consulting or including families or whānau, and blaming and/or criticising parents or parent figures. Chinese participants viewed New Zealand mental health services favourably but did not like the lack of consultation and inclusion of families.

Participants from all focus groups identified extended families and whānau as a key source of discrimination. Discrimination towards families and whānau took various forms including disparaging comments, hiding or ignoring mental illness, judging or blaming the family or viewing the family member as 'bad' or behaving 'badly'. Most participants thought this reflected a lack of awareness, information and knowledge about mental illness, shame and embarrassment, fears of being 'contaminated' and fear related to beliefs about the genetic nature of mental illness.

Participants identified societal norms, media stereotypes and the general social milieu as perpetuating discrimination. The label 'schizophrenia' was regarded as particularly stigmatising and a key source of discrimination. A minority of participants reported discrimination from friends, social networks, churches and clergy, employers and colleagues, and police.

6. Understanding Discrimination – Complexities and Tensions

This research highlighted how the notion of discrimination in relation to families and whānau is complex. Several contextual factors impact on discrimination within the family or whānau. These include: the unique nature of the family or whānau; challenges associated with being a primary support person; and difficulties associated with dealing with challenging behaviour associated with a family member's mental illness. Issues relating to severe family dysfunction, child abuse and other childhood adversity were emphasised in terms of understanding 'mental illness'. Recognizing consumer and tāngata whai ora rights to determine family or whānau involvement in treatment processes was also addressed. Participants across focus groups identified staff attitudes and behaviours and a source of discrimination and recognised that contextual variables impact on staff practices and interactions with consumers and families. There were widespread calls for a fundamental shift in thinking about mental illness from a dominant biomedical approach to one which is holistic and embodies cultural worldviews.

7. Strategies to Counter Discrimination Within and Towards Families and Whānau

Participants in this research identified an array of strategies that they believed would reduce discrimination relating to families and whānau. Strategies identified by participants cohere around seven key themes. These include: mental health services; public education; peer support and other support groups; primary and secondary schools; utilising cultural leaders, and promoting communication and traditional Māori values across communities; modelling other successful initiatives or campaigns; and media and social networking.

8. Concluding Comments

The nature and range of attitudes and behaviours participants identified as discriminatory suggest that the terminology used to talk about discrimination may require more critical appraisal. The unique context, dynamics, histories and relationships within families and whānau also mean there is a need for a particular lens with which to understand family and whānau related discrimination.

Many participants reported difficulties knowing if the attitudes they held, or the way they behaved, were discriminatory. Extended families, staff in mental health services and others may also experience similar difficulties. Explicitly naming the behaviours participants identified as discriminatory may lead to better identification of discrimination. A simple method to identify discriminatory behaviour has been identified as the five 'Ds'. The five 'Ds' include behaving in ways that are: derogatory, disrespectful, dismissive, demeaning and/or degrading, to support the basic premise that discrimination is not okay.

A key conclusion that can be drawn from this research is that issues relating to power dynamics, relationships and communication underpin discriminatory behaviour. It is well known that healthy, respectful and empowering relationships are critical to healthy family functioning (Ministry of Social Development, 2009) and recovery (Mental Health Advocacy Coalition, 2008). It seems prudent that strategies to reduce discrimination attend to the broader context of relationships, address power imbalances and the quality of communication.

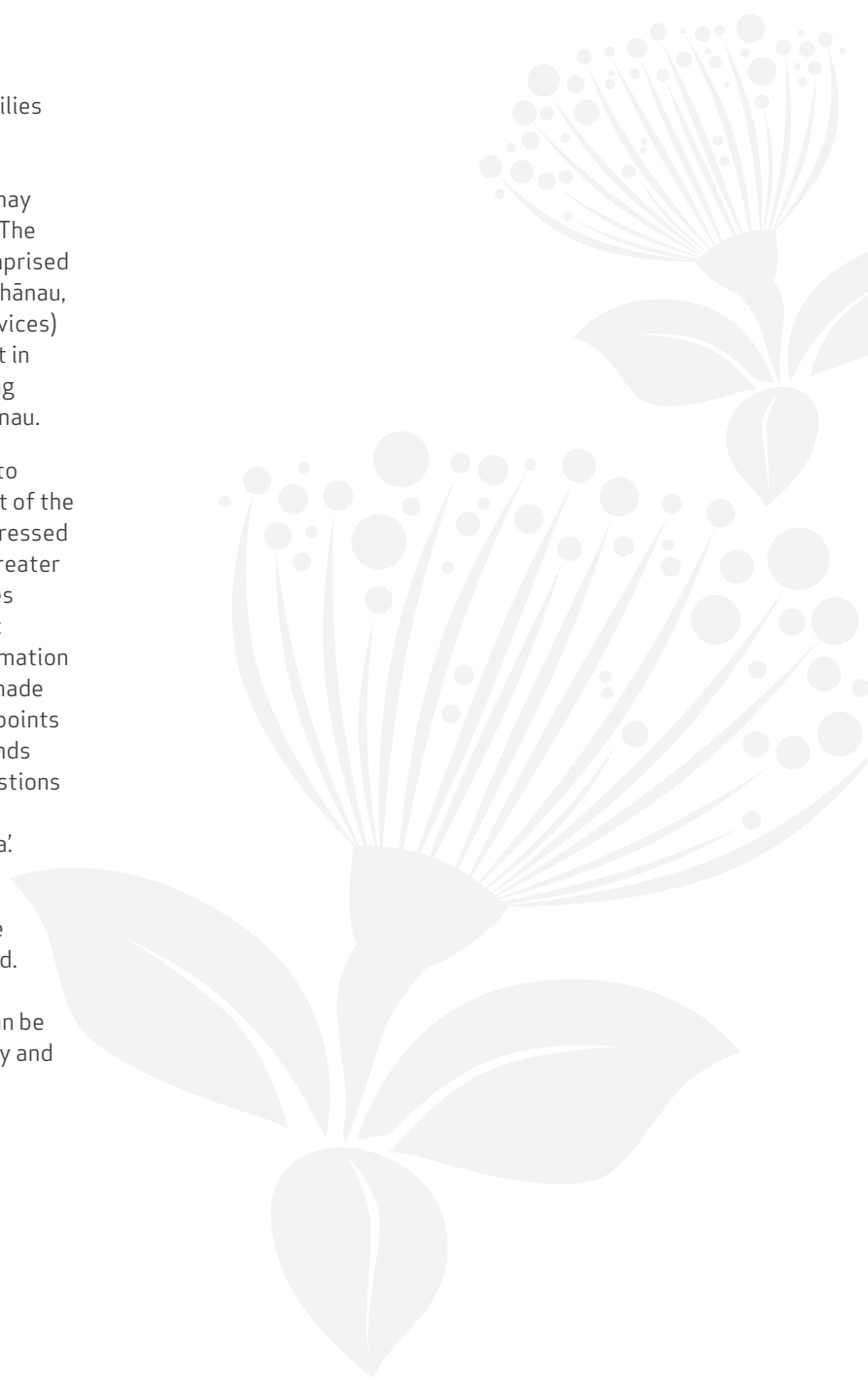
Whānau Ora provides a holistic and overarching framework that locates the whānau at the heart of health and wellbeing. This approach offers an integrated and holistic way to enhance the collective strengths of whānau. Whānau Ora embodies the principles necessary to create thriving relationships, to generate empathy and correct behaviour, and to nurture the kinds of relationships necessary to build family or whānau capacity.

The concepts underpinning Whānau Ora can be applied to all types of relationships in ways that can reduce discrimination within and towards families and whānau. Whānau Ora provides a conceptual and service implementation framework for endorsement of a holistic understanding of mental illness and its causes, family and whānau inclusive practice, and multi-faceted approaches necessary to recovery, healing and wellbeing.

This research has highlighted the power of dialogue in increasing self awareness and acknowledging discriminatory attitudes and behaviours within families and whānau. The discussion forum revealed power imbalances, and facilitated awareness of unhealthy patterns of communication and relationships that may impede recovery and/or exacerbate mental illness. The implementation of a series of dialogue forums (comprised of a mix of consumers, tāngata whai ora, families, whānau, extended families and staff from mental health services) could be an effective strategy for facilitating a shift in understanding about mental illness thereby reducing discrimination within and towards families and whānau.

Many of the strategies participants recommended to reduce discrimination are currently provided as part of the Like Minds, Like Mine programme. Participants expressed a strong demand for these services but called for greater reach, more availability and the provision of services and/or resources tailored to different demographic groups. Participants emphasised the need for information about these kinds of services and resources to be made available as part of routine practice and at various points of contact with mental health services. The Like Minds advertisements were highly commended and suggestions were made to extend the advertisements to target discrimination relating to the label of 'schizophrenia'.

The role of healthy functioning families and whānau in reducing discrimination, as well as in reducing the development of mental illness, cannot be overstated. There is significant potential for future research to explore the ways a broader analytical framework can be utilised to reduce discrimination and increase family and whānau capacity and wellbeing.





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