

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'



Heather Barnett | Alex Barnes

Mental Health Foundation of New Zealand Research Report 2010

 **Mental Health Foundation**
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Ko ngā tapuwae tuku iho o ngā Mātua Tūpuna, he tuara.

“The sacred descending footsteps of our forefathers/ancestors are the backbone.”

Metaphor:

The experiences of your ancestors will provide stability for a durable backbone.

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Mihi

E ngā mana, i ngā reo, i ngā karangarangamaha tena koutou, tēnā koutou, tēnā rā koutou katoa. To all leaders, experts, and relatives we greet you.

Kei te mihi ki nga whānau, turoro morehu hakahawea o te motu. Kua hakatutuki te kaupapa, kua hakamarama nga huarahi me te nonoke mo nga hunga mate hinengaro, me te hakahawea ra nei.

Greetings to all the families and survivors of discrimination. We have completed the subject giving pathways of enlightenment and clarity to how we can better understand the issues and struggle with mental illness and discrimination.

Tēnā koutou, tēnā koutou, tēnā koutou katoa.

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Foreword

The concept of the tuara, the spine, is one which holds great resonance amongst Māori. We refer to our whānau as 'he tuara mo tatou', those that help to support us, to guide us, to enable us to stand strong.

In this research we are told that the experiences of our ancestors provide us with the courage and knowledge we need to survive; they are 'he tuara', literally the backbone for our future.

The focus of this research centres on discrimination both within and towards families and whānau of people diagnosed with mental illness.

A comment from one of the participants expresses the challenges for families in understanding mental illness.

'Who knows you better generally than the people that you live with day in, day out? Who can support you more than anybody? Who can screw you up more than anybody is generally your family, but, also who can actually support your recovery more than anybody else?'

The research explores the experiences for families in living with mental illness and recovery. The derogatory language used to describe mental illness, the dominance of the biomedical model, limited knowledge and negative experiences with services all had an adverse effect on the attitudes and behaviours of families. Families and whānau felt conflicting emotions from shame, embarrassment, denial, fear and blame. They wanted individuals to change their ways; they blamed drug use or personality for negative behaviours. They sought to distance themselves, to exclude; or to seek legal or compulsory medical intervention.

It is a concern that participants from nearly all focus groups identified mental health services as the most prominent source of discrimination towards families and whānau. Discrimination included negative behaviours such as staff not providing information, ignoring cultural worldviews, not consulting or including families and whānau, and blaming and/or criticising parents.

While much of this study raises concerns, the unique context that our families and whānau provide offers room for hope. The report reiterates that strategies to counter discrimination are most effective when determined by families including family members who experience mental illness. One of these, the five Ds approach, explicitly names behaviours identified as discriminatory: behaving in ways that are derogatory, disrespectful, dismissive, demeaning and degrading.

The key conclusion of the research is that healthy, respectful and empowering relationships are critical to positive family functioning. Within this, the framework provided by Whānau Ora offers a way to enhance the collective strengths of whānau, as the pathway to recovery, healing and wellbeing. Dialogue is seen as a powerful source for optimism. Through discussion families often became more self-aware, learning to develop healthy patterns of communication and more constructive relationships.

And that's where we come back to he tuara – the unique context, histories, dynamics, and legacies of whānau and families which become the pathway forward. This, then, is the greatest lesson of this research – to trust in ourselves, to find that after all our greatest solutions lie in our families and whānau.



Hon Tariana Turia, Associate Minister of Health

Preface

The Mental Health Foundation is proud to be part of the Like Minds, Like Mine programme designed to reduce discrimination against people who experience mental illness.

Walk a Mile in Our Shoes provides an in-depth account of the experience of discrimination within families and whānau from the perspectives of people living with mental illness and their families and whānau. The research also explores discrimination towards families and whānau from sources such as mental health services, extended families and society more generally. The research area is complex and charts new territory in understanding discrimination in the unique context of families and whānau.

People living with mental illness, and families and whānau, conveyed a strong message that families can be a rich and valuable source of support. However, some participants also challenged families and whānau to address adversities within families, and to acknowledge discriminatory behaviour. There were widespread calls for changes in the way mental health services engage families and whānau and for a new approach to understanding and treating mental health problems that is holistic and validates different worldviews.

The research revealed that family members who experience mental illness want hope, respect, self determination, and to be listened to by their families and whānau. Families and whānau want these same things from mental health services, from extended families and communities. These qualities and features are undoubtedly fundamental to recovery.

The research offers a simple approach to recognising behaviours that are discriminatory. It emphasises that with appropriate and timely information, education and support, families and whānau will be even better positioned to effectively support a family member. The research highlights the importance of effective communication and positive relationships as key factors in reducing discrimination. Indeed, respectful and empowering relationships are critical to healthy functioning families and whānau, as well as to relationships mental health services and others have with families and whānau. The research report concludes with a renewed call for everyone to work together to challenge discrimination.

The research would not have been possible without the 85 people who shared their personal and heartfelt experiences. My thanks and appreciation goes to each and every one.



Judi Clements
Chief Executive
Mental Health Foundation of New Zealand

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.



chapter 1

Introduction



We are all members of families in one way or another.

Mental Health Commission, 2009b:6

This report gives an account of a research project designed to explore discrimination within and towards families and whānau of people diagnosed with 'mental illness', and to identify strategies to overcome family related discrimination.²

In this introductory chapter, Section 1 locates the research and outlines the theoretical foundations. Sections 2 and 3 discuss concepts of discrimination, and of families and whānau. Sections 4 and 5 outline what has emerged from previous research on discrimination within and towards families and whānau. Section 6 outlines what has emerged from previous research on strategies to counter discrimination within and towards families and whānau. Section 7 outlines models relating to Māori frameworks for health, Pacific models of health, and migrant and refugee perspectives. Other models include family-inclusive practice and advance directives. Section 8 gives a short summary of the methodology.³ For a detailed Literature Review and full references go to <http://www.mentalhealth.org.nz/resourcefinder/listings/search/>

Following the introduction, Chapter Two focuses on participants' accounts of meanings of discrimination in relation to mental illness. Consumer and tāngata whai ora perspectives on discrimination within families and whānau are reported in Chapter Three. Family and whānau perspectives on discrimination within families and whānau are reported in Chapter Four. Chapter Five presents an account of participants' perspectives on discrimination towards families and whānau from across all focus groups. This chapter combines consumer, tāngata whai ora, family and whānau perspectives. Chapter Six discusses the tensions and complexities associated with understanding the meaning of discrimination within and towards family and whānau. A range of strategies to reduce discriminatory attitudes and behaviour, identified by participants, is presented in Chapter Seven. Chapter Eight presents a broader discussion of strategies to reduce family and whānau related discrimination, and provides concluding comments.

1. Locating the research

The research was conducted as part of the Like Minds, Like Mine programme. This programme is based on the principle that discrimination against people who experience mental illness is damaging, and the biggest barrier to recovery.⁴ It is therefore designed to counter stigma and discrimination associated with mental illness. The programme seeks to change discriminatory attitudes and behaviours, to promote human rights, and to reduce discrimination at all levels of society.

The Like Minds, Like Mine National Plan 2007-2013 (Ministry of Health, 2007) outlines the direction of the current programme. Research about discrimination in relation to mental illness is a key component. The purpose of such research is to inform work designed to 'change discriminatory attitudes and behaviour by promoting rights and challenging organisations, communities and individuals not to discriminate' (Ministry of Health, 2007:8). It also contributes to 'removing barriers related to stigma and discrimination to allow people to better access support and information for their whānau' (Ministry of Health, 2007:8).

The current research project provides an opportunity to produce knowledge about discrimination relevant to New Zealand, and to identify strategies for reducing discrimination that are applicable to the local context, as well as to specific population groups. Through identifying discrimination towards families and whānau, this research can also play a role in the identification of institutional discrimination, particularly in relation to mental health services.

1.1 Previous research

This project has emerged from previous research undertaken as part of the Like Minds, Like Mine programme. The Mental Health Foundation's research report, *Respect Costs Nothing: A Survey of Discrimination Faced by People with Experience of Mental Illness* (Peterson, Pere et al, 2004), found that 59 percent of participants had at some time been discriminated against

² For the purpose of the Like Minds, Like Mine programme, the term 'mental illness' is used in this report. However, the authors acknowledge that 'mental illness' is a social construct with contested meaning. See Appendix One for further explanation of terms used in this report.

³ For a detailed account of the methodology and its appendices go to www.mentalhealth.org.nz

⁴ The term 'recovery' has diverse meanings. In this report, the term 'recovery' is understood as 'achieving the life we want in the presence or absence of mental distress' (Mental Health Advocacy Coalition, 2008:8).

by families or friends. This was higher than the percentage for any other source of discrimination.

New Zealand and international research shows that families and whānau can play a crucial role in supporting people's mental health and wellbeing (Boulton, 2005; Dixon, Steward et al, 2001; Durie, 1998; Lumb, 2007). However, research also shows that families and whānau can be the conduits of discriminatory attitudes and behaviour (De Ponte, Bird et al, 2000; Peterson, Pere et al, 2004; Read & Baker, 1996). Conversely, families can also be the subject of discriminatory attitudes and behaviour from external sources, not least from mental health services (Angemeyer, Schulze & Dietrich, 2003; British Columbia Minister of Health Advisory Council on Mental Health, 2002; Östman & Kjellin, 2002).

This research seeks to address both discrimination within families and whānau, and discrimination towards families and whānau. The rationale for this approach is that if families and whānau experience discrimination from external sources, this may impact on the presence of discriminatory attitudes and behaviour within the family or whānau.

1.2 Theoretical foundations

In accordance with the Like Minds, Like Mine programme to counter discrimination, this research is grounded in a human rights approach and informed by a social model of disability. A human rights approach asserts 'the dignity and value of all people and the right to be free from discrimination' (Ministry of Health, 2007:3). Within a human rights framework, participation, empowerment, the absence of discrimination and accountability by those in authority are all integral to ensuring rights (Human Rights Commission, 2004). A social model of disability is defined as 'a process that happens when one group of people create barriers by designing a world only for their way of living' (Minister for Disability Issues, 2001:1). As stated in the Like Minds, Like Mine National Plan 2007-2013, 'disabling attitudes and behaviours create barriers to participation in society' (Ministry of Health, 2007:3). The Treaty of Waitangi informs the Like Minds, Like Mine National Plan 2007-2013 and is integral to the current research.

2. The concept of discrimination

This research is specifically about discrimination, and the term 'discrimination' is used throughout the report. Because participants sometimes used the term 'stigma' as part of their talk about discrimination, this is also used where appropriate. Participants adopted their own meaning for 'discrimination' during the research process.

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). The New Zealand Human Rights Act 1993 (the Act) includes 'psychological disability' and 'psychiatric illness'⁵ as prohibited grounds for discrimination in the provision of goods and services. Discrimination against relatives or associates of people with a disability is also prohibited.

Discrimination involves negative and differential treatment 'on the basis of being a member of a particular social group that is considered inferior' (Mental Health Commission, 2004:67). Discrimination involves certain acts or failures to act that can lead to exclusion or loss of status (ibid).

Discrimination is 'a social process leading to the exclusion of certain people or groups from their usual and rightful participation in their communities...and [preventing] full citizenship' (Mental Health Commission, 2004:v). Discrimination can violate people's human rights and may occur systemically, organisationally, within communities, families or whānau, and/or between individuals (Mental Health Commission, 2007a; Ministry of Health, 2007).

Finally, 'discrimination of all kinds has a detrimental effect on mental health,' (Penn & Wykes, 2003:203). Mental illness exists in the context of other power relationships, including, for example, gender, race, class, sexual orientation and/or physical disability (Belle & Doucet, 2003; Corrigan, Thompson et al, 2003; Fernando, 2006; Hill, 1998; Stoppard, 2000).

⁵ Human Rights Act 1993 - 1994 amendment to include disability.

3. Concepts of family and whānau

There are no universal definitions of the terms 'family' or 'whānau'. These concepts are context bound, inextricably linked to culture, and differ depending on their use in a variety of social, economic, legal and other circumstances.

Particular definitions have been adopted in the context of this research. 'Family' has 'a broad and inclusive' meaning that recognises a diversity of households and living arrangements (Families Commission, 2009:3). 'Whānau' means 'extended family' or 'family group'⁶. Whānau also embodies whānaungatanga⁷ and whakapapa⁸, often involves living in intergenerational households, and is integrally connected to broader hapū and iwi relationships (Mental Health Commission, 2009b; Ministry of Social Development, 2009).

Families and whānau focus groups were mainly made up of people who live with or support a family member whose experience of mental illness has significant and debilitating impacts and has been ongoing for an extended period of time (including parents, adult children, partners or ex-partners and siblings). Moreover, tāngata whai ora⁹ sometimes spoke of whānau of choice (rather than whānau of origin or whānaunga¹⁰) when talking about the people whom they currently embraced as whānau.

4. Discrimination within families and whānau

Families of people with experience of mental illness are likely to have more contact with someone who experiences mental illness than anyone else. They are also likely to know about discrimination because they may experience associative discrimination themselves. However, family members do not typically have equal status. Indeed, the family member who experiences mental illness often loses status and power following a diagnosis, and other family members may feel they do not

know or recognise aspects of the person's experiences and behaviours.

Research suggests that families can be a key source of discrimination toward family members who experience mental illness, with reported proportions ranging from 21 percent to 59 percent (De Ponte, Bird et al, 2000; Dickerson, Sommerville et al, 2002; Peterson, Pere et al, 2004; Wahl, 1999; Dickerson, Sommerville et al, 2002). The nature of discrimination within families takes a variety of forms, as shown in Figure 1.

Figure 1
Forms of Discrimination Within Families

- Family distancing themselves
- Inappropriate or hurtful comments (e.g. 'you're just lazy')
- Name calling
- Behaving as if mental illness is contagious
- Providing unhelpful or flippant instructions (e.g. 'snap out of it')
- Showing a lack of interest in mental illness and avoiding the topic
- Not wanting others to know
- Considering people with experience of mental illness as stupid or unreliable
- Treating people as children
- Blaming the individual for family problems (De Ponte, Bird et al., 2000)

⁶ Māori Dictionary <http://www.maoridictionary.co.nz/index.cfm?dictionaryKeywords=whanau&n=1&idiom=&phrase=&proverb=&loan=&search.x=31&search.y=14>. Retrieved 29 April 2010. All further te reo definitions are taken from this online Māori dictionary on the same date.

⁷ Whānaunga means relative, relation, kin, blood relation. Whānaungatanga means relationship, kinship, sense of family connection - a relationship through shared experiences and working together which provides people with a sense of belonging.

⁸ Whakapapa means genealogy, genealogical table, lineage, descent.

⁹ Tāngata whai ora means Māori who have experienced mental illness and are on the pathway towards recovery (Ministry of Health, 2008:14). This term is commonly used to refer to Māori people labelled as experiencing mental illness.

¹⁰ Whanaunga means relative, relation, kin, blood relation

Views and attitudes of families and whānau towards people diagnosed with mental illness can reflect the place of a family or community in society, the social influences operating, historical familial experiences, as well as general perceptions and specific cultural beliefs about mental illness. In some cultures the stigma and discrimination associated with mental illness is so severe and pervasive that the family themselves can believe common negative myths and stereotypes about mental illness.

4.1 Family and whānau support roles

Relationships with family and whānau are often the closest relationships people have. When a family member experiences mental illness, families (or individual family members) often assume a support role. Mostly it is women, and often mothers, who take on this role.

However, many studies have suggested that being a primary support person for a family member with experience of mental illness can lead to significant negative impacts. Families' internalised stigma can also mean delaying seeking help for the family member concerned. Some research suggests difficulties in relationships between families and the family member who experiences mental illness. However, being a family support provider may also have positive aspects.

The mental and physical health of family members who provide support within the family is clearly influenced by a range of complex, dynamic contextual factors. Many primary support people also have responsibility for children and other dependent family members, for paid employment, and for the management of the household. Family support people's health is also affected by the adequacy of household income and material resources, and the availability of social networks and personal support. The level of engagement and satisfaction with mental health services and support from other services all impact on the family support role.

4.2 Childhood adversity, family dysfunction and subsequent mental health problems

New Zealand has been shown to have a high rate of childhood adversity, including sexual abuse, physical abuse, neglect, domestic violence, systematic terrorising, ignoring, isolating and/or degrading behaviour. It

frequently involves multiple forms of abuse occurring simultaneously. It is associated with an increased lifetime likelihood of mental illness, substance abuse and/or other negative outcomes during adolescence and/or adulthood.

A history of childhood adversity is critical to understanding the dynamics of current family and whānau functioning, and the role families can play in contributing to and/or maintaining psychological distress in the present. Inevitably, the impacts of childhood adversity will have implications for how consumers or tāngata whai ora currently engage with their family (and vice versa), the likelihood of discrimination within the family or whānau, and the place of the family or whānau of origin in terms of their involvement with mental health services.¹¹ There may be times when it is entirely appropriate for families of origin not to be involved in a family member's recovery process or in contact with mental health services.

5. Discrimination towards families and whānau

Families can also be the subject of discrimination from other sources, particularly mental health services (Phelan, Bromet et al, 1998; Larson & Corrigan, 2008; Lumb, 2007). Discrimination can negatively impact on family and whānau abilities to be part of a supportive network, to receive support themselves and to assist the process of recovery.

Because of a general societal tendency to treat mental illness as a source of shame and embarrassment, families may face discrimination by virtue of being associated with a family member who experiences mental illness. Lack of information about mental illness and recovery, and of access to appropriate services and support, can fuel family fears.

5.1 Discrimination by mental health services

Mental health services can themselves be a source of discrimination towards families. Within western cultural contexts, they have traditionally focused on the individual and assumed that illness and disease is experienced in a universal way.

¹¹ It is noted that not all 'trauma' or experience of 'adversity' arise in the context of the family. Further, some people who experience psychological distress, or are diagnosed with mental illness, do so in response to a seemingly 'natural' course of life events.



Families have frequently reported exclusion, discrimination and/or negative treatment from mental health professionals, who may see them as causing the onset of mental illness. Family members can feel that their intimate knowledge of a family member is not valued by mental health professionals, and that they have little power in relation to engagement with mental health services.

This can lead to a sense of alienation, which creates space for the development of negative and/or discriminatory attitudes within the family. Moreover, these attitudes can lead to the exclusion of the family member who experiences mental illness, and impede the pursuit of mutual family goals.

Research suggests that there is often little engagement with families or whānau in most mainstream mental health services in New Zealand, including a lack of information and a lack of respect or acknowledgement of families, as well as insufficient contact and support from mental health professionals. Recent New Zealand research suggests systemic issues sometimes limit support for family best practice within mental health services. Family dissatisfaction with mental health services has led to calls for 'family inclusive' practice.

In a bicultural and multi-ethnic society, such as Aotearoa New Zealand, competing cultural worldviews and perspectives of health and illness must also be central to the theories and ideologies that inform mental health practice. Social determinants of health and illness are being increasingly recognised, and the role of human rights and social development acknowledged as fundamental aspects of creating a healthy population.

6. Strategies to reduce family and whānau discrimination

Some research suggests that reducing discrimination within families and amongst mental health professionals may require different strategies from reducing it in the general population. Because strategies that may be effective for families in the early stages of mental illness may not be the most effective at later stages, strategies also need to be tailored to the changing circumstances of families over time.

Suggested targeted strategies to reduce discrimination within and towards families and whānau include effective communication; support and advocacy; and education and training. These interventions are interrelated and reinforce one another.

6.1 Effective communication

Services based on holistic and strengths based approaches to mental illness provide the necessary framework for appropriately and effectively engaging families and whānau in a way that is likely to reduce discrimination. Peer led services grounded in recovery principles, and involving collaboration with families and whānau, are known to enhance consumer and tāngata whai ora recovery.

Providing accurate, timely and appropriate information about mental illness and service provision can enhance family and whānau roles as support people, facilitate understanding of and participation in the recovery process, and reduce stress. When family and whānau are provided with information and appropriate and timely support, this can help to reduce stigma, promote mental health, and potentially prevent or reduce discrimination within the family and whānau.

6.2 Support and advocacy

Support and advocacy is concerned with the rights and needs of people with experience of mental illness and their family and whānau, but is not limited to clinical settings. It must also be relevant and accessible to people within the community.

Face-to-face contact with family advocacy organisations and peer support groups in the community have been shown to help generate supportive environments and promote self efficacy and advocacy strategies for families.

6.3 Education and training

In terms of reducing family related discrimination, education and training about discrimination is most effective when it occurs for individuals, community, and society.

7. Models of mental wellbeing and illness involving families or whānau

Various models of mental wellbeing and illness have been developed to provide a holistic and culturally grounded conceptualisation of mental illness, practice and service delivery. Central to these models of mental wellbeing and illness is the place of families or whānau.

7.1 Māori frameworks for health

Amongst Māori, the health of the individual is inextricably connected to the health of the collective. For example, Te Whare Tapa Whā (the four sided house), which names and acknowledges four pillars of health and wellbeing, explicitly includes whānau alongside te taha wairua (spiritual wellbeing), te taha hinengaro (mental wellbeing) and te taha tinana (physical wellbeing) (Durie, 1998). Kaupapa Māori services¹² and Māori mental health services have accordingly placed much emphasis on whānau involvement in the early detection, prevention and on-going support of a family member.

Tāngata whai ora sometimes refer to other tāngata whai ora as whānau. Where whānau relationships are strained or have broken down, services may provide mediation between tāngata whai ora and their whānau, facilitate connections with those who can lead a system of intervention (such as marae justice, where abuses have occurred), or even encourage tāngata whai ora to take time out from their whānau until such time as relationships improve (Durie, 2001:176).

Whānau ora, which constitutes the foundation for recovery for Māori, has historically been at the centre of Māori worldviews and has shaped Māori models of health for many years (Durie, 1998, 1999a; R. Pere, 1991). In this report:

- **whānau ora** (lower case) is used for the concepts underpinning whānau ora currently used in the health system

- **Whānau Ora** (upper case) is used for the recently endorsed model for service provision reflecting partnership and a new set of relationships between tāngata whenua and the Crown.

Both whānau ora and Whānau Ora are integral to reducing discrimination within and towards whānau.

Whānau ora - a conceptual framework

The overall aim of whānau ora is that 'Māori families are supported to achieve their maximum health and wellbeing, and provides an overarching principle for recovery and maintaining wellness' (Ministry of Health, 2008:14). Whānau ora locates whānau and cultural identity at the heart of Māori health and wellbeing and encompasses a context of inclusiveness, collectiveness and interdependence leading to strong whānau capacity (The Mental Health Assessment and Outcomes Initiative Tāngata Whaiora Roopu cited in Mental Health Commission, 2007a:151). Figure 2 identifies the concepts typically embodied by whānau ora.

Figure 2 Concepts of whānau ora

- **Whānau ora - thriving relationships based on common values and belief Whānau centred design and delivery of services**
- **Tino rangatiratanga - self determination**
- **Tūrangawaewae - place of standing, home**
- **Ngākau māhaki - empathy**
- **Tikanga - right behaviour**
- **Whāunaungatanga - relationships**
Mental Health Commission, 2007a:154

In essence, the theory and practice that informs mainstream mental health service provision reflects an individualistic, biomedical, symptom focused approach to understanding mental illness. This approach sits in stark contrast to the holistic, relational and whānau centred paradigm embodied by whānau ora. Moreover, mainstream services often exclude whānau from decision making processes and a lack of cohesion of services disallows whānau approaches to intervention (Ministry of Social Development, 2009).

¹² Services based on Māori worldviews, philosophies, beliefs, customs and practices.

Whānau Ora – a service delivery model

Whānau Ora, a comprehensive, cohesive, multi-sectoral, iwi-led approach to whānau wellbeing, is currently being implemented (Ministry of Social Development, 2009). The report of the Whānau Ora Taskforce documents a coherent and genuinely multi-sectoral approach to interventions with whānau. The Taskforce identifies five key elements and seven underlying principles of a whānau centred approach (shown respectively in Figures 3 and 4).

In essence, the theory and practice that informs mainstream mental health service provision reflects an individualistic, biomedical, symptom focused approach to understanding mental illness. This approach sits in stark contrast to the holistic, relational and whānau centred paradigm embodied by whānau ora. Moreover, mainstream services often exclude whānau from decision making processes and a lack of cohesion of services disallows whānau approaches to intervention (Ministry of Social Development, 2009).

Figure 3 Key Elements of Whānau Ora

- Whānau action and engagement
- Whānau centred design and delivery of services
- Iwi leadership
- Active and responsive government
- Appropriate configuration of funding

Figure 4 Key Principles of Whānau Ora

- Ngā kaupapa tuku iho (reflecting relationships and collective strength and the use of Māori values, beliefs, obligations and responsibilities to guide whānau)
- Whānau opportunity (access to information, technology, expertise, cultural knowledge and resources and Te Ao Māori)
- Best whānau outcomes (focusing on increasing whānau capacity to undertake functions for the wellbeing of the whānau as well as individual family members)
- Coherent service delivery (ensuring a cohesive, whole-of-whānau, integrated service delivery)
- Whānau integrity (strengthening the integrity of the whānau, whānau accountability, innovation, dignity, positive attributes, morale and capabilities)
- Effective resourcing (match the level of resourcing to the size of the task and tie resourcing to results)
- Competent and innovative provision (assisting whānau to achieve effective levels of self management, self determination and leadership, while addressing and providing effective responses to urgent problems for the whānau and individual whānau members)

The Whānau Ora model of service delivery, and its underlying conceptual framework, has significant implications for the Like Minds, Like Mine programme, in terms of future directions for reducing discrimination in relation to mental illness within and towards whānau.

¹⁴ Iwi means extended kinship group, tribe, nation, people, nationality, race. The term often refers to a large group of people descended from a common ancestor.



7.2 Pacific models of mental wellbeing and illness

Despite significant diversity amongst Pacific communities, Pacific people's share culturally bound understandings of the centrality of family in maintaining mental health (Agnew, Pulotu-Endemann et al, 2004; Samuel, 2008). For example, the Fonofale model accentuates an holistic approach to wellbeing within which the family is central (Mental Health Commission, 2001). There is often little delineation between the mental health status of the family member and that of their own immediate and extended family (ibid). Within some Pacific cultural belief systems, a condition often represented by disturbed behaviour can be seen as the manifestation of an external spiritual force (Faleafa, Lui et al, 2007). This can include ancestral spirits who have taken possession of the person because the person, or the person's family, has broken tapu through offending family or spirits (ibid).

In order to address the diversity amongst Pacific people, specific ethnic and culturally relevant Pacific resources regarding mental health, wellbeing and recovery are in the process of ongoing development (Faleafa, Lui et al, 2007; Samuel, 2008).

7.3 Migrant and refugee perspectives

Migrants and refugees are very distinct groups and have a diverse range of experiences, perspectives, needs and awareness of mental illness. Current research is limited regarding migrant and refugee families and communities in New Zealand.

Refugees come from very diverse cultures and have typically suffered high levels of violence, human rights abuses, persecution, torture and/or separation from families. In conjunction with these experiences, the shift to a new country, where cultural mores and expectations are very different, can lead to significant distress (ibid). However, mental distress is often viewed as something which must be hidden, so when people from refugee backgrounds experience mental illness they can feel very vulnerable and isolated. Family roles can often change as a result of mental illness, yet families often have

little knowledge of coping strategies. These different influences and experiences of re-settlement shape views and attitudes about mental illness.

People migrate to New Zealand from a wide range of cultural backgrounds with beliefs and perspectives of mental illness that are very different from those of 'mainstream' society. Migrants can experience a range of difficulties adapting to a new culture. Migrants from different cultures are likely to face greater barriers to mental wellbeing than those who share a common New Zealand culture, and may experience greater difficulties accessing appropriate mental health support.

7.4 Family-inclusive practice

Family-inclusive, strengths-based, recovery models of mental health service provision have been found to lead to improved outcomes for both individuals and families accessing services. Family-inclusive practice involves: collaboration and involvement when receiving services; provision of adequate support and resources for families, as well as involvement in planning, developing and delivering services; and engagement with services in a way that is beneficial to both families and services. This approach requires balancing the needs of families with those of individual family members who experience mental illness, while still adhering to a human rights framework.

7.5 Advance directives

Advance directives¹⁴ can also be a useful tool for assisting families to make decisions on behalf of the family member who experiences mental illness when the consumer has agreed for this to happen. An Enduring Power of Attorney, or a care plan, that details such decisions can also help strengthen the role of family and whānau in care and treatment decisions. Wellness Recovery Action Plans (WRAP), or equivalent consumer/tāngata whai ora self-written documentation (which might include an advance directive), instructing and nominating specific people who may act on their behalf, may also be beneficial.¹⁵

¹⁴ A formal written instruction which outlines the choices of a consumer or tāngata whai ora about their future mental health treatment.

¹⁵ Personal communication, Dr Dean Manley, Like Minds, Like Mine Project Manager, Mental Health Foundation of New Zealand, 13 April 2010.

8. Methodology: Summary of how the research was conducted

This summary briefly outlines the aims of the research, the methodology, the methods used to undertake the research, demographic information, data analysis and research limitations. For a detailed account of the methodology and relevant appendices, see <http://www.mentalhealth.org.nz/resourcefinder/listings/search/>

8.1 Aims

The aims of the research were to:

- Inquire into the views and attitudes about discrimination held by families and whānau of people labelled with mental illness
- Explore the nature of discrimination within and towards family and whānau of people labelled with mental illness
- Identify ways to reduce discrimination within and towards families and whānau of people labelled with mental illness

8.2 Preparation

A reference group was established during the conceptual phase of the research to provide advisory input throughout the duration of the project. Members included Māori, consumer advisors, family advisors, refugee background, researchers and other professionals working in the mental health sector.

A range of protocols were used to address ethical issues, and facilitators were well briefed about the requirements of ethical research practice. All ethical procedures were in

accordance with the Health Research Council's Guidelines on Ethics in Health Research 2006 (Health Research Council, 2006) and SPEaR Good Practice Guidelines June 2008 (Social Policy Evaluation and Research Committee, 2008).

8.3 Focus groups

The research involved nine focus groups, with a total of 85 participants from the Auckland, Manawatu, Wellington and Christchurch regions. The focus groups were comprised of:

Consumers/tāngata whai ora

- One group of Māori
- Two general groups (mostly Pākehā)

Families/whānau

- Two general groups (mostly Pākehā)¹⁶
- One group of Māori¹⁷
- One group of Chinese people¹⁸
- One group of young people 18-25 years of age

Consumer and family

- One group of pan-Pacific people¹⁹

¹⁶ Another focus group with people who have a refugee background was initially planned. Due to a range of factors, this group was unable to be formed.

¹⁷ While two whānau focus groups were originally planned, only one was formed.

¹⁸ This focus group was unique in that it was comprised of both consumers and families of people who experience mental illness. There are different perspectives on the merits and limitations of including consumers and families in the same focus groups when addressing sensitive issues such as discrimination within the family. However, this group was led by a Pacific facilitator, tapped into Pacific networks, and was deemed appropriate in the context in which the focus group worked.

¹⁹ This focus group was unique in that it was comprised of both consumers and families of people who experience mental illness. There are different perspectives on the merits and limitations of including consumers and families in the same focus groups when addressing sensitive issues such as discrimination within the family. However, this group was led by a Pacific facilitator, tapped into Pacific networks, and was deemed appropriate in the context in which the focus group worked.

Table 1 shows the demographic characteristics of the people who participated in the focus groups.²⁰

Table 1 Participant Characteristics – Focus Groups

Characteristic		Number
Gender	Women	60
	Men	22
	Unknown	03
Ethnicity	New Zealand European/ Pākehā	33
	Maori	23
	Pacific	17
	Chinese	09
	Unknown	03
Age (years)	18-24	09
	25-39	23
	40-59	37
	60+	13
	Unknown	03
Focus Group type		
Consumer or tāngata whai ora		29
Family or whānau		56

Consumer/tāngata whai ora focus groups

The focus groups involving people with experience of mental illness were mainly made up of people who work in the mental health sector, for example as consumer advisors or consultants, cultural advisors and/or mental health promoters. Almost all participants in these groups reported that they had been in contact with mental health services and had been diagnosed with a mental illness.

Families' and whānau focus groups

Families' and whānau focus groups were mainly made up of people who live with or support a family member whose experience of mental illness has significant and debilitating impacts and has been ongoing for an extended period of time (including parents, adult children, partners or ex-partners and siblings). Most people in the families' and whānau focus groups had had contact with mainstream mental health services, with most involving a family member's admission to a District Health Board inpatient unit. A minority of families and whānau had had contact with kaupapa Māori and Pacific mental health services.

Pan-Pacific focus group

People who attended the pan-Pacific focus group represented a wide range of positions within the family context. Some people spoke of being a parent or growing up with a sibling or parent who experienced mental illness.

Process

Focus groups were typically co-led by facilitators from the region where the group was held. In most groups, brief scenarios were read out by one of the facilitators to stimulate the initial discussion. The scenarios reflected common situations involving discrimination relating to mental illness. The facilitator also used a list of questions as prompts for group discussion. In conjunction with full transcripts and audio recordings, the facilitators' notes and summary reports were used as part of the process of analysis.

²⁰ Demographic information was not provided for three people.

8.4 Discussion forum

There was also one multi-region discussion forum, as a means to bring consumers and family members from each of the focus groups together. The forum had a more even ratio of consumers to family and whānau.

A total of 19 people attended the multi-region discussion forum. Three of these people had not attended a focus group. The majority of participants were women aged between 40 and 59. There were similar numbers of Māori and Pākehā, and a proportionate representation of Pacific and Chinese people.²¹ Table 2 shows the demographic characteristics of those who attended the discussion forum.²²

Characteristic		Number
Gender	Women	14
	Men	05
Ethnicity	New Zealand European/ Pākehā	07
	Maori	06
	Pacific	04
	Chinese	02
Age (years)	18-24	01
	25-39	06
	40-59	10
	60+	02
Focus Group type		
Consumer		08
Family or whānau		11 ²³

Process

Two health professionals with facilitation experience were contracted to facilitate the discussion forum (the forum). The structure, questions and activities for the forum were developed in conjunction with the facilitators.

The forum focused on exploring the meaning of discrimination, better understanding the nature and dynamics of discrimination within and towards families through collective dialogue, and identifying and developing strategies to counter discrimination. The forum discussion was digitally recorded and later transcribed.

Data analysis

A grounded theory approach was used to analyse the research data. Grounded theory has been defined as theory or concepts 'derived from data, systematically gathered and analyzed through the research process' (Strauss and Corbin 1998 cited in Bryman, 2008:541). In this approach, data collection and analysis typically 'proceed in tandem, repeatedly referring back to each other' (Bryman, 2008:541). In this sense, analysis of data from the focus groups was integral to the development of questions for the discussion forum and the analysis of data from the forum.

Managing and analysing lengthy transcripts containing unstructured data, the use of multiple data sources and multiple methods can be challenging. However, a comprehensive coding process was undertaken to identify dominant themes. Each section of coded data was then analysed to identify commonalities and differences across groups. Complexities and contradictions in the data were also identified.

²¹ The high proportion of women reflects the over-representation of women in family support roles.

²² It is noted that the notion of 'ethnicity' is fluid and contestable. For simplicity, these figures are based on the ethnicity recorded first by participants on the demographic information form. In reality, many people identified themselves as having multiple ethnicities, and some groups targeting particular populations included people from other ethnicities (e.g. Pākehā in the whānau and tāngata whai ora groups; Māori in the Pacific group; and predominantly Pākehā, but a range of ethnicities, in the general groups).

²³ The three people who had not attended the focus groups identified as having experience of mental illness and are included as part of the Consumer/ Tāngata Whai Ora number. It is noted that some people who attended the families' and whānau focus groups also reported having past or present experience of mental illness. No data was collected for this demographic.

chapter 2

Meanings of Discrimination



Being treated unfairly or less favourably than another person in the same or similar circumstances.

New Zealand Human Rights Commission

In this chapter, the research participants' perspectives on meanings of discrimination are discussed. These findings are primarily based on an analysis of the dialogue that took place at the discussion forum, which included families, whānau, tāngata whai ora and consumers. In this sense these findings reflect a collective dialogue between the various groups of participants, and are presented as one voice. While there was some variation between participants, there was general consensus about meanings of discrimination in relation to mental illness. Where distinct differences related to the meaning of discrimination were apparent, these are reported separately.

A predetermined definition of discrimination was not used during the research process. This approach is underpinned by the principle of self determination and the importance of allowing people to define their own meanings. Participants were therefore free to use and interpret 'discrimination' in ways that aligned with their own perceptions and experiences.

During the process of analysing the data from the nine focus groups, it became clear that participants held quite wide and varied interpretations of 'discrimination'. At times it seemed that definitions were very broad and encapsulated a range of issues. While many of the issues seemed to reflect abuses of power or other unacceptable ways of treating people, it is likely that some of the attitudes and behaviours may not have been about discrimination. Conversely, there were times when families spoke of holding beliefs or behaving in ways that seemed highly discriminatory, but which they did not define or perceive as discrimination.

To gain a better understanding of what participants meant when they used the term 'discrimination', we included direct questions at the discussion forum to address meanings of discrimination. (See Appendix Eight - <http://www.mentalhealth.org.nz/resourcefinder/listings/search/>).

This chapter discusses the following key themes:

1. Meanings of discrimination – general
2. Meanings of discrimination – mental illness specific
3. Meanings of discrimination – reflected in language
4. Meanings of discrimination – labels
5. Multi-dimensional discrimination
6. Expanding awareness of discrimination – experiences and exposure
7. Meanings of discrimination – encapsulating mental health services

1. Meanings of discrimination – general

Despite participants' diverse social locations and roles within their families and whānau, there was widespread agreement that discrimination involves labelling others and means the same thing across different structural dimensions (e.g. racism, sexism, homophobia, mental illness). Participants also commented that although discrimination may be unintentional, it arises from common underlying factors such as 'fear [and] ignorance', and 'a lack of commitment to try to understand, dialogue and love'. All forms of discrimination were regarded as leading to negative outcomes such as 'pain, shame [and] hurt'.

2. Meanings of discrimination – mental illness specific

Most participants agreed that discrimination associated with mental illness was 'obvious', easily identifiable, and could be readily differentiated from other issues or forms of discrimination. Participants provided a range of examples of the ways in which discrimination related to mental illness is signified. These examples are shown in Figure 5.

²⁴ Although not directly probed about the meaning of discrimination, many focus group participants identified discriminatory language as part of their discussions about discrimination.

²⁵ These questions were included as part of a group brainstorm and dialogue, and as part of paper-based questions which individual participants responded to in writing.

²⁶ Participants were diverse. For example, some had experience of mental illness, others of supporting a family member diagnosed with mental illness. Participants ranged from under 25 to over 60 years of age, were of diverse ethnicities, and included mothers, fathers, aunts, partners, adult children and siblings.

Figure 5

Signifiers of Mental Illness Specific Discrimination

- Negative or derogatory language and terms (e.g. 'you're mental')
- The pace of speech and the way people are spoken to (e.g. speaking very slowly and/or loudly)
- Negative or aggressive non-verbal communication and body language
- Pessimistic written communications (e.g. notes in medical records)
- A condescending or superior attitude
- Being ignored, avoided, excluded, marginalised
- Not being listened to or taken seriously
- Having one's worldview dismissed
- Judgments based on oversimplified 'text book' knowledge
- Pathologising all behaviour and/or emotion (e.g. crying, laughing)
- Not being given information or included in communication about issues that impact on the consumer, family or whānau

A minority of participants regarded discrimination associated with mental illness as quite 'blurry'.

Most participants regarded mental illness specific discrimination as more common, pervasive, explicit, socially acceptable and stigmatising than discrimination.²⁷ Participants reported that mental illness specific discrimination was present in families and whānau in a way that racism and sexism were not. This meant that in their view, the family was not necessarily a 'safe' place for people who experience mental illness in a way that it would usually be safe in terms of race.

In the case of mental illness even one's own family practise discrimination [so the] discrimination is from within whereas other [types of discrimination are] from outside the family.

The presence of mental illness specific discrimination was also regarded as 'society wide', in that it is prevalent across extended families, friends, communities, mental health services, government services and wider society.

3. Meanings of discrimination – reflected in language

Participants were asked what words they would use to express the meaning of discrimination. Participants were not initially asked to consider discrimination in relation to mental illness per se. However, it was evident during the discussion that most based their understanding of discrimination on lived experiences in relation to mental illness. Sometimes experiences of discrimination also reflected racism and being treated unfairly on the basis of age. Despite having only about 10 minutes to brainstorm, participants identified over 60 nouns and adjectives to express the meaning of discrimination. Examples are included in Figure 6.

Figure 6

Words to Express Meanings of Discrimination

Abandoned Abnormal Assumptions Belittled
Betrayed Blamed Caged Cast out Coerced
Contagious Controlled Denial Different
Embarrassment Excluded Failure Forsaken
Guilty Helpless Humiliated Inhuman
Internalised stigma Isolated Judged Limited
Lonely Loss of status Misunderstood Not
acknowledged Ostracised Other Outcast
Powerless Preconceptions Put in a box
Second class Shameful Stereotypes Stigma

²⁷ It is apparent that there are many parallels between discrimination related to mental illness and sexual orientation in ways that differ from racism and sexism. Corrigan (2005) discusses this issue in terms of the concealment (or invisibility and 'passing'), the age of 'onset' (or age related identity/development), and the type of stigma associated with mental illness and sexual orientation.



Some participants also identified words connected to a biomedical model and mental health services (such as 'diagnosis', 'hereditary', 'labels', 'monocultural', 'psychiatrists', 'classified', 'side effects' and 'unmedicated') to express meanings of discrimination. The language which participants used to talk about their experiences of discrimination reflected a strong sense of being 'Othered' or of being constructed as different from others thereby creating a 'them/us' dichotomy.

4. Meanings of discrimination – labels

Many participants reported that discrimination in relation to mental illness involved the use of derogatory labels and name calling that would not be regarded as acceptable in relation to other kinds of discrimination (e.g. related to ethnicity or physical disabilities). Participants reported the widespread use, within and beyond their families and whānau, of words such as 'mental', 'mad', 'crazy', 'nutty', 'nutter', 'psycho', 'freak', 'bad', 'a failure', 'black sheep', 'pōrangī',²⁸ 'vale',²⁹ 'valea',³⁰ 'fakatafaa'³¹ and 'puaka auouo'.³² Many of these words had been identified in focus group discussions with consumers, tāngata whai ora and Pacific families and consumers.

Pacific participants regarded discrimination and the use of discriminatory language in relation to mental illness within their families and Pacific communities as particularly marked.³³ Being called names or referred to as an animal, such as a dog, vulture or pig, was common. This form of discrimination was thought to reflect the fact that derogatory labels specific to 'mental unwellness' are ingrained in some Pacific languages. For instance, the terms 'vale' and 'valea' are part of everyday Samoan language, and the term 'fakatafaa' is commonly used within the Tongan language. While also applicable across other ethnicities and languages, this type of derogatory language was thought to reflect 'cultural conditioning, artificial stereotypes and preconceived ideas'.

5. Multi-dimensional discrimination

Several participants spoke of the multi-dimensional nature of discrimination as part of the discussion around meanings of discrimination. Many Māori and Pacific participants (consumers, family, tāngata whai ora and whānau) commented that stereotypes attached to perceptions of their ethnicity meant that they were also subject to racism. This was reflected in the way families and consumers were treated by mental health services, and the diagnoses given to 'brown' consumers by clinicians. In this way, race and mental illness interacted, compounding the experience of discrimination. We return to this issue in Chapter Five as part of the discussion of findings in relation to discrimination towards families and whānau.

6. Expanding awareness of discrimination – experience and exposure

During the dialogue about meanings of discrimination, many participants spoke about

the influence of being labelled with mental illness, or of being a family member of someone who has experience of mental illness, in terms of heightening their awareness of discrimination. For many, personal experience in relation to mental illness provided new insights and became a catalyst to gaining or intensifying an understanding of discrimination in a way that had not been present before.

When I was given a diagnosis I was scared and confused. What I thought someone else with mental illness was, I now was.

[Mental illness within the family] created a deep sense of awareness of the depth and consequences of discrimination on my son's life...I suffered with his experience.

²⁸ Meaning lunatic, insane, mad, crazy.

²⁹ Meaning a fool, imbecile. <http://www.samoalive.com/NFL/V.htm>. Retrieved 10 September 2009.

³⁰ Meaning ignorant, stupid. <http://www.samoalive.com/NFL/V.htm>. Retrieved 10 September 2009.

³¹ Meaning crazy, simple (personal communication, Sam Samuel, Vakaola, Porirua).

³² Meaning crazy pig (personal communication, Sam Samuel, Vakaola, Porirua)

³³ This section draws on data from both the Pacific focus group and the discussion forum.

For many participants, personal exposure to mental illness led to information seeking and greater knowledge about mental illness. Some participants also discussed positive changes in their behaviour towards people who experience mental health challenges. Several participants spoke of being more ‘tuned in’ to the discriminatory language others use to talk to, or about, people who experience mental illness. Personal exposure to mental illness also meant becoming more aware of the consequences of discrimination, the stigma associated with mental illness, and the impact of discrimination on individuals’ and families’ lives.

[Mental illness within the family] has made me more aware of my own discriminatory behaviour...[in the past] I had no deep understanding of mental illness...[I felt] compassionate but not really ‘knowing’.

[Exposure to mental illness] made me more aware of discriminative behaviour and multi-levelled discrimination... [it] personalised the discrimination.

7. Meanings of discrimination – encapsulating mental health services

Many participants addressed issues relating to power, clinicians’ attitudes and knowledge, mental health service practice, the biomedical model of mental illness and the dominant diagnostic system as integral to meanings of discrimination. The mental health system was regarded as undermining a holistic understanding of distress. This has a negative impact on people who experience mental illness, as well as their families and whānau. While this view was echoed across all participant groups, it was particularly prevalent amongst Māori and Pacific participants. To some extent, this reflected perceptions of racism and/or monoculturalism within mainstream mental health services.³⁴ Most participants regarded discrimination that occurs in mental health services as having a flow-on effect in terms of discrimination within families and whānau.

[D]iscrimination is very institutional. It actually starts from services. I’ve seen the damage to my people. They [clinicians] wouldn’t look at a holistic approach because it’s seen as a ‘Polynesian’ thing... [because of this] I blame them for the discrimination within the family and community... if only the clinicians will include the family at the time of assessing, then the family will understand and if the family understands then the community will. Discrimination is a clinician thing – it’s been passed down.

[Discrimination]... it’s a power relationship; someone’s got the information but [is] not giving it; [they] hold the dominance in diagnosing, [but] don’t believe in a holistic approach...it’s a power struggle and the power sits with mental health services and not with the whānau.

During the discussion about meanings of discrimination, participants were unanimous in the view that discrimination related to mental illness reflected a lack of awareness, understanding, information and knowledge amongst families, extended families, communities, educators, medical professionals and society generally. The lack of understanding was regarded as a key source of ‘fear’, ‘negative opinions’, ‘assumptions’ and ‘stereotypes’, and was fuelled by media notions of ‘dangerous crazy people’. Some participants also attributed discrimination to the beliefs about mental illness that they had been brought up with or exposed to as part of their family history (e.g. references within families or whānau to older relatives who had been in psychiatric institutions).

Participants overwhelmingly believed that the causes of discrimination could be effectively reduced through greater dialogue, sharing of experience, genuine interest, respect for everyone involved, and compassion.

The meanings of discrimination discussed in this chapter provide a point of reference for those implicit in the discussion of discrimination within and towards families in Chapters Three, Four and Five.

³⁴ Participants’ discussion of mainstream mental health services primarily focused on inpatient units and community mental health services provided by District Health Boards – these included adult, and child and adolescent, services.



chapter 3

Discrimination *Within* Families and Whānau: Consumer and Tāngata Whai Ora Perspectives



[I] feel like the source of my sadness came from the heart of my whānau.

Anonymous Participant

This chapter provides a discussion of themes relating to discrimination within families and whānau from the perspective of people who attended the two general consumer focus groups, the tāngata whai ora focus group and the Pacific focus group.³⁵

Participants across all focus groups used the term 'discrimination' to discuss a range of attitudes and behaviours within families that they perceived as discriminatory. As discussed in Chapter Three, some of these attitudes and behaviours may or may not meet a legal or technical definition of discrimination. What is important is that the negative attitudes and behaviours participants spoke about were experienced as discriminatory, and as counter to recovery. This issue is further addressed in Chapter Six, in considering some of the complexities of the research, and the need to take a more critical approach to understanding discrimination in relation to mental illness in the context of families and whānau.

Almost everyone who participated in the consumer and tāngata whai ora focus groups and the consumers in the Pacific focus group reported that discrimination was present within their family or whānau. There was widespread agreement that discrimination reflected a lack of information, education, understanding and knowledge about mental illness by family and whānau. A lack of acceptance, tolerance and compassion was also thought to underpin discrimination. Despite the presence of discrimination, most consumers and tāngata whai ora said they wanted their families or whānau to be involved in their lives and to better understand and support them, especially during times when mental health was most challenging.

While reports of discrimination within families and whānau were prevalent across all groups, the general consumer, tāngata whai ora and Pacific consumer groups, there were quite marked differences between these groups in terms of the nature of discrimination reported. For this reason, the findings from each of these groups are reported separately. The chapter is organised around a discussion of each of the main themes for each type of group, with illustrative quotes. The themes are presented

in order of emphasis, and reflect the priority participants attributed to particular topics.

1. General consumers³⁶

Consumers from the general focus groups spoke of widespread discrimination within their families. This was typically regarded as covert or subtle in nature. Some consumers said that discrimination occurred in the context of families' ill informed attempts to support them, rather than as overt attempts to behave unfairly or unjustly. Most consumers commented that their families' attitudes and behaviour reflected a lack of understanding or knowledge about mental illness. One woman from the consumer focus group commented,

[In] terms of my own family, and families I'm connected with, discrimination is quite subtle and may be not something that is incredibly overt but it's certainly there in terms of people being viewed differently because they have mental illness.

A man from the consumer focus group spoke of the way his mother altered her speech to talk to him following his diagnosis of mental illness.

It used to drive me nuts...when I was going nuts, my mother would always start talking really clear and really slowly [laughter] she kept on talking just slowly and really clearly, but yeah [families need] to actually listen to the person involved, even if they're psychotic, about what is and what isn't useful and what the person is going through at the time, how they like to be treated, what's happening.

The key themes for these groups included:

- 1.1 Biomedical approach
- 1.2 Limited expectations
- 1.3 Denying environmental causation
- 1.4 Hiding mental illness
- 1.5 Pathologising ordinary behaviour
- 1.6 Attributing negative meaning to realistic needs

³⁵ This group was made up of both consumers and families. There was a significant degree of alignment between the two, with, at times, no clear differentiation between them. To report these findings separately would mean repeating thematic content from this chapter, and would artificially separate the collective voice.

³⁶ The term 'consumer' is used in this section to include participants from the general consumer focus groups, as distinct from tāngata whai ora and Pacific consumers.

1.7 Denying or minimising mental illness

1.8 Withholding information

1.1 Biomedical approach

One of the most significant sources of discrimination identified by consumers related to the dominance of a biomedical approach to mental illness. Many consumers believed that discrimination within their families was strongly influenced by the biomedical approach and the negative impacts of diagnostic labelling. Consumers talked about the way families often adopted an uncritical acceptance of what they were told by clinicians, or read, about a biomedical interpretation of mental illness and specific diagnoses. In many instances consumers believed that their families' allegiance to the medical model was a way for the family to ignore family dysfunction and abuses. Consumers also believed that families' awareness of mental illness was filtered through dominant societal meanings and negative media stereotypes. Collectively these influences resulted in a range of negative and ill-informed ideas about mental illness and recovery. One woman summed up issues relating to the dominance of the biomedical approach:

I challenged a few family members about their predominant biological view of mental illness...and my sister did too... there's still family members that...believe it's just a chemical malfunction in the brain and prefer to believe that... there are other family members that have now moved from that...only through actually me breaking down to a point where I was so close to taking my own life...and actually communicating to them that this was about the environment and things that had happened to me and it wasn't just something that I was born with.

1.2 Limited expectations

Consumers believed that one of the most common forms of discrimination was family members' radically reduced and extremely limited expectations of the consumer once that person had been diagnosed with mental illness. These expectations were often influenced by what families were told by clinicians or had read about mental illness. Consumers said that their families often conveyed the

idea that the consumer might never be able to work again (or only in a limited capacity), return to school, aim for a career, move out of home or live independently, have children, and so forth. A younger woman commented:

With my family...on diagnosis there [was] an immediate reduction in expectations where they believe[d] that [I] can't do anything... everybody was then saying 'I have to do this for her and I have to do this for her'. And then building resentment because they think they have to do everything... they just have an immediate expectation of failure... It's longstanding... this person will never be able to achieve anything anymore.

A man spoke of his experiences relating to limited expectations:

[There is a belief in society] that mental health issues actually equate to intellectual disability. Because you know [if I say] 'Oh, I'm bipolar' [the implication is] 'Well you're a dumbbell now, you poor thing. You can't do this and you can't do that.'

Consumers believed that limited expectations were associated with a family's desire to protect the consumer, but often led to a restriction on consumers' rights and freedom, and the opportunity to explore life options and take reasonable and age appropriate 'risks'.

Importantly, there was a strong view among some consumers that when families began to understand mental illness in the context of the conditions of people's lives, they were much less likely to behave in a discriminatory way than when they accepted a strictly biomedical approach.

1.3 Denying environmental causation

Several consumers believed that their family's denial of childhood adversity and trauma was a form of discrimination which negated the consumer's life experiences. Denial was often associated with a family's strong attachment to a biomedical stance. This approach was seen as much less threatening for families than 'self examination' and 'accountability'. A younger woman spoke of her father's denial of the environmental contributors to her experience of mental illness:

My father hasn't even talked to me about my mental illness but...I had to get a psychological evaluation...there were so many circumstances going on at that time that had led to me being really unwell. But the only thing he said...was '...my mother was bipolar'. [It was like] What?! I've never met her, she died before I was born... it was [just] a genetic thing [to him] ...rather than trauma and [the many] environmental [contributors I'd experienced].

A mother talked about the denial of adverse behaviour within the family as key to her experience of mental illness:

We've got histories of controlling males and... strong but submissive women... there's a lot of abuse that's gone down...it makes a lot of sense that because of a lot of stuff [that's happened in the family] ...it would be more abnormal not to have experienced depression and anxiety...in the circumstances that were going on [inter]generationally.

One woman said she had been able to engage some members of her family in dialogue about mental illness from an environmental causative perspective. Adopting a non-judgemental approach had led to a reduction in discrimination:

To be able to talk about some things without blame, so it's not family blaming, it's not getting into family blaming, but just to talk about how some things had affected me and I'm sure they had had other experiences that had affected them...that dialogue...reduced discrimination within our family with some

members that were willing to...talk about it. And it's a hard thing for family members to talk about...because...it involves self examination... [and] dark corners.

1.4 Hiding mental illness

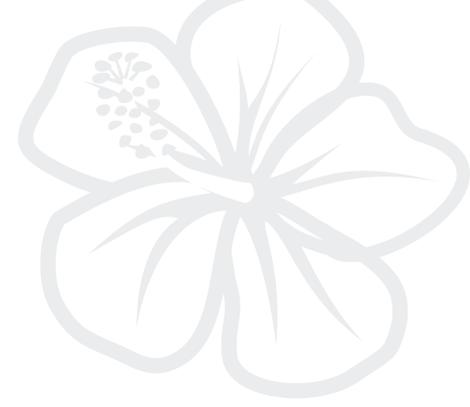
Another significant theme identified by consumers was the way families hid mental illness, including intergenerational experiences of mental illness. This took various forms, such as: not talking about mental illness; not acknowledging the presence of mental illness in the family; being encouraged to stay away from others when 'unwell'; discouraging or not allowing hospital visits by younger family members; or attributing mental illness to a physical condition. Participants reported a strong sense of 'keeping up appearances'. A younger woman recounted her experience while hospitalised:

My dad [and possibly step mum]...wouldn't let my little sister [early teens] visit me...and she really, really wanted to...I don't know whether it was because they didn't want her to see me in that setting or that headspace or whether it was that they were worried about the other people there.

A younger woman noted that her family attributed mental illness to physical causes as a way to hide it:

[If] they have to leave because they're feeling quite distressed [family will say] 'Oh she's feeling a little faint because it's hot.' You know they always make excuses, which then makes a person feel like they can't talk about [mental illness].

Most consumers spoke of families hiding mental illness because of fears relating to others' negative judgements and reactions, and potential ostracism and rejection. Contamination by association was also feared. Sometimes the practice of hiding mental illness reflected the need to 'save face'. For many, mental illness undermined social status or standing within a particular community, and was not seen as socially and/or culturally acceptable. One woman recounted how her stepmother's, her own and her sibling's experiences of mental illness had all been kept hidden:



My...stepmother was never diagnosed... but she took several 'sabbaticals' and 'convalesced' [she was later diagnosed with bipolar]. My father was...in the [armed services] and she was a [health professional]... all of their friends were lawyers and doctors... [there was a status thing] so mental illness was never discussed...the two of us [children] that have had experiences with mental illness ... have spent every episode ... hidden away...you don't contact anyone, you don't talk to anyone.

Asian consumers who attended the general consumer focus groups said that it was important for their families not to let others know about mental illness, as others were likely to believe extremely negative stereotypes about it. Having a family member who experiences mental illness would result in loss of face, particularly in terms of perceptions about the consumer's potential to achieve and succeed.

1.5 Pathologising ordinary behaviour

People in the consumers' focus groups also spoke of family members pathologising ordinary and reasonably expected behaviour. In addition, families often minimised the effects of adverse external events or experiences. Sometimes emotional expression by the consumer was interpreted negatively and provoked strong reactions from family members. In these situations, family members would say things such as, 'she nutted out', 'she's going off the deep end' or 'she'll be in the psych ward soon'. One of the consumer advisors commented on this in relation to a person she was working with:

[If] the family member is...having a conflict with another family member...[and it's] quite a legitimate concern...that [is] being interpreted as 'unwell' when they were actually just angry and frustrated over a relationship issue which anybody...would get angry and frustrated with.

1.6 Attributing negative meaning to realistic needs

Several consumers discussed the way their families would attribute negative meaning to needs associated

with mental illness and the effects of medications. For example, the need for quiet space, time out or a good night's sleep were sometimes regarded as 'bratty', 'lazy' or 'selfish':

My [relative] was quite sick so I decided to spend three months...with him before he died...I got into...a low state... I was suicidal... [we were living with] 8 to 10 people in a three bedroom house...and I needed a bit of space... the [family] weren't really wanting to give me space... when I would go away...to be on my own they started saying that I was being really bratty...or 'she's lazy because she's sleeping all the time'.

1.7 Denying or minimising mental illness

Some consumers reported that their families, or an individual within the family, did not believe that mental illness existed. Consumers also said that families sometimes minimised the effects of mental illness. This was particularly so when consumers experienced (clinical) depression, which was typically regarded as a 'normal' experience, and consumers could be told to 'suck it up', 'harden up' or 'get on with it'. In some instances, family members attributed the effects of mental illness to 'bad' behaviour. This idea was evident in one man's account of comments he had heard being made: 'Oh this mental illness thing is a load of rubbish. You just need a kick up the ass'.

1.8 Withholding information

Many consumers raised issues about families withholding information, such as illness, death, a funeral, or other important family news. Families often took control and made decisions amongst themselves about when to reveal this kind of information to the consumer:

Discrimination [can be] quite subtle [like] being the last to know some family information...if there's a crisis... the person who is seemingly unwell or has a history of mental illness [is] told last and the rest of the family members... deciding when that person can have that access about the information if it's bad news about an illness for example.

People [sometimes aren't told] that a relative has died...and later] proposing for example to go and visit the relative and then being told,



'You can't do that, they died two years ago.' And then having to manage not only the grief of the loss of the relative but the grief over the discrimination that they weren't told and that they weren't even given the opportunity to be a part of the funeral process.

2. Tāngata whai ora

There are many parallels between the experiences of discrimination reported by participants in the general consumer groups and those reported by Māori consumers, widely known as tāngata whai ora. However, particular experiences were unique to being Māori. Moreover, the emphasis participants placed on particular issues differed between these two groups.

Tāngata whai ora spoke of extensive and overt discrimination within their whānau. Most tāngata whai ora commented that this behaviour reflected the family's lack of understanding or knowledge about mental illness. Discrimination took multiple forms, as one woman explained:

When I became unwell for the first time they'd never experienced someone in our whānau who had become unwell mentally, they didn't know much about mental illness... I was discriminated really big time by my whānau mainly because they didn't understand/[T]hey can be so judgemental... when I'm really well... they always come to me, the minute I become unwell... they don't want to know me, and that's when I need them most, yeah...my family have taken me to the heights and then to the depths of hell.

The key themes for tāngata whai ora, in the order of emphasis accorded by them, included:

- 2.1 Derogatory language
- 2.2 Hiding mental illness
- 2.3 Being excluded, shunned, demoted
- 2.4 Denying environmental causation
- 2.5 Denying mental illness
- 2.6 Disconnection and estrangement

2.7 Colonisation and cultural alienation

2.8 Establishing new whānau

2.1 Derogatory language

For tāngata whai ora, discrimination often took the form of being referred to as 'bad', 'pōrangī',³⁷ 'a failure', 'a black sheep' and 'crazy'. Being called names and referred to in derogatory ways had long-term effects on tāngata whai ora. Speaking of discrimination through labelling and negative interactions, one man said:

I didn't know about mental illness...nor did my whānau, my whānau were quite shocked... they didn't know what it was all about... I just started getting labelled from my own family. I asked them, 'why are you fellas labelling me now that I'm suffering from mental illness?' and they had no answer for it, so I just said, 'well you fellas come back when you've got some manners.' And they still haven't got any manners. It's a bit of a shock really. Getting discriminated from your own whānau like that.

Another man said:

Yeah I have a similar story, I grew up with the word 'pōrangī', I didn't know the word [tāngata whai ora]...I was always yelled at: 'You're pōrangī', 'that child's pōrangī'. I left home with that word in my ear... I just wanted to get away from all those sorts of things...no one actually told me what I had for 50 years until I saw [the] John Kirwin ad... it was only 5 years ago...[seeing] the Like Minds, Like Mine ads [and] [name of kaupapa Māori] mental health service...that I finally got that monkey off my shoulder and they told me what I had.

A woman experienced exclusion from whānau despite other whānau members experiencing mental illness:

[O]nce I started acting out and getting depressed or going to hospital I was 'a failure', I was 'crazy' and 'not worthy' so I never got included in whānau stuff...it was them, I could see the illness in the family, I just happened to be the one diagnosed.

³⁷ Pōrangī means mad, crazy, insane, lunatic.

2.2 Hiding mental illness

Many tāngata whai ora spoke of how their whānau hid mental illness. This primarily related to not wanting others to know about the presence of mental illness within the whānau. Tāngata whai ora attributed this to shame, as in the case of one woman who said:

Yeah I definitely agree with that [shame]...it was shameful for them...they were ashamed of me, but they were more focused on how they felt...I had to leave home, I had to leave home to get away from my whānau.

2.3 Being excluded, shunned, demoted

Tāngata whai ora also reported being excluded, shunned or demoted within the whānau. Sometimes consumers were perceived as 'weak' or 'a failure', and some had been 'demoted' within the whānau following a diagnosis. A mother spoke of rejection from her whānau and the shame associated with whānau members who were public figures:

[F]or me it's about shame... my family... couldn't deal with [mental illness]... in my family we have some prominent people...who I think suck now because of their attitudes. [T]hey ...wanted to keep pushing it under [the mat] or... [blaming me]...[because of mental illness] my first baby...went to her dad and I got shunned for that ... that's what turned me away from [my family] because they didn't want to deal with me. So I did it on my own... it was because they didn't know how to deal with it and they knew they had to look at themselves.

A man whose sibling also experienced mental illness spoke of rejection within his whānau which resulted in him hiding his own mental illness from them:

My family were shocking... to the max... it was my brother [who had mental illness and was in the justice system]...my family didn't want to know. I said, 'How can you leave him in hospital?... they just shut the door...from that time on...the door was shut so... I didn't tell them [about my experience of mental illness]... it's that shame.

A woman was viewed negatively by her whānau and excluded:

I got demoted, my koro named myself... [and I had] mana...but once I started acting out and getting depressed or going into a hospital, I was 'a failure', I was 'crazy', and 'not worthy'. So I never got included in whānau.

2.4 Denying environmental causation

Mental illness was understood by some tāngata whai ora as resulting from child abuse, intergenerational sexual abuse and unresolved historical raruraru within the whānau.³⁸ One person spoke of the intergenerational impacts of war and the absence of counselling for Post Traumatic Stress Disorder and alcoholism within the whānau.

Discrimination and targeting of mental illness were sometimes perceived as an attempt by whānau to hide or deny adverse events that had occurred in the whānau. There was widespread recognition that these experiences were not unique to Māori, and occur across families irrespective of ethnicity. A mother connected childhood abuse to mental illness:

[M]y father has played a huge role in my [mental illness] because he's in control ...our mother's energy was always...with him. So for me I think the healing between me and my mother will come when he dies... in his family there's a long line of sexual abuse, his father was just rampant through all of his children. I got to the stage where his youngest daughter had a baby...I don't excuse my father but I can understand why he is the way he is...that sexual abuse is quite deep, and that's one of the main factors I believe as to why we are the way we are [i.e. experience mental illness].

Another participant also spoke of the link between experiences in the family and mental illness:

Someone calls it mental illness but I think it's almost just a natural reaction or a consequence of what is happening in the whānau.

³⁸ Raruraru means trouble, problem.

Another man also spoke of the link between experiences in the family and later mental illness:

I was diagnosed with Post Traumatic Stress Disorder from my foundational upbringing.

A woman, speaking about mental illness related to familial abuse, explained how the diagnosis itself can be used by whānau to pass on the blame:

A diagnosis of mental illness sometimes gives people something to pick on...it's shifted from [familial abuse to mental illness] so now we've got a label we can blame it on rather than on what it truly is...the biomedical model takes dominance over what's happened in a person's life and it's like, 'I didn't end up with this depression because of abuse as a child'.. [so] whānau or extended whānau have an excuse... they don't have to hold up the mirror and show the whole hapū what actually happened.

While several tāngata whai ora had removed themselves from whānau to avoid negative attitudes and behaviours, one person spoke of unsuccessful attempts to educate the whānau:

I tried my nurse's way but it didn't actually work because my family told them to p off... [the nurses] were wanting to have a korero with my own whānau about discrimination and stigma and they said, 'Hell no, we're not going to do that. What are we going to do that for? We don't need that.' 'Don't need that sort of thing, y'know.'

2.5 Denying mental illness

In some whānau, mental illness was not recognised and instead was perceived as 'bad' or 'weak' behaviour. A woman told how mental illness was attributed to her 'bad' behaviour:

My family were more in denial... instead of facing the fact that their daughter could have a mental illness, they didn't even know what it was... [it was] 'Oh she's been a naughty little girl...so let's punish her' - that kind of treatment - they didn't know that I was unwell.

Another woman spoke of denial and put downs within her whānau, and how this led to her leaving:

[M]y whānau thought I was a failure of some sort... [if] they saw me crying [they would say], 'you're not tough, toughen up'... they saw that I would reach out to people who helped me with my children, not my whānau, they were toxic people, and I almost feel that the source of my sadness came from the heart of my whānau...If you reacted, cried, [got] anxious... you were weak and you failed...I left my whānau, I had to.

2.6 Disconnection and estrangement

Most tāngata whai ora talked about discrimination as painful, hurtful, ostracising and alienating, and an ongoing burden in their lives. Some reported being treated in such negative ways by whānau that they had no option but to leave home, and/or had become estranged, as a way to survive and improve their wellbeing. Although several people had tried reconnecting with whānau, discrimination remained so pervasive that contact with them was difficult. One woman's attempt to reconnect with whānau meant a denial of her needs:

Part of my recovery [was that] I went back to the marae [following estrangement from whānau]... I stayed there for a year and a half in a rural part with no neighbours except our whānau...but even there living on the marae I felt discriminated against...I had to be... on call 24/7..if I took some space or decided I didn't want to sleep in the wharenuī because I needed a good night's sleep for my mental health and wellbeing that was perceived as a weakness - you weren't being part of the whānau... and that was a stab to my identity and impeded my recovery.

A woman from the tāngata whai ora group spoke of the irony that her whānau perform for public events, but do not extend that love to her:

[M]y frustration with my family is that I see them [doing lots for the community]...I'm thinking this is a lot of bullshit... you're out there doing...the karanga...or you're the

waiata lady or you're the cook or the cleaner... I go to all these other marae and you can feel the aroha...and I'm like, why can't [my whānau] just be like that? That would make life so much easier. So it's a burden.

One man spoke of having whānau that had discriminated against him in such harmful and overt ways that he no longer had contact with them. However, he spoke of gaining strength and guidance from his tūpuna:³⁹

The only way I can look after myself...is on behalf of my own tūpuna...I've actually listened to my tūpuna's words saying 'you're not a failure,' 'you need to go and do something.' So four years ago I went and looked for a job and I got one and I'm actually still in the same job and then two years later I came to [name of Māori service]...my tūpuna said to me, 'don't go back to your family again, they are a distraction to you and your health.'

2.7 Colonisation and cultural alienation

Some tāngata whai ora explained discrimination within their whānau as being due to the effects of colonisation, urbanisation, the break down of traditional whānau relationships and the loss of manaaki:⁴⁰

I believe that...a lot of it is [because] whānau haven't got the same time they had for each other now as they did growing up on the marae...when we lived in that environment, we looked after each other. Today in this society nobody's got time for anybody. If they see something wrong with that person [the instant reaction is that they need to] go and see a doctor. [The time] just to sit there and listen and be with them and each other isn't there any more.

2.8 Establishing new whānau

Several tāngata whai ora spoke of creating new whānau as a way to compensate for estrangement from their whānau of origin. This could take various forms, such as having one's own children, finding other whanaunga, and/or creating connections with other tāngata whai ora or people who understand mental illness:⁴¹

I've got mates, heaps of mates on the outside of my own whānau that are actually better than my whānau because they understand, because we all stick together and we all help one another out. But if you go to your own whānau and you ask for their help...they won't give it to you because they know you're a mental health patient and that's the reason why...I've stayed away from my whānau for the last six years.

A mother conveyed significant grief and sadness from being alienated from her whānau:

I left my whānau, I had to. And I made friends with whānau here that were not blood related because we could relate to what was happening, but because of that leaving I have carried pain in my soul for the whānau that I never had. I missed out on a nana, a kuia and aunts and cousins...part of my recovery and healing is trying to make peace because in that you lose your identity...I had to redefine what whānau meant to me which was my children... I've put my energy into creating new family... [and] I found another way of reconnecting with my hapū.

Most tāngata whai ora said that despite experiencing discrimination and a range of negative attitudes and behaviours from whānau, they understood why their families behaved as they did. Many tāngata whai ora emphasised that the whānau often had no knowledge of mental illness, and/or were unable to acknowledge adverse historical events within the family that led to mental illness. Most tāngata whai ora conveyed a desire to receive greater understanding from their whānau,

³⁹ Tūpuna means ancestors, grandparents.

⁴⁰ Manaaki means care, helpfulness, kindness.

⁴¹ Whanaunga means kinship, relation, relationship.



and to be able to reconnect in a way that was conducive to wellbeing. One woman said that although her family regarded her as the ‘black sheep’ and restricted her movements and whereabouts, they were also very supportive. Another woman captured the general sentiment of the group:

[F]or me my wellbeing includes my whole environment, my whānau and whatever other surroundings there are...without my whānau it can just put my whole world out of synch...I am now beginning to learn where I belong, where I come from, [to] build up my self confidence... [but] when I go home...within a second I can just go down.... love them but can't live with them.

Some tāngata whai ora spoke of the way many experiences that are now defined as ‘mental illness’ were historically valued amongst Māori, and tāngata whai ora held mana or esteem in their communities. Sometimes tāngata whai ora experiences were deemed to be received in order to help others, to advise the whānau, hapū or iwi, and to intervene at a more spiritual level. These experiences were not regarded as an ‘illness’, but rather as a role or ability that needed nurturing, to the betterment of the whānau, hapū or iwi. The focus was on the wairua implications of these experiences and the spiritual capacity and connections. At times, tāngata whai ora were regarded as recipients of historical wrongdoings by someone else. Tāngata whai ora at the focus group spoke of the way experiences which could once be celebrated were now deemed an illness that whānau felt ashamed of.

One man quoted a kaumatua he had spoken to about traditional perceptions of mental illness, and the way tāngata whai ora should be regarded:

He ōrite te mana o tena o tena o tena.

Mana is the same of that person, of that person, of that person.

Everyone is the same. Everyone has the same mana regardless of who or what they are.

3. Pacific consumer and family perspectives

While there are many parallels between the Pacific group and the consumer and tāngata whai ora groups, there are also experiences unique to being a Pacific person, being from a particular Pacific nation, and/or belonging to a particular Pacific community. The perspectives of people who attended the Pacific group varied depending on place of birth, ethnic identification, specific cultural heritage and language.

Some people reported that the notion of mental illness was alien within a historical cultural context. Instead a spiritual understanding prevailed. For example, in Tonga there was no concept of mental illness. However, others said that within their communities, significant negative cultural meaning was attributed to mental illness.

Most people in the Pacific focus group reported that they and their families knew nothing about mental illness or addictions before they experienced mental illness. Families often experienced ‘shock’ and a sense of powerlessness when they learnt that their family member experienced mental illness, was admitted to hospital, or came under the Mental Health Act. Several participants thought the sense of shock and powerlessness was partially due to a lack of information about mental illness and services, and a lack of information in a first language.

Many participants said that the lack of knowledge or understanding about mental illness within their families and the wider community had led to a high level of discrimination. A lack of awareness or acceptance amongst older family members and parents of adult children with experience of mental illness was particularly problematic. Discrimination was conveyed in a variety of ways.

The key themes for Pacific consumers and families included:

3.1 Derogatory language

3.2 Shame

3.3 Hiding mental illness, and being excluded

3.4 Exploitation

3.5 Countering discrimination within families

3.1 Derogatory language

Participants reported that for most Pacific groups, the language used to describe mental illness was regarded as derogatory and discriminatory. Within a traditional context, people with mental illness were often regarded as 'crazy people' or 'funny people' and subjected to ridicule and abuse. Participants reported that these attitudes continue both in some communities in Aotearoa and in some Pacific villages today:

[W]hen I think of mental illness in the Samoan context I think about the language... vale which means crazy, crazy person ...and valea which means you are mental, you have lost your mind...we continue to use these words... without understanding and awareness of the barriers that using such words create... they are integrated into everyday language as well as biblical language...so there is that...inbuilt, ingrained cultural discrimination.

The nature of language used to refer to consumers had a significant negative impact on individuals who experienced mental illness. They identified themselves as 'that' person who was 'vale' or 'valea':

Being a family member and also experiencing mental illness...[the language] was one of the challenges...I was thinking 'oh, I'm vale'... [this was] the labelling frequently used by my household or my people.

Participants reported that despite recent changes in the way people who experience mental illness are referred to in Tongan communities, the language remained derogatory. For instance, the term 'fakatafaa' (meaning 'crazy' or 'stupid') was now widely used. This terminology was seen as actually more negative than older terms, as it was like calling someone 'the crazies of the crazies of the crazies'.

A growing awareness of mental illness had led to a change of language within Rarotongan communities. For example, terms now in common usage include 'maki manako' (sick mind) and 'Te Anau Tamarangi' (heavenly children or children of God),⁴⁵ These changes reflect a belief in Christianity and acknowledgement that 'God is in everyone of us, once you discriminate...you discriminate against God'.

3.2 Shame

Mental illness was regarded by many participants as bringing shame to families. The discussion revealed that the experience of shame reflected the dominant concepts and language used to refer to mental illness in the wider community:

[I]t brings shame on the family, it causes isolation ...people call [my sister names]...it's quite bad with our community.

It was like a natural disaster, a volcanic eruption, stressful, the shame...especially my mum...she was saying 'what did I do, why did my daughter have this mental illness' ...for mum and dad being old, traditional, religious, conservative Tongans, they believe in counselling directly with God, you don't go to psychiatrists, there are natural healers and then God.

3.3 Hiding mental illness and being excluded

Consumers and family members spoke of how a sense of shame and fears relating to 'contamination' and/or beliefs that the family had been 'cursed' had meant families hid mental illness, and/or shunned and rejected the family member who was experiencing mental illness:

[M]ental illness has definitely been part of the whānau for many many years and it has been severely hidden...it's not been 'oh he has a mental illness,' it's just shut the door...his mum wont have him anywhere near the house...the doors shut on him, all around... I had a father ring me at about 7 in the morning [he said]: 'come and pick up so and so, go and find him a home, I don't want him in my home anymore.'

⁴⁵ Personal communication, Sam Samuel, Vakaola, Porirua.



3.4 Exploitation

A group member with considerable experience working in the mental health field also spoke of the exploitation of family members diagnosed with a mental illness. He gave an example of a family member who made the following comment:

On a Wednesday I am the valed person, but come Thursday I am their son becous it's benefit day, they collect the benefit, give me \$10 and they take the rest.

3.5 Countering discrimination within families

Within several families where discrimination prevailed, the presence of one family member who knew about and understood mental illness was often influential in reducing discrimination and enhancing acceptance. This family member often took the role of providing a safe haven and a bridge between the family and the person with experience of mental illness. One participant said that increasing awareness and education about mental illness within his family meant there was growing acceptance:

[I]n the last 5-6 years quite a lot [of information] has come out...the children have grown up with knowing about [mental illness].

Summary

The majority of participants in all consumer focus groups reported that discrimination was widespread within their families and whānau. However, some participants noted that discriminatory attitudes and behaviour were not fixed, and that with increased awareness and knowledge, family members' attitudes and behaviours often improved.

The general focus groups reported that discrimination was typically covert. The tāngata whai ora focus group and the Pacific focus group reported that discrimination was typically overt. While levels of support within families varied from really supportive to not supportive at all, only one person in any group said there was no discrimination within their family or whānau.

Despite reporting discrimination, general consumers typically wanted their families involved in their lives and in treatment processes. Tāngata whai ora, many of whom were disconnected or estranged from whānau of origin, preferred connection and involvement of whānau they had chosen. Nevertheless, most tāngata whai ora retained hope that at some time in the future, their whānau would have greater awareness of mental illness and more healthy relationships, so that they could reconnect. Pacific consumers reported wanting their families involved both in their lives and in treatment processes.

The nature of discrimination varied across participant groups. A strong theme across all focus groups was families' experience of shame associated with mental illness, associated with hiding mental illness from other people. Denying environmental causation or denying mental illness were prominent themes in the general consumer and tāngata whai ora focus groups. The use of derogatory language and name calling were strong themes in the tāngata whai ora and Pacific focus groups.

One of the most prominent themes identified in the general groups was the connection between discrimination and a dominant biomedical model, and this model was linked with the notion of limited expectations. The general group also reported that families pathologised 'ordinary' behaviour and attributed negative meaning to realistic needs. For many tāngata whai ora, periods of disconnection or complete estrangement provided escape from discrimination within their whānau. Exploitation of family members who experience mental illness, although a less common theme, was reported in the Pacific group.



chapter 4

Discrimination *Within* Families and Whānau: Family and Whānau Perspectives



We as the family members should come face to face with discrimination and consider what we can change about ourselves.

Anonymous Participant

This chapter provides a discussion of themes relating to discrimination within families and whānau from the perspective of people who participated in the families and whānau focus groups. To recap, there were five family focus groups and one additional group of Pacific consumers and family combined. This chapter includes the views of those from the five groups: two general families groups, one whānau group,⁴⁶ a Chinese group and one small group of young adults. It does not include the views of family members from the Pacific focus group.⁴⁷ The quotes used in the text to illustrate key themes reflect relatively recent rather than historical experiences.

Families and whānau develop a range of strategies to support a family member who experiences mental illness. In many circumstances, families come into a support role with scant knowledge of mental illness, and with little support themselves, as they learn to negotiate unfamiliar territory. The Like Minds, Like Mine programme acknowledges that 'strong and conflicting emotions can arise in families/whānau when a family member is living with mental illness, including compassion, concern, anger, fear and rejection.'⁴⁸ This chapter echoes a mix of these emotions. In Chapter Six we tease out some of the tensions and complexities associated with the lived experience of mental illness in the context of families' day to day lives.

As discussed in Chapters One and Two, there are numerous problems in defining discrimination. This is especially so in the context of close family relationships. In this research, participants in the families groups typically provided the primary support to a consumer. More often than not it was a female family member who provided this. Many participants spoke of the extreme stress associated with supporting a family member (and sometimes more than one family member) who experiences mental illness. For many, the pressures experienced were significant.

Sometimes extreme stress impacted on the mental health of the person providing support. In many situations, as well as providing primary support to the consumer, the family member undertook full or part time work, parented children, cared for grandchildren or other members of the family or whānau and generally managed the household. Some families and whānau spoke of the financial impacts on the family.

In families where there were high expectations on children, especially amongst Chinese families, the sense of disappointment and loss of hope associated with mental illness was particularly pronounced. While attitudes and behaviours that occurred within families may be adversarial or at times even abusive, and not conducive to wellbeing, they may not necessarily be about discrimination.

Sometimes the way families interacted was more a case of 'families being families' - reflecting the unique nature of the family or whānau. We return to these definitional and contextual issues in Chapter Six.

This chapter is organised around the dominant themes that emerged, using quotes to illustrate key findings. The themes are not presented in order of priority, but rather in order of the nature of particular attitudes or behaviours. Many themes are not discrete entities, and there is considerable overlap between them. Themes are also highly context dependent.

Quotes used in the text often capture a multiplicity of issues, but are typically located under a theme that is of most relevance to a particular issue. It is important to note that the quotes have been drawn from an extensive body of dialogue. While every attempt has been made to provide some context for the quotes, it is not possible to include the broader dialogue.

⁴⁶ The whānau focus group was comprised of people connected to a kaupapa Māori social service, including several members of one extended whānau and others. There was limited discussion about discrimination within the whānau. Most of the whānau focus group discussion related to discrimination towards the whānau from mental health services and extended whānau (as addressed in Chapter Five). Considerable discussion also centred on historical experiences of mental illness within the whānau - often involving old psychiatric institutions - and the effects of colonisation. These experiences and memories had influenced participants' attitudes about mental illness in a positive way. In the general families' focus groups, there were evidence and self reports of negative attitudes and behaviour, including discrimination, in relation to mental illness within the family.

⁴⁷ To recap, this focus group comprised consumers and families of people who experience mental illness. This group was led by a Pacific facilitator, tapped into Pacific networks and was deemed appropriate in the context in which the focus group took place.

⁴⁸ Friends and Family What you do makes the difference - Like Minds Like Mine fact sheet (Mental Health Foundation, 2007).

Family and whānau perceptions of discrimination within the family cohere around two central themes.

1. Perceptions about the presence of discrimination
2. Feelings, attitudes and behaviour towards consumers

In the context of participants' discussion about feelings, attitudes and behaviour towards consumers, 19 subthemes were identified. These include: fear, differential treatment, desire to change lifestyle, blame, behaviour vs mental illness, recreational drugs and mental illness, attitudes towards independent living, relationships and communication, contradictory feelings, adjusting to progress, attitudes towards consumers raising children, derogatory language and name calling, assuming authority, anger directed at consumer, abuse within families and whānau, social exclusion, distancing/exclusion, and compulsory hospital admission.

1. Perceptions about the presence of discrimination

Initially, the majority of people in the general families,⁴⁹ young people's and whānau focus groups reported that there was little or no discrimination within their families. As discussions progressed, however, many participants in the general families' focus groups talked about times they or other family members had held negative attitudes and/or behaved in ways that they thought could be considered discriminatory towards consumers in their families.

The whānau focus group conveyed a strong sense of being against discrimination, and there was little evidence of discriminatory comment in the ensuing dialogue. However, this group occasionally spoke of discrimination within others' whānau. Most of the whānau focus group discussion related to discrimination towards the whānau from mental health services and extended whānau, as addressed in Chapter Five. A considerable amount of discussion also related to historical experiences of mental illness within the whānau, which often involved older psychiatric institutions. These experiences and memories created a particular feeling in the whānau focus group and

seemed to influence participants' current thinking and attitudes about mental illness in a positive way.

People who participated in the Chinese focus group readily acknowledged that there was widespread discrimination within their families. This usually related to highly entrenched negative attitudes and beliefs about mental illness. Many participants reported a lack of locally available information in Chinese languages, and a lack of knowledge, understanding or acceptance of mental illness within individual families and their wider cultural communities.⁵⁰

While discrimination is discussed in this section as simply being either present or absent in the family or whānau, it is recognised that discrimination is often a subtle, insidious and covert entity, which may involve, for example, decisions being made for consumers or tāngata whai ora in their absence and/or without their knowledge or consent.

Most of the participants in all five family and whānau focus groups said that they knew very little, if anything, about mental illness before their family member was diagnosed. A woman spoke of not knowing about the different labels associated with being mentally unwell:

I didn't know there were labels and different categories of mental illness. You were either well or you weren't well, and we'd become quite tolerant of the unwell, but did not know they had a mental illness... I believe that there are many that are incarcerated that shouldn't be, that have...undiagnosed mental illness.

Another woman from the same focus group expressed her dismay when told her son had a mental illness:

No I knew absolutely nothing and I was devastated to find this doctor telling me that my beautiful 16-year-old son had a mental illness. I mean, I thought - who does he think he is, y'know, doing that to me. He's sitting there, and he was bright and chirpy - no, I knew nothing, and struggled.

⁴⁹ As noted in Chapter One, the general families' focus groups comprised a majority of participants who identified as Pākehā or European. However, a minority of Māori and people of multiple ethnicities also participated in these groups.

⁵⁰ These findings were similar to those from families in the Pacific focus group.

One woman reflected on her own judgments about mental illness before experiencing mental illness within the family:

I knew nothing but I think I was also very judgmental...what I am trying to say [is] I think I had a preconceived notion that people that had a mental illness had it for a reason because, I don't now, they weren't parented properly, or they ...terrible upbringings or whatever, there was always a reason for it... being really honest [it] was probably really judgmental. I certainly don't think that now.

2. Feelings, attitudes and behaviour towards consumers

Families and whānau conveyed a range of feelings, attitudes and behaviours about discrimination and mental illness within their family.

2.1 Fear

Several family members spoke of the fears they experienced in relation to the presence of a family member experiencing mental illness. Fear related to the consumer's future and children, and what would happen to the family. Fear was often associated with a lack of knowledge or information about mental illness, where to go for help, or the effects of getting treatment. Potential discrimination from others also fuelled these fears.

[F]or me there was a lot [of] fear, we had been married four years, but I hadn't known anything about it, my husband had Bipolar Disorder... the fear of the unknown, of what might happen to him...my children, to me...I didn't know what it was and I felt very dumb...I didn't even know what his disorder was.⁵¹

A parent from the Chinese focus group, who spoke English as a second language, told of her fears and feelings in relation to her children who experience mental illness:

As family members, we are also scared...I don't dare to tell people he is sick. I am afraid they will discriminate against him. ...it was

the fear of what he could do to himself, but also what he could do to me...I didn't know [my daughter was sick]...the counsellor, she told me my daughter must go to a doctor. However, I did not let her do that...I was afraid she would become more and more stupid if the doctor gave her injections and medicine...It's us who discriminate against this.

Fear also arose where a consumer's behaviour was regarded as adversarial or threatening. A sibling from the Chinese focus group spoke of fearing the effects of her sister's behaviour:

I felt the pressure and was very scared. It was as if there was a bomb in our house that could go off anytime. Very often my sister smashed up the place when she came home and had an attack. When my parents could not take the stress any more, they fought and quarrelled with my sister. We were scared because we didn't know whether it would be messy at home or whether a war was brewing.

2.2 Differential treatment

Families and whānau discussed a range of ways in which a family member with experience of mental illness was treated differently within the family. For most, differential treatment reflected a desire to ensure the care and welfare of the consumer or tāngata whai ora, a response to changes in the consumer's behaviour or ability to communicate, and a desire to support their day to day functioning. Examples included encouragement to get out of bed, ensuring access to and consumption of food, prompting regarding personal hygiene, and providing stimulation and company.⁵² One mother from a general focus group spoke of keeping her daughter motivated and active:

[We] make sure she completes all of her... commitments, and she's got lots of them, and we just keep her moving...she'll say, 'But I want to go to hospital! [We say] 'You're not going to hospital, you're getting out of bed and...you're doing this and this and this.'

⁵¹ This quote is from a family member in the Pacific focus group. Because it is so eloquent and there was no suitable alternative place to insert it, we have included it in this chapter.

⁵² As noted in Chapter One, the views included in this chapter reflect a range of different positions within families, for example, parents of adult consumers; adult children of parent consumers; adult siblings of adult consumers; partners of adult consumers.



A mother from a general focus group whose adult son experiences mental illness commented that treating her son differently was about loving and caring for her son and respecting his needs:

[The family context] it's hugely complex isn't it. It's not just about them. It's about the individuals in the home and we all react to it differently. I've learnt a lot from my son...I don't think I was going to learn in any other way...and I do treat them differently actually because I have to, he's different, he deserves different [treatment].

Another mother with an adult son who experiences mental illness commented about his appearance and hygiene:

A lot of the discrimination I feel comes about from some of the ways that the mentally ill dress. Some of them are scruffy and untidy... they're not living well, they're dirty and they're scruffy and really untidy and they bring a lot, quite a lot of discrimination against themselves.

Sometimes the consumer was treated differently in response to perceived needs resulting from the effects of mental illness. For example, managing 'aggressive' behaviour resulting from the consumer's belief that others were trying to kill them, supporting a consumer who was too afraid to go to Work and Income, or caring for mokopuna when a family member was not able to care for her children.⁵³

2.3 Desire to change lifestyle and/or behaviour

Families often spoke of wanting to change the way a consumer lived and/or particular behaviours. Sometimes this reflected the family's discomfort with what was perceived as a squalid lifestyle, or the consumer's unkempt appearance, poor hygiene and/or undesirable behaviour. Often, the desire to change consumer behaviour reflected wanting to avoid negative impacts and consequences for the consumer and/or their family. These situations were often associated with concerns about finances. A mother in a general family focus group spoke of her son's behaviour and efforts:

My son...he's bought every single old computer...half the lounge was taken up with old computers...and his bedroom was chocka. ...when he's unwell he drives badly and he's got a lot of tickets and every time he's been allowed to come out of hospital he heads for the shop on the way and he hasn't got any money left now to pay those fines because he's bought another set of computers....you don't know where to intervene and where not to.

A sibling in a general family focus group spoke of the impact of her sister's behaviour within the family:

[T]here's a balance... in my case my sister, who has schizophrenia ...she gets herself to a point where she's spending all her money and that's when she'll go and involve my parents. And that's not right for them either....there needs to be a balance....at some point someone...has to step in...you need to look after yourself.

Several participants discussed difficulties relating to boundaries with consumers, and many experienced an inner tension about when to intervene or not. This was particularly so with younger adult consumers.

2.4 Blame

Several participants spoke of families and whānau who attribute blame for the consumer's mental illness, either to the consumer or to other family members. A woman in the whānau focus group said she had been blamed by her mother for her father's mental illness:

Before I got married...there was a lot of unpleasantness and a lot of unhappiness... mum and dad chucked me out. I went and lived with [boyfriend's] mum and dad...[then] we got engaged. It was after that dad got sick again, and I got blamed for it. 'You made dad sick...you made your father get sick.' And I got blamed. I was...nineteen. And I got blamed for that. I carried that....I'd done this to my dad...I carried this for years.

One Chinese woman whose sister experiences mental illness spoke of a range of issues within the family. In particular, stress and fear created anger and blame:

⁵³ Mokopuna means grandchild.

When my parents could not take the stress any more, they fought and quarrelled with my sister. We were scared because we didn't know when it would be messy at home or whether a war was brewing... before my father died, my sister called my father to wish him happy New Year. After the call, my father said...'She destroyed our family.'

A mother from a general family focus group spoke of the challenges associated with supporting her son who experiences mental illness, and the impact this had on her relationship with her partner:

My partner [and I] we split up because of my son, so whether you call that discrimination I'm not sure, but that's all in the too hard basket eventually.

Another way that blame was played out within whānau related to a mother who attributed her son's mental illness to mākutu or mate Māori.⁵⁴ At other times she blamed the fact that he had changed religion.

2.5 Behaviour vs mental illness

Some participants grappled with difficulties associated with behaviour which they attributed to mental illness. This was often differentiated from behaviour attributed to 'personality'. Families said that other people often attributed adverse behaviour to mental illness, when the behaviour was actually about how the person had always been. An adult child of a parent who experiences mental illness emphasised how her mother's behaviour was sometimes 'bloody awful', and that this was not about mental illness:

[P]eople have sort of pooh poohed a lot of things that were her personality...'Oh, no, no, no, you mustn't be sad, it's just her illness' and you're thinking, 'no, actually, that's my mum being bloody awful, that's not her illness... But people... they sandwich everything that she is into this illness... if I was to do something horrible to you, you'd be able to say, 'Oh gosh she did that really awful thing and she should take responsibility for that.'

A parent from a general families' focus group reiterated the idea that some behaviour was not okay:

It's not always OK... wherever it comes from, whether it's her or her illness, some of that behaviour's not OK.

One of the young adults commented that behaviour associated with mental illness, as well as her father's way of being, had led to her parents' separation:

[My] dad... he thinks of millions of things at once and he has to do them, and if it doesn't work out he gets really upset... and like all his mood swings and everything... he's always got ideas so if you say 'get over it' he'll just go onto the next one. So that's why my parents aren't together because Mum just got over it. She was just like 'look I can't be bothered with your newest craze.'

At other times, changes in behaviour associated with mental illness could make family life very challenging. A mother from the general families' focus group whose son experiences mental illness spoke of balancing her own needs with those of her son:

[It was like] walking on eggshells... when my son first started to have problems... my life was hell... I've realised that I can support him without having to forgo my life... I don't have to be afraid in my own home, I don't have to walk on eggshells all the time. I can still have a life and yet still be his mum, and still support him.

Another mother conveyed the emotional intensity of living with a son who experiences mental illness:

It was always very hard to express to other people what you're going through... how intense and what was happening at home, like he would pull the stove over... [he would] smash windows, break car windows and he was involved with the police. He was self-harming... I'd come home from work... [and] the ambulance would be in my driveway. He'd have self-harmed and tried to hang himself.

⁵⁴ Mākutu means 1. (verb) to inflict physical and psychological harm and even death through spiritual powers, bewitch, cast spells. 2. (noun) witchcraft, magic, sorcery, spell. Mate Māori means Māori sickness - psychosomatic illnesses attributed to transgressions of tapu or to mākutu.

One of the participants from the young adult focus group discussed how she had found her sister's behaviour challenging until gaining a better understanding of mental illness:

I know them better now than I did before... when it all first happened... I get along with them more now than I did back then because my sister, she'd just randomly be crying all day, throwing tantrums, you wouldn't have a clue what was wrong with her.

2.6 Recreational drugs and mental illness

Participants said they occasionally felt self-conscious, embarrassed and/or stressed about issues connected to the family member who experienced mental illness. Sometimes these feelings related to the effects of a consumer combining recreational drug-taking with prescription medications designed to treat mental illness. These actions were often associated with behaviours that had consequences for both the consumer and other family members. Two participants from the young adult focus group highlighted this issue:

[I get] self conscious...when he has done... embarrassing things and being unpredictable, [you] don't know if he will do something or not... I don't know if you'd call it discrimination but...because my brother was into heaps of drugs and stuff as well...no one in our family trusted him...for ages I disowned my brother... like he'd had so many chances and he just screwed everyone over...I don't know how much of that was actually an illness and how much was actually just drugs...now he's way better so we get on a lot better.

[T]hat's the same with my brother. With his meds he does weed and everything and that totally counteracts what meds he's on. So he's like 'yeah, I'm feeling good, I'm feeling good.' That's only because he's high, off his tree, that it's like, well, 'when you're on your come down... your meds won't be working. So, you know, ... do you want to feel better without having to resort to that or do you just want to keep doing drugs?'

2.7 Attitudes towards independent living

Some families raised concerns about a family member going flatting or being able to sustain independent living. This reflected a range of issues such as being able to uphold the requirements of a tenancy, the suitability of other flat mates, and self care.

[My] son... would like to flat, but he doesn't want to flat with any mentals [lots of group laughter]. But then if he is going to go into a flat...young guys would be drinking, [they] may take a few drugs...he can't afford to be in that situation...what 'normal person' would want to live with [someone with mental illness] as a choice...I wouldn't inflict that on somebody who's got a normal life...My son has flatted with people [who experience mental illness] but.... there were problems that they all had [laughter] like very dirty and messy...The landlord wouldn't let them stay so they had to keep moving.

At first we actually left him out flatting and thought that would be the best thing for him because [of] our dysfunctional family situation. But he spent a lot of time in bed and he was not looking after himself...I discovered... the only meal he'd had was an evening meal with his flatmates and he wasn't doing anything and I just knew that I had to bring him home and feed him up.

2.8 Relationships and communication

Families often discussed changes in a family member's behaviour when they were unwell, and the impact this had on their relationships and ability to communicate with one another. Some participants noted that a person's role within the family influenced how they felt about the consumer and what mental illness meant within a family. Issues for mothers were particularly noted. A parent from the Chinese focus group spoke of the impact on mothers of mental illness within the family:

Besides the mental patients,⁵⁵ the people who suffer the most stress are the parents, especially the mothers....You take more care of your children, that's why you feel more stress...it is one thing that we accept mental patients or that we have a mental patient

⁵⁵ This participant attended the Chinese focus group. English was not a first language. Terms used in the quote are verbatim.

in our family. At the same time it is very important how you support yourself.

Another woman in the Chinese focus group reflected on the impact of her sister's mental illness:

The difference in relationship affects how you see this matter and how much you can take.... My sister is sick. I can understand how my mother feels and I have carried the burden she carries...my parents fled from China...their only hope was their children...my sister...got ill before she turned 20. My parents could not take this blow...they went through periods of fights...they thought my sister was being disobedient ...I felt the pressure and was very scared.

Participants from the young adult focus group made the following comments associated with relationships and communication within their families:

[S]ometimes when it's really bad...it's like they're a different person and you can't kind of talk to them because it's not them...when my brother got committed...it was...like it was not my brother...he did not act like he normally did. And it was kind of scary because that's not what he's like.

[W]hen she was really ill it was hard because she was quite abusive. So she would just walk in [and] she'd start yelling at you. So I completely shut down...and I couldn't even have a conversation...I mean I try and be a support when she has psychosis in the night, I normally get up and help her...and she often can't even remember me getting up to her...we try and help her, you know just say 'how are you feeling?'

A woman in a general families' focus group spoke of the challenges associated with communicating with her sister when she is unwell:

That relationship thing is something I've really struggled with... how do I have a meaningful discussion with this person who's entire world is consumed with these people who are chasing me and following me and going to kill me. She lives in an entirely different world to the world I live in and that's her reality...How do I build a relationship?

A mother discussed communication issues in the context of a son who experiences thoughts involving grandiose ideas and threats to his life:

It's easy to talk about discrimination as bad...I don't know whether you have a normal conversation with your family member who's ill like you would with anybody else...I don't think you do... [When he says] 'I am the king'...I can understand why people would 'go woaha'... do we really want him here when he's behaving really weirdly. [M]y son gets quite aggressive when he gets unwell and he goes round threatening people...so you can understand some discrimination actually.

Living with a family member who experiences mental illness sometimes affected relationships between parents:

I did come to the decision [and] said I could no longer have [son's name] at home. I had to decide whether it was my marriage...or my son...He's out in the community, he's doing well...he doesn't live as cleanly as I'd like him to... as well as I'd like him to. I support him in the community, he comes two or three times a week for meals, I bake and I take things round, and it's really worked out well...But it's a hard thing to do.

2.9 Contradictory feelings

Some families and whānau recognised that they had contradictory feelings or 'double standards' in relation to a

consumer family member and mental illness. For example, while families would not allow discrimination from others, they recognised that they often treated the consumer unfairly in relation to other family members. Sometimes families said they talked overtly about the consumer in a disparaging way. This was typically associated with 'coping' or 'letting off steam' in situations involving consumers who were perceived as having a high level of need and/or required support over a long period of time.

2.10 Adjusting to progress

Discussion within the families' focus groups revealed that it was sometimes difficult to adjust to a consumer's progress and improved wellbeing. Mothers also found it difficult to 'let go', especially in relation to young adult consumers. A lack of adjustment to progress and letting go were often associated with the fear that the consumer might have another crisis or be unable to cope. These fears sometimes made it difficult for families to adjust how they responded as the consumer's needs lessened. This was so for a mother whose daughter experiences mental illness:

[For] a long time...I just wanted her to stay on that medication...it's the only thing that was keeping her well... I knew that I was holding her back then...for me it was the fear of her actually becoming unwell again and us all going through that scenario again.

An adult daughter who is the primary support for her mother also discussed challenges associated with adapting to her mother's progress and identifying appropriate boundaries:

I guess my sort of discrimination...comes from... maybe I 'mother' her in ways that I am overstepping the bounds...it's hard to know where those boundaries should lie... she's been talking about ...spend[ing] some money... my alarm bells go off immediately...but some of things she's talking about spending money on aren't really that unreasonable and whose money is it anyway? It's her money, it's her right.

2.11 Attitudes towards consumers raising children

Some families expressed strong views about consumers having or raising children. This sometimes reflected concerns about raising children in the context of what was perceived as an 'unpredictable' or 'transient' lifestyle resulting from the experience of mental illness. Sometimes concerns about consumers raising children reflected attitudes about a family member's behaviour, and sometimes it had more to do with fears about mental illness being inherited. Four participants in one general families' focus group conveyed their sentiments about consumer family members and children:

[My] sister...she's never healthy for more than a month or so before she has to move houses again because of whoever is chasing her - she can't live in one house for more than a month or two. How do you raise children in those circumstances?

My brother's in a relationship and he's practically married this woman he's known for a few months...at the end of the day he can do what the hell he wants, gets her pregnant, fine, whatever, I mean, I can't control everything, I think the Privacy Act's a load of bullshit when it comes to mental illness, it basically stops them getting the help they need in a lot of situations...But at the end of the day, when it comes to relationships...they don't behave in adult ways, but they are an adult, and you can't control that.

Yeah I think [consumers having children] is PC gone wrong.

I must admit I don't want [my daughter] to have children...to have to experience as a mum what I've had to experience. I don't. And I know that's so discriminatory... I've looked at the stats, I've read about it, it's highly likely that she'd have bipolar ... and having a baby's huge...and she can hardly look after herself.



One participant from the Chinese focus group said that she typically told people that her sister has mental illness. However, she worried about perceptions that mental illness may be genetic:

When I get into a new relationship or talk about marriage with my boyfriend...I will wonder whether he minds that this gene probably runs in our family...will our kids get the same disease because of my genes.

The whānau focus group spoke passionately about situations they knew of where other whānau had discussed preventing mothers diagnosed with mental illness from having any children, or any further children:

[With] another whānau member...[there] is concern that she does have more children because she currently has a number of children that she's not able to care for...[they have talked about] a way that she could not have children.

My children's birth mother... was very adamant that she was to have a hysterectomy so she couldn't have any more children...I was flabbergasted to think that someone could think like that...just cut them to pieces so they can't do any harm or produce anymore...it's horrible.

A kuia in the group spoke of how important it was to maintain whakapapa irrespective of mental illness:

[We] weren't brought up like that, it was just something that happens...we weren't into... trying to prevent [mental illness] by selection, that was a grotesque thing to judge your whakapapa in that way. Your whakapapa is a gift...you don't try to prune it.

2.12 Derogatory language and name calling

Some people discussed the way a consumer family member was sometimes labelled and called derogatory names within the family. At times this seemed to reflect sibling rivalry. At other times it was more likely to reflect stress and frustration.

[W]ith a sick child... I think it looks from the other [siblings] that you are favouring them because they're getting all the attention....my younger one... he calls [the consumer] 'psycho' and 'crazy'...outside they're yelling at each other...being younger... he thinks it's funny.

My son usually calls my daughter 'oh you're crazy, you're a retard'...my son really looked up to my daughter...[but] when she became unwell... they started a huge massive fight for years and he would call her names... and terrible things...now that he's older he's starting to understand a bit more.

One of the Chinese participants recounted an example of a woman she knows who is often in hospital, has very little support and is subject to domestic violence:

Her husband treats her very badly...her husband is a very important reason why she does not recover, he is the main reason. People outside their family only see a glimpse. He often says to her at home, 'you're crazy, don't talk to me.' Her hands tremble when she talks. It's very difficult for her to recover.

As discussed in Chapter Three, Pacific families also spoke about the many derogatory names used to refer to or speak to consumers within families.

2.13 Assuming authority

Some people in the general family focus groups indicated that they attempted to manage the consumer's life and/or make decisions on their behalf, irrespective of the consumer's consent to do so. In some families what was expressed as genuine love and concern sometimes morphed into over-involvement, close scrutiny and/or surveillance of the consumer.

An adult daughter of a mother who has experienced mental illness for many years illustrated an example of the dissonance families sometimes experience when trying to get help for a family member. Here the best of intentions led to an invasion of privacy.

[T]he most frustrating time for me was when [mum] was clearly becoming unwell... I've lived with it for nearly all of my life, and the professionals just weren't listening...[so] I became a detective...started to...write notes... [about]...what she was doing, what she was saying... I had to go round to her flat, I had to take photographs, I took before and after photos, because I wasn't being listened to... I fought basically, to actually get her back into hospital...if I just accepted what they had said...she'd be living under bridges.

Later in the focus group the daughter reflected back on the above situation and conveyed awareness of her behaviour and the difficulties associated with balancing family and consumer rights.

Sometimes it's hard to know what should be your right and what you would like to be your right...there's a big difference. Sometimes I think I would really like it to be my right to jump in and take over everything with mum. But it's not my right and it shouldn't be my right because she's a human being of her own accord. She has...a need of privacy...of her own dignity.

The mother of a young man who experiences mental illness, frequently harms himself and often damages property within the home, had resorted to invading her son's privacy by reading service notes without his consent.

I used to sneak information, like my son would bring home a piece of paper for part of his treatments so I would go in and read it...[it] was probably not very good, but I used to find that that's the only way I could see...where this counselling was going...it's awful really to have to be in that position where you have to sneak, y'know, you feel sneaky...I felt...dishonest about it. He didn't want to talk about anything, he never talked to me about anything.

2.15 Anger directed at consumer

Sometimes the stress associated with not understanding mental illness, while also supporting a distressed family member, led to expressions of anger towards the consumer. In Chinese communities the 'success' of a child (especially when there is only one child) has great meaning and significance for the status of the family. Moreover, in China, mental illness is seen as a 'disease' which is 'condemned', and consumers are subject to high levels of discrimination. This background then shapes feelings about mental illness within a New Zealand context.

A mother from the Chinese focus group who experiences depression and severe insomnia spoke of her feelings towards her once high achieving daughter, and the sense of hopelessness experienced when both her children were diagnosed with mental illness:

My daughter was outstanding...she was good in everything... All of a sudden she [was] not talking, ignoring people, and crying all day long...one day...I said to her, 'keep crying and I'll kick you out'...after seeing the school counsellor... [I realised] we didn't show her enough care... I realised we were in the wrong... I thought... 'oh no, my daughter is going to be like this forever'... when my son came, he was worse...my whole world collapsed.... That's why I ended up with depression...I am very tired every day,

mentally and physically...I am very sad...I am now living in despair...my husband does not understand...I am a human being not a robot.

Another Chinese family member spoke of the connection between the stress she felt, and anger directed towards her son:

I believe that we who are there as family members to support him, will also face a lot of stress. Sometimes we are very worried and that makes us get mad. I realised that every time I get mad at him, it's when I can't take it any more. I realised when I show my stress, he feels very helpless and his self discrimination gets worse.

2.16 Abuse within families and whānau

While few participants in the families and whānau focus groups spoke of abuse within their families, the issue of abuse was addressed by consumers and tāngata whai ora. One participant in the families focus group spoke out about the injustice associated with children who are abused and then subjected to discrimination from within their families, especially when families retain decision making authority in relation to the young person's care:

I have a young woman that I whāngai⁵⁶ and she's been in and out of institutions and her whānau discriminate. It's a lot of early childhood trauma...some of our whāngai are like scapegoats...they're not treated [well]... they still have that discrimination...and [her biological family] still have the last say about her mental health care...yeah...the whole whānau - I think it's so important to talk about what may be some of the problems rather than just the diagnosis, the labels.

This quote provides an example of the whānau colluding with psychiatry and the biomedical model, thereby validating removal of the young woman's human rights and remaining unaccountable for abuse within the whānau.

2.17 Social exclusion

Families and whānau spoke about various forms of social exclusion as a way of avoiding discriminatory comments and behaviour and perceived stigma. Some families and whānau excluded themselves and/or the consumer from social engagements, due to prior experience of discriminatory behaviour. Others had not directly experienced discrimination, but wanted to protect the consumer from potential discrimination. Some families and whānau felt the stigma of mental illness so acutely that they avoided social contact. At times, avoiding potential discrimination had led families not to seek and/or permit treatment. This was particularly pronounced amongst participants in the Chinese focus group:

I asked my step son, 'did your mum bring you to the doctor?' He said '[W]e stopped going [to the doctor] because my mum... thinks that people who see a psychiatrist are crazy and will beat others up'...[the mother] was afraid others would discriminate against her son... this delayed treatment for this boy.

A mother in the general families' focus group spoke of siblings excluding one another:

My daughter supports her brother very very well...in the winter she makes sure that he's got warm clothing...she's very good and kind but she just would not involve him in her social life. Perhaps the way he dresses sometimes, or presents, and in some ways I don't blame her.

One mother said she wanted to avoid placing pressure on her son in a social situation where family members had been discriminatory in the past:

If an invite came for the whole family and he was not well enough...I wouldn't put him under that pressure and take him. That would be my decision...I've not long taken him to his grandmother's birthday. We put things in place for him and people to watch him and look after him and he had a wonderful time.

⁵⁶ Whāngai means 1. (verb) to feed, nourish, bring up, foster, adopt, raise, nurture, rear. 2. (noun) foster child, adopted child.

For some families, the behaviour of a consumer was sometimes perceived as so 'disruptive', 'embarrassing' or 'unpredictable' that families declined invitations to attend social events, or did not invite the consumer to attend. Although generally supportive, siblings sometimes felt embarrassed about the consumer's behaviour and were reluctant to invite the consumer to their flat or other social events. Stress associated with a consumer's behaviour over many years also prompted social exclusion. One woman in a general families' focus group conveyed these feelings:

I think it is the behaviour...when we were coming up to a family event, there's like this [groan] - I planned my entire wedding day around minimising disruption. My little sister is now planning her wedding and she is saying 'oh I hope she [sister with mental illness] doesn't come'...[group laughing] ...it's those major family things... people had got to the point where they were just exhausted.

A woman in a general families' focus group spoke of behaviour that the family felt embarrassed about:

I know that our family would... rather...she not come to events because there was food or alcohol...she would continually be at the food table or drinking and not know when to stop drinking and then become very loud. So there was always that fear that there was going to be an episode or an argument which usually happened.

2.18 Distancing/exclusion

Several participants spoke of themselves or other family members distancing themselves or having become estranged from the consumer. This often reflected emotional pain from the effects of issues related to growing up with or supporting the consumer over a long period of time. A woman whose mother experiences mental illness recounted how and why her sister excludes their mother from her life:

I've been carrying around a letter written by my mum to one of my sisters because it's going to be my sister's 40th birthday... they haven't spoken in about 16 or 17 years....her way of

copying is just to shut down. She can't be around mum...nobody seems to understand that she's got valid reasons...and she's got a lot of hurt. I think that that grief...prevents...people from our family from being too much in contact with mum... so they stay away.

Another woman who had been a primary support person in the family said that the pressures of this role at a young age had resulted in her shifting towns:

I was in my early 20s and I was the primary caregiver of my sister...part of my reason for moving [from place] to [place] was that I was near breaking point myself in dealing with it. And I think that's a really valid decision, especially for someone in that age.

One of the participants in the young adult focus group spoke of now excluding her brother because she had become impatient with the effects on his behaviour when he stopped taking prescribed medications:

I have noticed here that I've excluded my brother from my activities a bit through that time [worse stages...a real bad stage]...it's going to sound very horrible...he had three episodes before his current one...he always came into his episodes because he didn't take his medication...he still expects us to always take care of him...the least he can do is keep taking his medication...I find myself rarely talking to him any more.

Under extreme circumstances, a minority of family members took measures to restrict visits or phone calls from a consumer in the family. Some families had taken legal action as a means to sustain their own mental health and/or protect themselves from the consumer's behaviour. The following three participants from the general families' focus groups were mothers who provided primary support to adult sons:

I've [had] trespass orders...for my own safety and sanity...but ... ultimately they haven't helped because if you have a trespass order against somebody, there's an expectation that if they disobey it that you will follow it

through, and then these kids end up in the justice system which doesn't help them...so... for both our sakes it's easier that he doesn't know where I live.

I put security doors on rather than a trespass order. That was because I couldn't do the trespass order... I admire you for doing it, but I couldn't do that, but we put security doors on...if he came round and was angry...then he couldn't get in.

[H]e was coming around...all hours of the night, knocking on the window, and if I didn't answer the phone he'd be around and then he'd ring ring ring ring...if I didn't answer the phone he'd just come around. So, I got an order out. I didn't want to...I've got high blood pressure...I did feel guilty at first, but I don't now... I changed my phone number...I was getting well over a hundred calls a day... I couldn't stand it anymore...not because I don't care or love him.

2.19 Compulsory hospital admission

Some families spoke of being unable to cope with a family member when their behaviour became overtly threatening or aggressive. In these situations, families sometimes sought a compulsory admission to hospital.

I've asked him once about episode where he tried to kill his brothers and he can say, he knows about it, he remembers it, but he was acting quite rationally because he had to defend himself otherwise he would be dead... So how can I manage that situation at home? There is a time when he has to go into hospital ...because we just can't live with it.



Summary

The majority of participants in the focus groups for general families, young adults and whānau reported that there was little or no discrimination within their families. In contrast, Pacific and Chinese families readily acknowledged widespread discrimination within their families. They provided a range of examples of negative attitudes and behaviours towards consumers that they had experienced or had witnessed in their families and wider cultural communities. Participants in most groups spoke of struggling with the day to day realities of supporting a family or whānau member who experiences mental illness. Irrespective of whether families acknowledged the presence of discrimination within their families, many described or revealed discriminatory attitudes and behaviours.

The majority of participants in all family and whānau focus groups said that they knew very little, if anything, about mental illness before their family member had this experience. For many, mental illness came as a shock, but became something families sought knowledge about and learned to accept. Participants in all of the families' focus groups provided high levels of support to the consumer in their families and whānau.

For many families, a lack of understanding about mental illness was often associated with fear. This sometimes led to blame, either of themselves or others. Some families treated consumers differently from other members of the family. This was often about wanting to help the consumer and responding to particular needs. Sometimes families wanted consumers to change specific behaviours or ways of living to avoid negative consequences, either for the consumer or for the family. A few families talked about the difference between behaviour that was 'just behaviour', as opposed to behaviour that was attributable to mental illness. Some participants discussed issues relating to the effects of mental illness and consumers' use of recreational drugs. Many families spoke of difficulties with relationships and communication. At times, families said they held contradictory feelings and 'double standards' in relation to discrimination towards consumers. Some expressed difficulties adjusting to a consumer's progress and recovery. A minority of participants spoke of derogatory name calling. Several participants expressed concerns about consumers raising

children. Sometimes family members assumed authority and decision making for adult consumers in their family.

At times, stress associated with the impacts of mental illness in the family led to anger which was directed at consumers. Several families said they sometimes excluded and/or distanced themselves from a family member who experiences mental illness due to embarrassment, a desire to avoid disruption, or discrimination from others. When a consumer's behaviour became harmful to themselves or threatening to others, some families took informal steps to keep the consumer at a distance, or sought legal intervention or compulsory hospitalisation.

Almost all participants in the family focus groups conveyed mixed emotions and inner conflicts in relation to the lived experience of supporting someone with mental illness within the family. The range of emotions experienced was compounded by the experience of discrimination towards families and whānau themselves. This is the focus of the next chapter.



chapter 5

Discrimination *Towards* Families and Whānau



The way we talk to each other makes a difference.

Herzig & Chasin, 2006:3

In this chapter, dominant themes relating to discrimination towards families/whānau and consumers/tāngata whai ora are reported. The most prominent sources of discrimination identified by participants were mainstream mental health services and extended families and whānau.⁵⁷ There was widespread agreement across all groups except the Chinese focus group that this was the case.

Societal norms, media messages and the broader social milieu were also identified as creating and perpetuating discrimination towards people who experience mental illness. Although less prominent, other sources of discrimination identified by participants included friends and social networks, churches, workplaces and police. For Chinese participants, extended families, friends and social networks were the most prominent sources of discrimination towards families and family members who experience mental illness.

Most families who participated in the focus groups were speaking from the position of having a family member whose experience of mental illness seriously affected his or her day to day functioning, was longer term, and involved one or more hospital admissions. Most consumers and tāngata whai ora were speaking from a position of being well educated about mental illness, and having a comprehensive analysis of discrimination. Most had experienced relatively recent personal contact with mental health services. Those who worked in the mental health sector had a comprehensive knowledge of mental health services (i.e. the nature of service provision in their geographic area, how to navigate services, linkages with other services) and were attuned to discrimination currently experienced by other consumers.⁵⁸

Because reports of discrimination towards families/whānau and consumers/tāngata whai ora were so similar, the key findings from these groups are presented together. Where the views of these groups diverge, separate findings are indicated. Three key themes were identified in relation to discrimination towards families, whānau, consumers and tāngata whai ora:

1. Discrimination from mental health services
2. Discrimination from extended families and whānau
3. Societal norms, media messages and social milieu

1. Discrimination from mental health services

The most prominent theme across all focus groups, except for the Chinese group,⁵⁹ related to discrimination from mental health services.⁶⁰ Five prominent issues relating to mental health services were identified by both consumers and families. These included:

- 1.1 Lack of consultation and inclusion of families or whānau
- 1.2 Lack of information
- 1.3 Dominant biomedical model of mental illness
- 1.4 Parent blaming and/or Criticism of primary support person
- 1.5 Race and age discrimination

⁵⁷ Participants primarily spoke of the mainstream inpatient and community mental health services provided by local District Health Boards. For brevity, the term 'mental health services' is used throughout this chapter to refer to these services. They include adult services as well as child and family services, but exclude kaupapa Māori and Pacific mental health services and specialist services (such as mother and baby inpatient units).

⁵⁸ Participants working in mental health services are likely to have a particular perspective on and interest in these services that gives them a distinct viewpoint from which to understand discrimination. However, there was a high level of consistency between the views of these consumers and tāngata whai ora, and those who did not work in the mental health sector. Moreover, the views of consumers and tāngata whai ora working in the mental health sector were highly aligned with those of families and whānau – most of who did not work in the mental health sector. While it could be argued that the inclusion of consumers and tāngata whai ora who work in the mental health sector lends itself to a particular (negative) view of services, other research and anecdotal evidence indicates that it is likely other groups of consumers or tāngata whai ora would hold similar views of mainstream mental health services (e.g. Barnett & Lapsley, 2006; Peterson & Gordon, 2009).

⁵⁹ Participants in the Chinese focus group spoke of dire experiences involving mental health services in China. New Zealand mental health services were viewed favourably. However, Chinese families did not like the fact that they were not included or listened to by mental health services in New Zealand.

⁶⁰ A few participants mentioned individual staff members who work with families and whānau in a respectful way and attempt to provide an holistic approach, as far as this is possible within mainstream services.

Consumers and tāngata whai ora also emphasised the role of diagnoses, labelling and the language used within mental health services as a source of discrimination. They attributed this primarily to the dominance of a biomedical model of mental illness.

During the discussions, there were times when it seemed that some of the issues participants were talking about related to family/consumer and staff power dynamics, and attitudes, behaviours and practices which, while not conducive to recovery, were not necessarily about discrimination. When facilitators in the focus groups (and later in the discussion forum) questioned participants about what they meant by discrimination, there was emphatic and unanimous agreement that the issues identified in relation to mental health services were about discrimination.

1.1 Lack of consultation and inclusion of families or whānau

Participants spoke at length about the way staff in mental health services, including community mental health teams, failed to consult or include families or whānau in consumers' treatment or planning processes. Several consumers and tāngata whai ora also reported that they had not been asked by staff in mental health services whether they would like family or whānau involved.

A consumer spoke about family members being ill advised about how to help:

When I was seeing the community team...my parents...weren't around or available, and my aunt who was here who was quite involved. [She] tried to find out what was going on so she could help, and she'd phone the community team and ask...what she could do to help...and they just...wouldn't tell her anything at all... and I wasn't asked whether I wanted her to be involved ever.

A woman from a families' focus group explained her fears about not being heard by the experts when the consumer in her family is experiencing mental illness:

[I] have been fed up with the ambulance at the bottom of the cliff approach...I live with this child...I can see when he's...going downhill, he's heading into that decline and it's frustrating when he's saying no he's fine and the experts are listening to him and not me... when he's not probably able to make that judgment...at that time.

A male consumer conveyed his ideas about family involvement:

And [families are] an ultimate form of support...right there, rightly or wrongly...but [they are] being really kept out of the process. So it's really to the services' detriment that they're doing that.

A woman from a families' focus group talked of how, when staff did talk to family members, it was not to consult them:

I've always thought that they've told me what's going to happen...there's never been a discussion around it...I mean, yes they're interested in a little bit of my history...but it's always been telling me what's happening. And after the fact, they've already probably started her on that treatment.

Some families spoke not only of a lack of inclusion in relation to their family member's treatment, but active discouragement and exclusion by mental health services. A mother from a general families' focus group spoke about being separated from her daughter while her daughter was hospitalised:

[W]e were banned from seeing [my teenage daughter] on the last episode...we weren't allowed to see her for ten days...under the Mental Health Act...we just were not allowed to see her... family doesn't really come into the medical model, you just throw things down their throat... there was no negotiation...you had to sit and listen and then... 'she's going

into seclusion for 24 hours!...and I say 'I don't want her to go into seclusion, I will be with her for 24 hours.' [They said] 'no you won't.'

As part of the discussion on mental health services, participants across focus groups reported that most clinicians positioned themselves as 'experts' regarding the consumers they dealt with, despite brief and /or infrequent contact with those consumers. This meant dismissing or minimising the day to day realities of the consumer's and family's lives. Families and whānau also reported that there was a lack of receptivity to their intimate knowledge of the consumer. A participant from the whānau focus group commented, 'they interview you for half an hour and then they know everything about you and you, they know you better than the whānau does'. A consumer reflected on the issue of clinicians' positioning themselves as experts and discounting family knowledge:

[T]here's tremendous value in...[services] sharing knowledge [with your family]...who knows you better generally than the people that you live with day in, day out? Who can screw you up more than anybody is generally your family but also who can actually support your recovery more than anybody else.

Māori and Pacific families - holistic worldviews

Māori and Pacific participants viewed family or whānau as intrinsic to a holistic approach to mental health. To exclude the family was regarded as an exceptionally discriminatory practice. At kaupapa Māori services, the inclusion of whānau was integral to the process of holistic treatment, recovery and healing. Two participants in the tāngata whai ora focus group spoke about the benefits of whānau inclusion:

The service I use now is whānau inclusive and that's what I like about it. It involved the whole whānau. [At] the [mainstream] clinical services my kids were left at the door...that's my experience with discrimination.

If I had been handed on to a Māori kaupapa way back...which I wanted but never got... all my clinicians were Pākehā...I got it in

2001 when I went to [name of kaupapa Māori service] and it's the best thing that ever set me on the road to recovery...I wasn't even given that option... [it was] this is all you're getting.

In Chapter Six, issues relating to family and whānau involvement in the context of historical child abuse and severe family dysfunction are further discussed. Many tāngata whai ora did not want their whānau of origin involved in their treatment processes. Instead, as Chapter Three notes, whānau they had chosen became surrogate families.

For Pacific people, the lack of inclusion of family, as well as issues relating to language barriers, were regarded as discriminatory, and viewed as an important source of discrimination within families. This was explained by a Pacific man:

[T]he core of the discrimination comes from... the clinicians... consumers...all say...they may have been asked if they want family members there but they are unwell...the [clinicians] use technical languages... when we aren't well...the Island born they only think in their [first] language... because clinicians are mainly Pākehā, they are used to the illness or Western model...the time has come to marry the Western model and the cultural model... discrimination is very institutional...I blame them for the discrimination within the family and community...discrimination...is...passed down.

A Pacific participant who had been a primary support for his Pacific Nation born father, for many years, discussed the way services ignored his views. He highlighted the potentially dangerous impact of poor translation in relation to his father's medications for a physical illness as well as mental illness:

[M]y father told me this medication is too strong...for my mum, English is a second language... I was 14 years old...No one's told me about mental illness or medication... my dad's also epileptic, mum's asked me to medicate my dad ...[she thinks] pills are pills, epilepsy, mental health pills they are the same...financially we weren't that stable,

she ran out of the epilepsy pills so turned to the mental health pills...he started getting unwell...who is responsible for properly translating to my parents what they are meant to do?... it's the clinical services.

In this instance the son, who was only a teenager when providing primary support to his father, was ignored during meetings with mental health services, including when a Pacific staff member was present.

I'm a NZ born and as a NZ born you're regarded as not knowing the language. So I'm sitting there, the [Pacific] nurse is there, my mum is there, my dad is there, the doctor is here. The doctor talks to my dad. He says his bit and the nurse translates it. What I hear my dad say is not correctly translated. The nurse thinks: 'I know what he is talking about'. But I grew up with my dad. I know his experiences. It wasn't what she thought.

Young adults

Parents of young adult consumers, and young adult siblings of consumers, reported that they experienced high levels of discrimination from staff in mental health services, and that this led to poor care for their family member. These experiences were applicable to inpatient as well as community mental health services. A participant in a general families' focus group spoke about being excluded from discussions with staff in mental health services:

[W]e've got to the point where we will journal symptoms and that sort of thing and hand them over to the mental health professionals...I think as a sibling you almost have less voice...my parents just weren't accepting [my sibling's mental illness], [they] didn't understand, so I was the primary [support]. But the mental health service would go to my parents who didn't understand and they [services] wouldn't listen to me.

Younger family members across the families' focus groups were also widely ignored and excluded by staff in mental health services. Several had been the primary support for their parent consumer from a young age, especially when

the parent's partner had passed away or the parents had separated, but they were typically excluded from planning and treatment processes. A participant in a general families' focus group outlined their experience:

[T]he children of mentally ill - we are called the invisible children - because a lot of the time new people [staff in mental health services] don't ask about how the children are coping...I became my mum's primary caregiver at about the age of 15, when my dad left...children are very similar to siblings in terms of not being heard... they think...we're too young.

In addition to widespread reports of failing to consult or include families, some participants reported that family members had been actively discouraged or banned from visiting or supporting consumers who were hospitalised. Some consumers viewed the exclusion of family members as detrimental, because they wanted their family's support. Two participants in a consumer focus group spoke about their experiences where services tried to keep their family members excluded:

I didn't know until years later but...when I was about 14, services said to my dad basically 'butt out'... 'this is her problem...you just need to kind of stay out of it'. I found out five years later, after I had been discharged from the psych ward... five of the most tumultuous years, 14 to 19, that we were very detached from each other...to me [it was] like obviously he doesn't really care. To him it's like 'Oh God, I have to do the right thing because this is what the doctors said'...that five years could've been so much easier for both of us.

My father was actually told [by one of the nurses] when I was in the ward that he was doing more harm than good and that was because he was suffering depression. But I was actually really glad that he didn't listen to that and he came visiting me every day. I know there were actually times when I wasn't told that he was visiting...it was actually kind of really good that he was suffering from depression at the time because we could walk alongside each other.

1.2 Lack of information for families and whānau

Families and whānau reported that they were given very little information about mental illness, particular diagnoses, the purpose and effects of particular medication, the provision and navigation of mental health services, and the availability of other support services for families and consumers. Information that was provided was strictly biomedical in focus. Information using recovery principles and practices was not provided.

Some families and whānau wanted to receive generic information, while others wanted to access confidential information irrespective of the consumer's consent. Some family members believed that as a consumer's primary support person, they had a right to, and need for, access to treatment information. A participant from a general families' focus group explained:

[T]here is no support for the families. The hospital does not give out information about... diagnosis, the medications...they don't even refer the families to an organisation to get that support...We weren't involved in their treatment plans, and the family members lived with the family...we didn't know about the side effects, we're thinking...they're just playing on it...to get sympathy and...in actual fact it was the medication making them do other things... it would have been made a lot easier if the doctors had talked to the family... [They] didn't even ask our loved ones if they wanted the family in there.

Some families also expressed concerns that mental health services did not provide information about other support services in the community:

And...when they're out of hospital and they're living on their own...the support they don't get that they should get when they move out of hospital...and you keep asking and asking and asking and you never get any results and they live in pigsties ... all [that mental health services are] interested in is giving them the jabs and the pills.

One mother described her concern when a school general practitioner prescribed medication for a minor without consulting the child's parent/s:

My daughter was 14 going on 15 and came home with some anti-depressants that the doctor at the school had prescribed for her. I knew nothing about it and I was absolutely terrified....I think that's really sad that that's allowed to happen today....

The lack of inclusion of families and whānau and lack of information about mental illness often fostered fears amongst family members. Participants across focus groups reported that these factors led to the reinforcement of stereotypes about mental illness, and perpetuated discrimination within families and whānau.

1.3 Biomedical approach to mental illness/ absence of holistic worldview

The dominance of the biomedical approach and lack of holistic conceptualisation of mental illness were regarded as key sources of discrimination by families and whānau, consumers and tāngata whai ora.⁶¹ Many participants commented that there was an absence of a recovery paradigm in most mental health services. Moreover, the adoption of more holistic paradigms, such as Māori models of health, was regarded by many participants as much more in line with understanding people's experiences and the multiple dimensions that contribute to mental health.

For Māori and Pacific families and consumers, the insistence on a biomedical approach, in conjunction with a lack of cultural understanding and a shortage of Māori and Pacific staff within mainstream mental health services, exacerbated feelings of discrimination.

Participants across focus groups conveyed a strong view that mainstream mental health services reduced people's experiences to a set of symptoms. The spiritual, social, cultural and historical context of a person's life was negated. The singular focus on symptoms was believed to result in a treatment philosophy based solely on medication. This meant the neglect of therapeutic

⁶¹ References to the 'biomedical model' mean of, or relating to, or involving biological, medical and physical sciences as a framework for understanding the causes of mental illness and informing treatment approaches.

approaches and support services that could help improve people's lives. While a minority of participants had been in contact with kaupapa Māori and Pacific mental health services, which were typically viewed positively, this usually happened after they had been hospitalised in mainstream services.

Participants across focus groups also discussed the detrimental effects of medication, with many commenting that too much and too many medications were prescribed. Staff were often said to be unresponsive to feedback from families and consumers about these issues. Use of the English language with Pacific families and consumers whose first language was not English (and with older family members who do not speak English) was particularly alienating, potentially harmful, and led to strong feelings of discrimination.

Consumers, tāngata whai ora and whānau also often addressed the way an insistence on a biomedical understanding of mental illness meant minimising the effects of childhood adversity and trauma, and gendered power relations within the family. As one person said, people experiencing mental illness are often 'manifesting the actual family issues.' Two women from consumer focus groups linked gender politics and 'mental illness':

Depression has historically been a woman's ailment or issue, because men are allowed to get angry whereas women aren't and just have to suppress, or depress that anger and that emotion...that's a bit of gender politics... all of those dynamics [influence mental illness] which is why the biomedical model is so farcical because it's trying to isolate something...and what we're hearing here...is that we can't isolate it in one area at all.

[W]e've got histories of controlling males...and there's a lot of abuse that's gone down... and a lot of undiagnosed, what you could call 'mental illness'. I mean, I'm not a fan of...identifying with that ...it would be more abnormal not to have experienced depression and anxiety for the conditions and the circumstances that were going on generationally.

Many consumers and tāngata whai ora reported that the dominance of a biomedical approach fuelled misinformation and reinforced myths and stereotypes about mental illness, making discrimination more likely within families and whānau.

Diagnoses, labelling and language

Consumers regarded current diagnostic practices, which involve labelling people with particular disorders, as a key source of discrimination. Mental health service use of negative language and a deficit approach to describe consumers was also seen as discriminatory. Many believed the use of diagnoses, labelling and deficit based language reflected the dominance of a biomedical approach. This approach instilled a sense of hopelessness, was not consistent with a recovery paradigm, and was said to fuel discrimination within families and whānau.

Consumers commented that mental health services widely regarded 'schizophrenia' as 'severe', 'enduring', 'life long' and 'incapacitating'. Given that the only information families often received came from mental health services, this approach was all that families had to rely on to shape their own understanding of mental illness. Further, the media and dominant discourses about 'schizophrenia' were thought to reinforce ideas about the 'unpredictability' and 'undesirability' of people who were given this particular diagnostic label. Participants attributed the success of the Like Minds, Like Mine campaign, which has targeted 'depression', 'anxiety' and 'bipolar', for changing negative stereotypes about these diagnoses.

Sometimes diagnostic labelling was seen as a source of discrimination within extended families and whānau. Indeed, some participants reported that there were several people in their extended families who experienced mental health challenges. However, only those who had been diagnosed with a mental illness were actively discriminated against. As several consumers and tāngata whai ora commented, once a person was labelled with a particular diagnosis, whatever they said, did and felt was pathologised by mental health services as well as by their families and whānau.

1.4 Parent blaming/Criticism of primary support person

While the biomedical approach was seen as the dominant analytical framework used by mainstream mental health services for understanding mental illness, both consumers and families also reported that clinicians' sometimes blamed families for a consumer's mental illness. While blame was often subtle, there were numerous examples where it was overt.

As noted previously, one of the participants was denied access to her teenage daughter while the daughter was compulsorily hospitalised. The participant noted that in this situation it was difficult for her not to feel blamed or judged by services:

When you get that message [i.e. you can't see your daughter] you think it's you, you immediately think sheesh it's me, they think it's us, they think it's the influence of the family.

Another participant who had spent many years supporting her mother spoke of the frustration she experienced when services failed to listen to her and viewed her concerns in a negative way:

It's interesting sometimes because...I look at some of the times when I've actually tried to get my mum into hospital... I'm pushy because I know that this is what's best for her...other people, clinicians, interpret that as.... 'angry', 'over involved' [aggressive] 'difficult'...this is my grief...I'm exhausted, I'm overwhelmed...I need to know she's safe.

While some consumers and tāngata whai ora attributed mental illness to childhood abuse and other family related trauma, they also noted that it was unhelpful for clinicians to blame or take a judgmental stance in relation to families and whānau for these abuses.

By contrast, a minority of consumers reported that some clinicians insisted that the consumer had experienced abuse, neglect and/or other adversity within the family environment when this was not the consumer's experience. The insistence on a particular negative view of parents, meant that consumers felt they then had to defend their parents to clinicians, while also witnessing parents feeling

blamed and unsupported. A woman from a consumer focus group said:

I think also clinicians or mental health professionals being aware to let the reins of their pet paradigms go, if there's contrary evidence from the person and their family... I think it's essential in terms of perpetuating negative stereotypes against a family that's already struggling...to add an extra layer of blame and guilt is not helpful and actually can separate that person from their family.

Several participants in the families and whānau focus groups reported feeling blamed by mental health services for their family member's mental illness. Many had been subjected to comments indicating that they had caused or contributed to the mental illness. Blaming often went hand in hand with staff members' negative appraisal of parents' involvement in supporting the consumer. Several family members (typically mothers or adult daughters) had been told they were 'overly anxious', 'overly involved' or 'overly protective'. A participant in the general families' focus group with a daughter who experienced mental illness spoke about being excluded:

[My] daughter was 15...had a bipolar episode...in hospital for 6 months, came out drugged up to the eyeballs and quite incapacitated, and they [mental health services] said she can go back to school... they implied to me that I was being too anxious and there are counsellors [at school] and we will negotiate this for you. They didn't. No one negotiated anything... [at a later date] they suggested that she leave home because of this 'over-protective' mother...the counsellor actually said that to her.

An adult child in the general families' focus group spoke of not being listened to by the professionals when she knew her mother was experiencing mental illness:

[T]he most frustrating time for me was when [mum] was clearly becoming unwell ... the professionals... they just wouldn't listen. I was told 'this is mother and daughter relationship difficulty' which nearly made me want to

scream because...I knew that this was her becoming unwell. [S]o we had to wait [for mum]... to become so unwell that she just can't care for herself...[mental health services] would say to me, 'No, no, no, this is her choice, it's her right to live this kind of life.' Yeah. And I said... 'This is not quality of life for my mother.'

Staff in mental health services made negative comments in relation to adult children who experience mental illness, as well as to quite young family members who were dependent on a parent or parents. Some parents acknowledged that they felt protective. However, they also discussed how challenging it was not to feel this way when their adult child's experience of mental illness was distressing and debilitating. Although some families acknowledged that they might have contributed to a family member's mental illness, it was unhelpful to be blamed for this by clinicians.

Parent blaming and exclusion of parents by staff sometimes had the effect of parents disengaging from the family member. These practices were not regarded by consumers/tāngata whai ora or families/whānau as conducive to recovery. A female consumer spoke of what keeps family members from being more involved:

[Parent blaming] is disempowering a family if they are wanting to be supportive or what have you, because guilt is one of those emotions that people get really stuck in and it almost stops people from being able to really get involved, be proactive, like, it's pretty disempowering for a family member.

1.5 Racial discrimination

Whānau and Pacific families and consumers reported experiencing racial discrimination from staff in mental health services. This involved being excluded or ignored, being spoken to in a derogatory manner, having cultural worldviews or interpretations of experience negated, and having religious beliefs dismissed. There was a strong perception of racism among whānau and Pacific families and consumers. A mother of a daughter who experiences mental illness explained how her daughter was discriminated against because of her race:

When I first took her in, they just made a lot of assumptions...they...say 'what drugs do you take,' 'do you smoke,' 'do you drink?' When she says 'no' they say, 'are you sure you're not,' 'do you smoke cigarettes,' 'do you drink,' 'how much do you drink,' [she says] 'well I don't drink! The other thing is about boundaries, they just keep coming right up to her ...nose 'and so you went to school and ...and when did you drop out?' [T]hey make all these assumptions about you just because you're brown, and then they talk to her partner; her partner at the time was Pākehā.

A minority of participants reported a mix of discrimination related to age, gender and/or ethnicity. Although it was difficult to differentiate different forms of discrimination, participants believed that if a person was young and Māori or Pacific they would encounter discrimination. Sometimes gender was also seen to influence clinicians' judgments about mental illness. For instance, the behaviour of young males, particularly young Māori males, had been interpreted by clinicians as 'bad' rather than as reflecting mental illness. This resulted in the young person coming into contact with the criminal justice system, rather than receiving the treatment their families and whānau believed they needed.

2. Discrimination from extended family and whānau

Participants across all focus groups reported that extended families and extended whānau were a key source of discrimination towards the family or whānau, and towards consumers or tāngata whai ora.⁶² The most common issues discussed in relation to extended family and whānau were the use of discriminatory language, disparaging comments or judgments, and various forms of exclusion. A participant in a general families' focus group spoke of discrimination by her extended family:

My brother is diagnosed with bipolar...with our first cousins there is discrimination...[they're] quite judgmental...when he is around and the kids are around, they kind of worry...what kind of effect he will have on the children. But... it's the actual adults that will have the effect [group agree] because of the role modelling... what they say and how they chatter about him. The kids then are taking that in...I have noticed in our whānau discrimination ...and the labelling...[and the idea] he is not normal... [he's a] freak.

A participant in the general families' focus group spoke about the lack of understanding from her extended family:

[M]y sister-in-law would come to me and speak to me about the voices she was hearing where all the rest of the [extended] family shut her down when she tried to talk to them...she took her own life which they have to live with now because they didn't listen... I think there's got to be more understanding, more empathy.

A participant in the general families' focus group struggled with the lack of support from her family:

I felt deserted, you know, my aunts and uncles and grandparents knew what was going on... when [mum] was unwell...my dad...they separated.

Participants in the consumers' focus groups spoke of more covert forms of discrimination, subtle comments or innuendo, and subtle forms of exclusion by extended families. Tāngata whai ora and Pacific participants in particular reported that discrimination from extended family was overtly negative. Much like the experience of discrimination within families and whānau, consumers were called derogatory names, actively shunned or rejected, and/or regarded as 'bad'.

For all groups, discrimination from extended families and whānau was thought to be associated with being ill informed about mental illness and/or feeling ashamed to be associated with someone who experiences mental illness, or who behaves in ways seen as 'unusual' and/or 'unacceptable'. Three participants from a general families' focus group explained their experiences of discrimination:

I have a brother-in-law and a sister-in-law... when there's anything on in the family, my son is not invited. I get an invite for myself, my husband and my daughter, but my son is never invited. For a long time I didn't go. I sent my husband, and said I won't go. If you can't invite all my family then I don't go. But because it's his only brother, it became very difficult.

My [close relative] died about six weeks ago and my daughter said 'I do not want the brothers at the funeral'. Then just yesterday there was a death that we knew so we asked him if he'd like to go along and he did and he fitted in very well. That sort of sticks with you, that you've got two boys who would've gone and would've fitted in very well, but they weren't welcome

My father-in-law is a vicar and my sister-in-law is a vicar and they have never in the five years we have had [mental illness in the family]...come to us or talked to us about my daughter...[and] they are good loving people in the community.

⁶² The meaning of whānau is usually broad and inclusive. However, participants in this research typically differentiated their more immediate whānau from their extended whānau. For this reason, discrimination from extended whānau is included in this section.

For Pacific and Chinese families, feelings of shame were intensified because of very negative cultural meanings attributed to mental illness. Sometimes a lack of understanding about mental illness seemed to be due to relatives being uncomfortable or unsure of how to relate to consumers. Irrespective of the motivation, consumers were often excluded by extended families and whānau from celebrations and other social events. A man from the Pacific focus group explained his experience:

It's an illness that brings shame to a family, it brings shame... I was talking about [my] sister before, people call[ed] her [names] so whenever people [said she is] your sister, before I came into mental health, I used to say 'No she [is] our parents' foster child' cos of that shame... it's quite bad with our community.

A woman from the Chinese focus group spoke of her experience of shame from family members and within her community:

These people [with mental illness] are everywhere around us. In one case, the family members were too ashamed to talk about it. They felt that this kind of disease was too shameful, hence they did not tell people about it. And they turned their back to this child. In the end the child committed suicide.

In some extended families and whānau, several people experienced mental illness. Participants reported that mental illness was not spoken about and remained hidden. This was especially so within families where the person/s experiencing mental illness had never accessed mental health services or been given a diagnosis. Consumers who said there did not appear to be discrimination towards their families also noted that this may have been because no one outside the immediate family knew that there was a family member who experienced mental illness. A woman from a consumer focus group spoke of her family's inability to openly talk about mental illness:

In my family there's actually quite a lot of people with mental illness... and I find that no one talks about it unless we get drunk. Then all of a sudden everyone's sharing all these strange things that happened... but if you try and talk to them again about it when they're sober they don't want to talk about it. They're all men so I think there's definitely... especially with Asians, there's a thing about men not having any problems, and not talking about emotional sort of issues.

Some extended family members were regarded as being afraid of 'contamination' by association. This fear seemed to be linked to the notion that mental illness is hereditary. As discussed in Chapter Four, some family members and extended family members held strong views about consumers raising a child or children. A pregnant woman from a consumer focus group spoke about discrimination towards her from family members:

Some of it [discrimination] also is around a family member's understanding of mental illnesses... there are some people in my family who have a very biological medical model view... therefore they might perceive the fact that I'm having a baby as being a risk taking venture... I'd pass on some genetic tendency... however if there's more of a holistic view... in terms of trauma, psychological impacts of environmental stuff... then I believe that it's easier to understand and it wouldn't be seen as such a barrier to actually having children.

Fears about contamination were particularly pronounced amongst Pacific and Chinese families, for whom there were also strongly negative cultural meanings associated with mental illness.

The perception amongst extended family or whānau that the consumer was 'bad' or 'behaving badly' was also sometimes experienced. A mother from a general families' focus group spoke about her need to defend her son:

[In] my family...with my father...my brother... my ex-partner and his family... I'm forever defending my son's behaviour or trying to justify it...they just think that I'm being too soft...but perhaps it's their lack of understanding...it seems that it's easier for them to think he's just being a little shit.

Some families reported being overtly blamed, or feeling blamed, by the extended family for a family member's mental illness or for behaviour associated with it. A mother from a general families' focus group spoke about being blamed for her role in her child's mental illness:

I think the hardest thing...I have had within family is...my children are adopted. My son is adopted who has the mental illness and has quite a lot to do with his birth mother which to me is wonderful...but she blames me terribly for the way that he is and she often rings me up and calls me all sorts of names...and... tells me if I hadn't of done this, if I'd done it different, he would've been different so I find that extremely difficult.

Almost all participants who reported discrimination from extended families and whānau attributed it to a lack of information, knowledge and understanding about mental illness. For many relatives, this lack was thought to be compounded by dominant myths and negative stereotypes about mental illness. These interrelated factors were thought to create a cyclical process of misinformation and perpetuate fear within extended families and whānau.

3. Societal norms, media messages and social milieu

Many people spoke of a lack of understanding, compassion and tolerance around mental illness within their community and wider society. In particular, a diagnosis of 'schizophrenia' was connected to a broad set of myths, associated fears and social exclusion. Discrimination was also discussed in the context of dominant cultural norms about 'acceptable' and 'appropriate' behaviour, speech, dress, appearance and ways of living. This social milieu meant that many families and whānau experienced shame and felt reluctant to tell others that they had a family member who experiences mental illness.

Many consumers spoke of the way dominant societal norms and media stereotypes shape people's thinking and fuel fears about mental illness. This type of knowledge was often all that families/whānau and extended families knew about mental illness. Discriminatory language and derogatory concepts are used as part of everyday language to refer to people who experience mental illness (e.g. 'mad', 'crazy', 'nutty', 'pōrangī',⁶³ 'vale',⁶⁴ 'valea',⁶⁵ 'fakatafaa'⁶⁶). Pacific participants, in particular, discussed the way derogatory language and concepts were used to label people who experience mental illness within Pacific communities. Societal norms and media messages, informed at least in part by the biomedical model, also reinforced negative appraisals and expectations of people labelled with mental illness. Collectively, these forms of knowledge were perceived as leading to discrimination within families and extended families, in communities, at work, across agencies and in wider society.

Other sources of discrimination

Although given less emphasis research, friends, social networks and community organisations were also sources of discrimination. Discrimination took the form of exploitation, being ridiculed by friends, and friends staying away from consumers and their families. Three participants from one general families' focus group talked about this:

⁶³ Meaning lunatic, insane, mad, crazy.

⁶⁴ Meaning a fool, imbecile <http://www.samoalive.com/NFL/V.htm> Retrieved 10 November 2009.

⁶⁵ Meaning ignorant, stupid <http://www.samoalive.com/NFL/V.htm> Retrieved 10 November 2009.

⁶⁶ Meaning crazy, simple (definition supplied by Sam Samuel, Vakaola, Porirua).

I personally found the church quite discriminating, my mother when she was unwell gave all her belongings to the church... she sold golden plates for 50 cents and family heirloom stuff at ridiculous prices, stuff that came over with my grandmother from England in the early 1900s, gone, gone, gone [and the church people all knew she had mental illness].

Just on a different track about discrimination, if my son had a car accident and was in hospital, people probably would go and see him...but not many people go and see him...we haven't actually got any friends left.

Some of my older friends kept at a distance. I don't say they discriminated, they just... felt helpless. I don't know what their views were really...I was told I should've left him in Australia where he was on the streets in the gutter by people... it's my son, he'[d] be dead if I hadn't...he was escorted on and off the plane.

A participant in a consumer focus group spoke of reactions from friends to her experience of mental illness:

Your being, your pride, when my friends found out I was experiencing mental illness they started to make fun of me, they started to say things.

In Chapter Three, consumers spoke about a hierarchy of diagnoses which led to particular diagnoses being stigmatised and associated with extremely negative meaning. This issue was also raised by families. For many, the demystification of 'depression', 'anxiety' and 'bipolar' through the Like Minds, Like Mine campaigns was seen as beneficial, in terms of being able to talk about these experiences more openly. However, several participants noted that this change had meant other people now saw these disorders as relatively 'minor'. Participants pointed out that all three of these diagnoses span a spectrum and can at times have severe impacts for the consumer and their family. A participant from a general families' focus group spoke of her experience:

I don't think [people] understand how serious [bipolar] is, when I was saying my mum's got bipolar disorder, they just say, 'Oh OK everyone seems to have that these days.'

Families believed that the diagnosis of 'schizophrenia' remains associated with the most significant forms of stigma and discrimination. Participants in one of the families' focus groups said:

Speaker 8: I think most places they would discriminate if they know that [someone has schizophrenia]. Speaker 2: Depression seems a whole lot better than schizophrenia. Speaker 1: Absolutely. Speaker 4: It's almost like there's a sort of a mental health spectrum, there's 'acceptable' things and not...somehow one's OK and the other's not. Speaker 5: I think people have a better understanding of what depression is. Speaker 3: One out of 10 of the population has experienced depression at some point in their life. Speaker: [In the] Like Minds ads it would be really good to have somebody with [schizophrenia].

At other times, other people made dismissive comments about the existence or impact of mental illness on families:

I think people don't understand that, there's just such a lack of knowledge. People just don't understand. And I still to this very day am so deeply hurt when I hear people say, 'Oh I just don't believe in that. I think it's just all in your head.'

Sometimes ex-partners, friends and others who had little knowledge of mental illness indicated that parents should change how they treated the consumer. One mother had this to say in response to a suggestion that she adopt a tough love approach to her son:

Yeah this tough love business used to really upset me...he was hurting like you wouldn't believe...he'd do the most crazy things to himself because he hated himself so badly... it's hideous the things...suggested...I used to hold him, bleeding...blood everywhere ...

he was like a baby and he would sob...he was 24 at the time... these young men need huge help...there's lack of understanding, there's still people like my ex-partner who just said he needs a jolly good... 'sorting out.'

Several families spoke of consumers who needed access to mental health services coming into contact with the criminal justice system and the police, with whom a lack of understanding of mental illness led to inappropriate action. Two mothers from a general families' focus group spoke of their son's experience with mental illness and the law:

[M]y son was arrested for telling a police dog to shut up, and they locked him up, they put him in this cell... he doesn't like loud sound... they...took him into the station...they were judge, jury and executioner...[they] said if he pled guilty they'd let him go straight away otherwise they were gonna hold him over until Monday morning. So, he pleaded guilty...I would like to see mental health awareness training to police; Child, Youth and Family; Work and Income; and any other government department.

[O]ne of my boys [who experiences mental illness] got very badly assaulted by the police. He got hit on the head twice with a baton and [there] were dog bites and everything. It was in the paper but nothing [came of it].

One parent spoke of discrimination in her workplace when she needed to provide support to her son:

[T]his is discrimination in a sense...I had to take a lot of time off work...with issues with my son and I feel that I'm judged on that... I ran out of sick leave really quickly because I was taking all this time off to look after him. I know that I haven't been offered more hours that I could've been.

Another participant from the tāngata whai ora focus group addressed the social and material realities of living with mental illness, and suggested that these factors were the subject of discrimination, rather than mental illness per se:

If we're discriminated [against] it's become of all the other social factors that come because of mental illness such as unemployment, housing issues, being Māori...other demographics fall into it, you're low income, unemployed, on the sickness benefit or whatever...my whānau gets targeted as a poor Māori whānau.



Summary

The most prominent and widely discussed form of discrimination towards families and whānau reported across all but one focus group was from mental health services. Multiple forms of discrimination were identified. These included: lack of consultation and inclusion of families; lack of information; the dominance of a biomedical approach to mental illness and absence of a holistic conceptual framework; parent blaming and/or criticism of a primary support person's involvement; and racism, particularly in relation to young Māori and Pacific people. Consumers also identified diagnoses, labelling and deficit language use as discriminatory. Chinese participants typically viewed New Zealand mental health services favourably. However, this view reflected a comparison with the poor quality of services in China, and extreme discrimination within the Chinese community towards people who experience mental illness. Like other families in this research, Chinese families did not like the lack of consultation and the exclusion of families in New Zealand mental health services. When participants were challenged about some of the attitudes, behaviours and practices they identified as discriminatory, there was widespread and emphatic agreement that these did reflect discrimination.

Participants across all focus groups identified extended families and whānau as another key source of discrimination. While the nature of discrimination from extended families and whānau varied, it often consisted of: subtle through to overtly disparaging comments and discriminatory language; hiding and/or not talking about mental illness; judging or blaming family member/s for a consumer's mental illness; viewing a consumer as a 'bad' person or exhibiting 'bad' behaviour; and excluding, shunning or actively rejecting the consumer. The kinds of discrimination reported in the general and young adult focus groups, while just as pervasive, were typically more covert than those reported in the Māori, Pacific and Chinese focus groups. While discrimination was pervasive across extended families and whānau, most participants believed that this reflected a lack of awareness, information and knowledge about mental illness; shame and embarrassment; fear of being 'contaminated' through being closely connected to mental illness; and fears arising from beliefs about the genetic nature of mental illness.

Societal norms, media stereotypes and the general social milieu were also identified as having a significant impact in terms of perpetuating and fuelling discrimination towards consumers and/or their families or whānau. The everyday nature of derogatory language used in relation to people who experience mental illness also contributed to a collective mindset in which mental illness is maligned. There was a common perception amongst participants that these factors compounded a widespread lack of understanding and acceptance of mental illness, and a lack of tolerance of behaviour and/or lifestyles that deviate from dominant norms.

Other less frequently reported sources of discrimination towards families and whānau reported by participants included friends, social networks, churches and clergy, employers and colleagues, and police. Many participants believed that particular diagnoses were also a source of discrimination. 'Schizophrenia' was still widely seen as the most feared and mystified diagnosis. The destigmatisation of depression, anxiety and bipolar has sometimes resulted in these experiences being minimised or seen as relatively minor.

chapter 6

Understanding Discrimination: Tensions and Complexities



We should be the change that we want to see.

Anonymous participant quoting Mahatma Gandhi

The Like Minds, Like Mine programme is founded upon the premise that discrimination is not acceptable. However, it has become increasingly clear during the course of this research that the notion of 'discrimination' in relation to families and whānau is complex. Research relating to discrimination and mental illness has often involved an uncritical acceptance of the term 'discrimination' with little attention to its fluidity and the relationship between meaning and context. Chapters Three to Five discussed participants' perceptions about discrimination within and towards families and whānau. At times that discussion, too, may appear simplistic and descriptive, as though the meaning of discrimination is clear-cut, and the context of discrimination within and towards families and whānau is a fixed, homogenous entity. This is far from the case. People's experiences in relation to mental illness and discrimination, especially those associated with families and whānau, are shaped by multifaceted social, cultural, economic, political and historical influences.

The family or whānau occupies a unique place in the life of a person who experiences mental illness. The family or whānau differs markedly from other sites of discrimination, such as those relating to employment, housing and the provision of goods and services. Any attempt to identify effective strategies for change must take account of this uniqueness and the complexities associated with understanding discrimination in this context.

This chapter draws on an analysis of data from the focus groups and discussion forum, using the findings reported in Chapters Three to Five, to inform a discussion of the tensions and complexities related to mental illness and discrimination in the context of families and whānau. It focuses on six major issues:

1. Meanings of 'discrimination'
2. The unique nature of families and whānau
3. Being a primary support person
4. Managing behaviour perceived as challenging
5. Family dysfunction and child abuse
6. Contextualising discrimination from mental health services.

1. Meanings of 'discrimination'

This research has highlighted the widespread use of derogatory language and labels to talk to or about people who experience mental illness within families and whānau. As well as labels such as 'crazy', 'nutter', 'pōrangī', 'vale', 'valey', 'fakatafaa', participants reported being referred to as 'lazy', 'selfish', or 'weak' when behaving in ways that could reduce stress and/or allow management of the effects of mental illness and medications. Many participants spoke of disparaging comments ('she nuttered out' or 'she's going off the deep end') made by family members in response to the legitimate expression of feelings such as anger or frustration. Some participants also spoke of a complete lack of acknowledgement of mental illness from family members, such as being told to 'suck it up', 'harden up', 'get on with it' or even that mental illness is 'a load of rubbish'. Occasionally, participants reported that the family member who experiences mental illness was regarded as simply 'bad' or behaving 'badly'.

Collectively, these explicit types of discrimination towards people who experience mental illness led to extremely negative expressions of what discrimination meant to participants (both consumers/tāngata whai ora and families/whānau), such as feeling 'abnormal', 'cast out', 'controlled', 'isolated', 'ostracised', 'stupid' and 'powerless'. These forms of discrimination provide overt and easily identifiable evidence of discrimination within and towards families and whānau. In this context the meaning of discrimination is very clear.

In the discussion forum, consumers/tāngata whai ora and families/whānau jointly identified what they referred to as discrimination.

- **Derogatory choice of language and words (e.g. 'you're mental')**
- **The way people are spoken to (e.g. speaking very slowly and/or loudly)**
- **Negative or aggressive non-verbal communication and body language**
- **Patronising and/or negative written communications (e.g. notes in medical records suggesting the person is difficult or the condition is chronic)**
- **A condescending or superior attitude**
- **Being ignored, avoided, excluded, marginalised**
- **Not being listened to or taken seriously**
- **Having one's worldview dismissed**
- **Judgments based on oversimplified 'text book' knowledge**
- **Pathologising all behaviour/emotion (e.g. crying, laughing)**
- **Not being given information or included in communication about issues that impact on the consumer, family or whānau**

There was strong and widespread agreement amongst participants that these signifiers were about discrimination specific to mental illness.

These behaviours and practices are clearly unhelpful, often offensive and sometimes abusive. However, they may not necessarily be about discrimination. In this sense there is less clarity about what does and does not constitute discrimination. While it is fairly safe to conclude that some (e.g. derogatory language specific to mental illness, being spoken to as if the consumer is deaf or has limited intellectual function, and pathologising all behaviour) are indeed about discrimination, it is possible that others may reflect something other than discrimination. For instance, behaviours identified as

discriminatory might reflect characteristic ways of behaving within a family or extended family. Behaviours and practices within psychiatric contexts may reflect common ways of working across diverse medical contexts, or institutional discrimination.

Nevertheless, what is important is that participants were emphatic that these types of behaviours and practices were discriminatory. The collective and cumulative impact of being treated in these ways was critical to consumers' and families' perceptions about the meaning of discrimination.

Discussion in the general families' focus groups revealed less clarity about what constitutes discrimination, particularly in relation to discrimination within the family. In this context there was a tendency for families not to perceive their own attitudes and behaviours as discriminatory. This perspective was often in stark contrast to overtly discriminatory comments made during the focus groups, and subsequent acknowledgement of discriminatory behaviour at the discussion forum. The definition of discrimination used by the general families' groups, in relation to the family, often seemed quite narrow. By contrast, Pacific and Asian family perceptions of discrimination within and towards families were highly aligned with one another, and also with consumer and tāngata whai ora perceptions of discrimination within the family.

While highly aligned across focus groups, the meaning of discrimination towards families and whānau appeared broad. Discussion reflected a broad set of issues to do with mainstream mental health services. In this more externalised context, the notion of discrimination captured a diverse array of attitudes, behaviours and practices which were considered discriminatory. Indeed, one Pacific man commented, 'it's discrimination against the whole nation'. With the exception of the Chinese focus group, participants were unanimous in their assertion that mental health services operated in ways that were discriminatory towards families, whānau, consumers and tāngata whai ora.

Participants' discussion of discrimination towards families and whānau from extended families reflected a range of similar attitudes and behaviours that participants across groups agreed were discriminatory.



The Pacific and Chinese families' and consumers and tāngata whai ora focus groups were highly consistent in how they used the term 'discrimination', and in what behaviours they perceived as discriminatory both within and towards the family.

It seems likely that for the general families' groups, the greater the social distance from the source of discrimination, the broader the definition of discrimination. Conversely, the closer the social distance – such as in the context of personal relationships within the family – the narrower the definition of discrimination. It is likely that this definitional fluidity led to less recognition of discriminatory behaviour within the family.

During the process of analysis it became apparent that behaviours which families and whānau identified as discrimination when they came from mental health services (such as withholding information or not consulting) were sometimes perceived as 'protecting' the consumer or tāngata whai ora when they came from within families or whānau. Similarly, lack of inclusion of families or whānau by mental health services was perceived as discrimination, but lack of inclusion of consumers by families was not necessarily seen this way. Yet when extended family and whānau excluded a consumer or tāngata whai ora, members of the immediate family or whānau often identified this as discrimination. In other words, what consumers and tāngata whai ora want from families and whānau aligns closely with what families and whānau want from mental health services, extended families and others: to be respected and listened to; to have their experiences and worldviews taken seriously; to be active agents in decision making processes; to have the right to self determination; to have hope; and to be free from discrimination.

These findings lead to asking why family participants in the Pacific and Asian focus groups readily identified and acknowledged discrimination within their own families, but participants in the general families' focus groups did not. The dialogue during the focus groups provides ample indication that this finding does not reflect an actual difference in discrimination within families.

It is more likely that the difference has something to do with different backgrounds in relation to mental illness, different interests and motivations for participating

in the research, and different sources of recruitment. As noted in Chapter One, most participants in the general families' groups were in some way connected to organisations or networks supporting families. The Pacific and Asian focus groups included participants who were connected to mental health promotion, Like Minds, Like Mine networks, or Chinese peer support networks. The whānau focus group was comprised of people with some connection to a kaupapa Māori social service, and included some counsellors. These diverse organisational backgrounds are likely to have influenced the different views held by participants in the different groups.

By recognising the fluid nature of 'discrimination' and the shifting context in which discrimination was identified, it is possible to see just how challenging it can be for families, whānau and others to know whether the way they are behaving is discriminatory. It also means that identifying strategies to bring about change in relation to families and whānau requires a more complex lens than might be required in relation to those with whom people have more socially distant relationships (such as employers or landlords). This leads to a discussion of the unique nature of families and the tensions and complexities related to understanding 'discrimination' within families.

2. The unique nature of families and whānau

Families and whānau occupy a unique position in society and in our personal lives. The institution of the family, and increasingly, the whānau, is embedded in dominant social and cultural discourses and reinforced by a range of public policies, political party values and religious beliefs. The common idea is that the family or whānau is the foundation of a healthy society. These discourses are underpinned by an ideology that the family or whānau is necessarily an affirming, healthy and harmonious place for children to develop with the love and guidance of parents.

For most people, the family or whānau provides meaning through genealogy or whakapapa, represents shared history over generations, and offers some meaning in terms of a potential future. Families and whānau are often characterized by intimacy, personal connection and longevity of relationships. The nature of relationships within families and whānau means a certain level of

both dependence (e.g. as children; as aged; as disabled or unwell family members) and interdependence. Roles within families are characterised by power relations (e.g. between parents, between parent/s and children, and/or between siblings). As family members age, roles and power relations change and relationships may be reconfigured. In families people often share the 'highs' and 'lows' of life. Behaviour within families can be the 'best' and the 'worst' in a way that it typically is not with other people or within other social contexts. Within families and whānau, people have unique rights and responsibilities that they are unlikely to encounter anywhere else. Irrespective of the nature of family relationships, or the extent of direct contact with family members, people remain in some way connected to family or whānau over a lifetime.

Society is bombarded with a range of myths and stereotypes about the 'ideal family'; yet this notion is at odds with a significant body of research which highlights the highly diverse and shifting nature of families and family dysfunction and/or abuse. In the current research project, many of the consumers and tāngata whai ora spoke of the realities of lives affected by family dysfunction, insecurity, hostility, domestic violence, broken relationships, neglect and/or abuse. In many instances, respectful, meaningful, secure family or whānau relationships were something to be hoped for. Indeed, the family or whānau sometimes existed only in name, as several participants had become disconnected or estranged from their families of origin. For several tāngata whai ora, family or whānau meant finding new people with whom to create intimacy and meaningful, respectful, loving relationships. For some participants, the emotional pain resulting from family life was something to heal from, reconcile and find peace with.

The uniqueness of the family or whānau, and its particular social and cultural context, is therefore highly significant in understanding the nature and dynamics of 'discrimination' within and towards families and whānau of people who experience mental illness.

3. Being a primary support person

Many family participants across focus groups spoke of the significant challenges associated with being a primary support person of a family member who experiences

mental illness. This was particularly so for those supporting a family member whose experience of mental illness was profound, distressing and/or had significant impacts on their day to day functioning. Families often spoke of challenges associated with a family member who had experienced mental illness over an extended period of time, and for whom there seemed to be little sense of recovery. Occupying the primary support role often meant providing emotional and practical support over a long period of time, being, or feeling the need to be, available to the family member 24 hours a day, seven days a week, and rarely having a break. Being a primary support person often went hand in hand with:

- **Not having known about mental illness in the past**
- **Being given little and/or unsatisfactory information about particular diagnoses and the effects of medication in the present**
- **Feeling unsupported and sometimes actively denigrated by mental health professionals**
- **Receiving little support and/or being blamed and judged by extended family or whānau and/or friends**
- **Being ignored, avoided, excluded, marginalised**
- **Witnessing or being subjected to stigma and discrimination from others in relation to the family member who experiences mental illness**

In addition to being a primary support person, many of the participants from the families' focus groups spoke of being engaged in full- or part-time employment, being an income earner, parenting children, caring for grandchildren, providing support to older family members, managing a household, and taking responsibility for household work. Not surprisingly, family members often reported feeling 'stressed out' and 'exhausted'.

The pressures associated with providing primary support could adversely affect relationships within the family. In many instances, the primary support person was required to negotiate interpersonal conflicts within the family or whānau that arose in response to the presence of mental illness in the family. Some spoke of managing sibling rivalries or situations where some family members resented or resisted contact with the family member who experiences mental illness.

The multiplicity of roles and the range and intensity of demands on the primary support person were often experienced as highly challenging. Sometimes the unique set of challenges faced by those providing primary support led to disparaging comments and/or adverse behaviour towards consumers. In some instances, a sense of desperation had led the primary support person to behave in ways that undermined the consumer's dignity, sense of control and/or self determination, and breached the consumer's human rights and right to privacy.

4. Managing behaviour perceived as challenging

Many of the participants from the families' focus groups discussed behaviours associated with the family member's experience of mental illness that the family found challenging. Much of this behaviour related to the day to day nature of the family member's distress and/or effects of medications. Examples included: excessive crying; self-harming; not wanting to get out of bed; being unable to function or engage in 'ordinary' activities (e.g. going to sports or school, finding or maintaining paid employment, undertaking study or training, looking after their children, managing their finances; having poor hygiene; eating infrequently and/or consuming poor quality food; and being unable to sustain independent living. Some families described situations in which the consumer at times destroyed property, seriously harassed family members or behaved in a threatening or aggressive manner. While families recognised that these behaviours were typically connected to the person's distressing experiences (e.g. a male consumer who repeatedly self harmed; a male consumer who attacked his sibling in self defence, as he believed that the sibling was trying to kill him), they were nonetheless experienced as exhausting and difficult to cope with.

5. Family dysfunction and child abuse

Several consumers and tāngata whai ora spoke of growing up in families where there was significant family dysfunction, child abuse and/or violence. Some family and whānau members also acknowledged these types of family environments within their own or others' families. Several participants commented that historical conflicts and/or current hostilities meant that the family had been unable to reconcile differences or develop healthy communication. In several instances, child abuse and violence remained 'a family secret', and/or the person who disclosed abuse was ostracised by the family. As noted, this sometimes meant that the family member who experiences mental illness (often as a result of childhood trauma) had become a target for denigration and further abuse within the family or whānau. Some consumer participants reported that this had led to disconnection or estrangement from families or whānau.

The presence of severe family dysfunction and child abuse raises issues about the meaning and inclusion of 'family' and 'whānau' in treatment processes involving mental health services. Some participants who had experienced extreme family dysfunction and/or child abuse, especially tāngata whai ora, indicated that they did not want their whānau of origin involved in decisions affecting their lives. Instead, they sought the inclusion of whānau they had created by choice. Given the high proportion of inpatients reported to have experienced child abuse, and the role of abuse in contributing to mental illness (discussed in Chapter One), these issues need to be given due regard when considering who is and is not included in a consumer's mental health treatment. These findings sit at odds with dominant discourses about the importance of involving families and whānau in decision making and mental health treatment processes, and highlight the importance of consumer and tāngata whai ora self determination in decisions regarding their lives.

6. Contextualising discrimination from mental health services

Mental health services were identified by participants in this research as the most prominent source of discrimination towards families and whānau. This finding echoes other research which highlights the presence of discrimination in New Zealand mental health services. Participants' reports of discrimination from mental health services often seemed likely to reflect the conditions and/or culture of the organisational environment, an imbalance of power, and limitations associated with the biomedical approach.

Some attitudes and behaviours identified by participants in the current research were undeniably discriminatory (e.g. derogatory comments directed at consumers and/or family members; assuming negative attributes about Māori consumers and/or their whānau). However, other attitudes and behaviours were more likely to reflect the influence of various contextual variables. For instance, staff members working in mental health services often talk about being under immense pressure, having high demand and long waiting lists, working with limited resources or having limited capacity, and often feeling burnt out.⁶⁷ The pressured nature of working within mental health services, like other parts of the health sector, can lead to expediency (ibid). Under these conditions staff may have little time to interact with consumers and/or families and the quality of communication may be undermined.

Mental health services are also typically characterised by hierarchical power relations (Manley, 2009; Minkowitz, 2006; Slade, 2009). Psychiatrists occupy the role of 'experts' and hold ultimate decision making authority (Manley, 2009; Minkowitz, 2006; Slade, 2009). Despite infrequent contact with consumers/tāngata whai ora and/

or their families/whānau, psychiatrists have the power to decide on particular courses of action. Other staff members who may have the most contact with a consumer or tāngata whai ora, and be most familiar with the person's life, may not necessarily have much influence in decisions made about a person's treatment process (Lumb, 2007). Equally, consumers, tāngata whai ora, families and whānau often have very little influence on decisions that have such significance for their wellbeing (Minkowitz, 2006).

The legal authority invested in mental health services also means that they have the power to detain, restrain, forcibly treat and seclude consumers and tāngata whai ora (Ministry of Health, 2009). Staff can also limit, exclude or prohibit families and whānau contact with consumers or tāngata whai ora while detained. These practices heighten the power imbalance between staff members and consumers, tāngata whai ora and their families or whānau.

At times practices perceived as discriminatory by participants (such as dismissing Māori and Pacific worldviews, discounting child abuse and broader contextual factors, and focusing only on symptom reduction) seemed to reflect the shortcomings of the biomedical approach to mental illness, rather than overtly discriminatory behaviour.

⁶⁷ For example, see Boyd & Sigglekow (2010).

Summary

In Chapter Two and the current chapter, the plurality of meanings associated with the term discrimination has been highlighted. The diverse contextual factors that may contribute to negative attitudes and behaviours from families and whānau towards consumers and tāngata whai ora (irrespective of whether these behaviours are defined as 'discrimination') have been identified. Contextual factors which have particular salience to discriminatory behaviour within the family and whānau include: the unique nature of the family or whānau; challenges associated with being a primary support person; and difficulties families and whānau experience in dealing with challenging behaviour associated with mental illness (particularly when appropriate mental health service support is not available or accessible).

Consumers and tāngata whai ora have highlighted issues relating to severe family dysfunction and child abuse within their families and whānau. The importance of recognising these issues in terms of understanding the meaning of 'mental illness', and what it means to have families or whānau involved in treatment processes, has been highlighted. In this regard, consumers and tāngata whai ora have asserted their right to distance or remove themselves from dysfunctional and/or abusive families and whānau. In some instances this meant disconnecting or becoming estranged as a means of self preservation. Consumers and tāngata whai ora told us quite clearly that these measures were associated with significant emotional pain. Most remained hopeful that at some time in the future, family relationships would be sufficiently healthy and respectful to resume contact with families and whānau of origin.

A range of contextual variables, such as hierarchical power relations, working conditions and the organisational culture, shape the attitudes and behaviours of staff working in mental health services. Practices associated with a biomedical approach to mental illness also influence the way mental health services engage with consumers/tāngata whai ora, families and whānau. Participants recognised that a fundamental paradigm shift is necessary to ensure a holistic approach to mental illness and to appropriately capture Māori and Pasifika worldviews. A change of this magnitude would require a significant change in the way mental health services are

structured, particularly in relation to sites of power and to leadership. It would also require a more general critique of the political and economic determinants that maintain the dominant biomedical approach. Nevertheless, participants from across focus groups were keen to see a meaningful shift from the current focus on individual symptoms to the broader social, cultural and historical context of people's lives.

So where do these complexities lead to in terms of understanding discrimination within and towards families and whānau? There is no simple answer. However, the nature and range of attitudes and behaviours identified as discriminatory in this research (both within and towards families and whānau) suggests that the terminology used to talk about discrimination, in relation to families and whānau, may require a more critical approach. Moreover the unique context of families and whānau requires a particular lens with which to understand discriminatory attitudes and behaviours. Nevertheless, the fundamental purpose of the Like Minds, Like Mine programme is to counter stigma and discrimination associated with mental illness because it is damaging and is the biggest barrier to recovery.

chapter 7

Strategies to Counter Discrimination Within and Towards Families



Discrimination of all kinds has a detrimental effect on mental health.

Penn & Wykes, 2003:203

A range of strategies to counter discrimination within and towards families and whānau were identified by participants across the nine focus groups. The 19 people who attended the discussion forum were also asked to rank these strategies in terms of the top three priorities, and to include any additional strategies that could potentially reduce discrimination. Because there were many parallels between discrimination within and discrimination towards families, many of the strategies suggested could effectively address both sources of discrimination.

The most commonly reported strategies cohere around seven key themes, presented here in order of the priority accorded to them by participants:

1. Mental health services
2. Public education
3. Peer support and other support groups
4. Primary and secondary schools
5. Utilising cultural leaders, communication and traditional values
6. Modelling other successful initiatives or campaigns
7. Media and social networking

1. Mental health services

Mental health services were identified as the top priority in terms of reducing discrimination. Participants identified a range of strategies to improve the way mental health services engage families and whānau. They believed these would result in less discrimination towards families and whānau (and therefore within families and whānau). In summary, these included a shift in thinking and practice to ensure a holistic approach to mental illness that incorporates cultural worldviews and healing practices, including the implementation of whānau ora, and family and whānau inclusive practice.

1.1 Holistic and cultural paradigms

Participants across focus groups and at the discussion forum strongly stated that there needs to be a paradigm shift so that a holistic approach to mental illness, rather than a biomedical approach, becomes the norm. Some people spoke of the need for change involving the blending of cultural worldviews with the benefits of a biomedical model. As one participant commented, 'It's time to marry the Western model and the cultural model.' The majority of participants across focus groups, irrespective of ethnicity, believed that this blended approach would be beneficial to all consumers and families. Participants recommended that all staff working in mental health services need to be educated in accordance with a holistic approach to mental illness, and to have access to ongoing education and training. Moreover, services need to be appropriately resourced to ensure holistic practice.

Participants considered it important to ensure the participation of consumers, tāngata whai ora, family and whānau in all strategic planning processes in District Health Boards. The provision of counselling for young family members was also recommended.

Māori and Pacific participants strongly recommended that mental health services become grounded in more broadly defined Māori and Pacific models of health. This would foster Māori and Pacific ownership of their own cultural worldviews, values, beliefs and languages. This was regarded as critical to the provision of a holistic approach to understanding mental illness and healing. Moreover, participants recommended that all mental health services ensure that the consumer's and their family's cultural and spiritual worldviews, and interpretation of experience, are the foundation for engagement. The use of spiritual practices, traditional cultural stories, waiata, music, arts, carving and weaving was regarded as important to healing processes and recovery. Māori and Pacific participants spoke of the importance of being referred to Māori or Pacific mental health services. Where these services were not available, mainstream mental health services needed to ensure close working relationships with other relevant Māori and Pacific services and local communities. Ideally, Māori and Pacific participants wished to see Whānau Ora or kaupapa Māori mental health services, and Pacific mental health services, available in all regions.

Māori participants strongly recommended the endorsement of Whānau Ora, and regarded this framework as fundamental to holistic practice. Partnerships with tāngata whenua were regarded by Māori participants as integral to the implementation of Whānau Ora. To develop partnerships, the relationship between Māori and the Crown (and mental health services as agents of the Crown), accorded under the Treaty of Waitangi, needed to be fully recognised by officials. Participants spoke of using a Te Ao Māori approach in all work with tāngata whai ora and whānau, and ensuring that appropriate tikanga informs all practice.

Chinese participants recommended the inclusion of culturally relevant perspectives as part of their engagement with mainstream services. They were also strong advocates of ethnic specific peer support, discussed later in this chapter.

1.2 Family and whānau inclusive services

The majority of participants identified the routine inclusion of families and whānau by mental health services as a top priority. While consumers and tāngata whai ora also wanted family and whānau involvement, they asserted their right to determine who constitutes 'family' or 'whānau'. This was especially important for tāngata whai ora and other consumers who had created new whānau in response to the severity of dysfunction, and/or abuses within their whānau of origin.⁶⁸ Importantly, tāngata whai ora recommended that mental health services needed to ensure a Whānau Ora⁶⁹ approach so that whānau of origin could be engaged concurrently by mental health services. This approach would enhance the likelihood of improved whānau communication and relationships, and increase the likelihood of tāngata whai ora successfully reengaging with their whānau of origin.

Listening to families and whānau, respecting and valuing their views, and actively engaging families and whānau in discussion regarding proposed treatment processes were seen as critical components of family and whānau inclusive practice - with the proviso that consumer or tāngata whai ora consent was granted. Engaging younger family members (especially those who occupy a primary

support position in relation to a consumer or tāngata whai ora) was also an important aspect of family inclusive practice.

Many participants spoke of the gap between rhetoric and practice in terms of services' work with families and whānau. They expressed a strong desire for full acknowledgement and appropriate valuing of primary support people. A key issue identified was the need for services to allow adequate time for getting to know and respectfully engaging consumers, tāngata whai ora, families and whānau. A minority of participants believed that services needed to listen to, value and take support workers' views seriously, especially in situations where there was little support or involvement from families or whānau.

Participants overwhelmingly agreed that there is a need for information to be provided by mental health services to consumers, families and whānau as part of routine practice, as well as at different times during the course of contact with services. In particular, participants wanted the following information to be provided by mental health services: generic information on mental illness (not only from a biomedical standpoint); specific diagnoses; the purpose and effects of medications; how to navigate mental health services; referral to other services; and information about support services in the community. Some participants noted that the need for information changed over time, with the greatest need during initial contacts with services. However, when diagnoses and medication changed, as was often the case, new information was needed. Likewise, as consumers and tāngata whai ora transitioned between services, or exited mental health services, additional information about available services and support was required.

Some participants spoke of difficulties gaining access to services, or a timely response, for family members who had particular diagnoses and/or who self-harmed. A quicker response from crisis teams, as well as appropriate follow-up from mental health teams, was needed. Support for families and consumers during transitions between services, and between discharge and independent living, was also regarded as a key need. The availability of a 24 hour 'helpline' (including a whānau helpline) in all areas, akin to the national 111 emergency service, was seen as a

⁶⁸ Whānau of origin refers to the family groups which people are born or adopted into at a young age.

⁶⁹ The concepts underpinning whānau ora and the principles of Whānau Ora are discussed in Chapter One.

potential strategy for accessing information and gaining access to services.

Some of the strategies identified by participants may, at face value, appear to have little to do with discrimination. However, participants across focus groups were adamant that the suggested changes in attitudes, behaviours, practices and paradigms were critical to reducing all forms of discrimination experienced in relation to mental health services.

Mental Health Services

- Holistic approach to mental illness
- Whānau Ora
- Family and whānau inclusive practice
- Information
- Access to and timely response from services
- Support during transitions
- National 24/7 helpline

2. Public education

Participants across all focus groups spoke of a widespread lack of awareness and understanding of mental illness in the public domain. Those who attended the discussion forum identified education as one of the top three priorities in terms of strategies to reduce discrimination. Many participants throughout the research recommended that education and raising awareness about mental illness was needed at all levels of society (i.e. families, whānau, hapū, iwi, communities, churches, workplaces, institutions and agencies, and the media). There was a common perception that education of this kind was not known about, not widely available, and/or not appropriately tailored to particular demographic groups. Participants recommended a range of strategies for public education, and suggested using a variety of mediums that would be culturally relevant and age appropriate.

Promoting education and reducing discrimination through the provision of books, booklets, pamphlets, advertising, films and/or DVDs about mental illness was widely recommended. Other than Like Minds, Like Mine advertising (which was often spoken about by participants), there was a general lack of awareness of other Like Minds, Like Mine activities and initiatives. Participants were keen to see portrayals of the lived experience of mental illness, and 'more realistic' stories of people's experience at different stages of mental illness. Some recommended conveying the idea that the person (i.e. the consumer or tāngata whai ora) is separate from their behaviour. This approach would have a twofold effect. First, it would allow family members to separate the person from the hurt they may feel in response to behaviour associated with a person's unwellness. Secondly, it would encourage people not to conceptualise mental illness as all encompassing, but rather to see the person as a person who sometimes has particular experiences.

Many participants spoke of the need to counter the negative way in which people diagnosed with 'schizophrenia' are portrayed in the public domain. Some thought it would be useful to counter negative stereotypes by providing examples of people diagnosed with 'schizophrenia' living well and presenting 'just like anyone else'. The use of comedy was seen as a useful way to bring humour to public education. Some participants recommended discontinuing the use of diagnostic labels altogether.

Holding public forums and facilitating hui with local iwi were regarded as useful ways to educate large numbers of people and encourage public dialogue. Further, they would provide a forum for people who experience mental illness and their families and whānau to tell their own stories.

The facilitation of a series of dialogue forums was also identified as an effective mechanism for bringing people together, engaging those from diverse positions and shifting attitudes about mental illness. The discussion forum held as part of this research was based on the principles of dialogue methodology. This approach proved exemplary in its power to create positive change in people's willingness to connect, engage and think about mental illness from different, and often conflicting, standpoints. With respect, genuine interest, compassion

and sharing of experience, the dialogue forum can be an immensely potent strategy for reducing discrimination.

Participants also recommended providing education in culturally relevant contexts, using culturally appropriate styles of delivery, and using languages most familiar to particular ethnic groups (e.g. diverse Pacific communities, Chinese communities).

The facilitation of youth competitions, story writing, film making and/or song writing was also identified as an effective strategy for engaging and educating young people. The leadership and participation of young people, and the use of young people telling their own stories about mental illness, were seen as particularly important mechanisms for ensuring relevant educational content and a genre appropriate to young people. Participants recommended that funding be made available to target youth, using these types of strategies.

Public Education

- **Public meetings and hui to provide education and encourage dialogue about mental illness**
- **Dialogue forums**
- **Books, booklets, pamphlets, songs, films and or DVDs about mental illness and people's lived experiences**
- **Culturally specific and age targeted forums and modalities for education about mental illness**

3. Peer support and other support groups

Throughout the research, participants repeatedly stated that greater awareness and education were the keys to reducing discrimination. For many participants, the key to knowledge was through support from others who shared similar experiences. Hence, participants widely recommended the establishment of peer support and/or support groups, and/or increasing the range of support groups that target particular population groups (e.g. adult children, parents, young family members). Peer support and support groups were ranked in the top three strategic priorities.

Support groups, especially peer support groups, were considered an important mechanism for supporting families and whānau, and/or consumers and tāngata whai ora. Many participants said that being able to talk to someone who shares similar experiences would be immensely helpful. This was especially so for younger family members, who often said that other people do not understand the sometimes very 'far fetched' experiences associated with living with someone who experiences mental illness. Peer support and getting together with others who share similar experiences were also recommended as a way to increase understanding about how best to support consumers and tāngata whai ora.

Some participants noted that groups working with whānau were already operating in some areas, but that more effective advertising and/or more services of this kind were needed. Further and more support of this nature was needed. A Chinese mental health peer support organisation, Bo Ai She, was regarded as a successful example of effective peer support. In this group, members eventually become supporters, thereby ensuring the continuation of the group over time.

While peer support and other support groups were already in operation in some areas, many participants reported that people did not know these groups existed. One way to remedy this situation was to ensure that family and whānau, and especially primary support people, were given information and invited to attend a local support group at the point of first contact with mental health services.

Participants recommended that funding be made available to enable the establishment of peer support and/or support groups, and to ensure their effectiveness and sustainability over time.

Peer Support and Other Support Groups

- Support groups
- Peer support groups
- Whānau groups
- Ethnic specific peer/support groups
- Chinese peer/support groups
- Information re peer/support groups

4. Targeting primary and secondary schools

Schools were identified as a key site for bringing about greater awareness and education about mental illness, and thereby reducing discrimination within and towards families and whānau. School-wide education, undertaken within the school curricula and in an ongoing capacity, was regarded as an important strategy for ensuring that young people become educated about mental illness and discrimination. Several younger participants said that education needed to start at primary school level and be provided in a manner appropriate to young people, such as using creative modalities. The young adult participants indicated that with greater education and awareness, other young people would be less 'mean and nasty' about mental illness.

Some participants indicated that staff members in schools often had little awareness and possessed little knowledge of mental illness. The education of all senior staff and school counsellors was therefore regarded as critical to reducing discrimination towards consumers/ tāngata whai ora and families/whānau. In particular, participants recommended that staff be sufficiently educated to know how to identify students who are experiencing mental health challenges, know how to support them, and know where to get help.

The provision of a graduated process of school reintegration following a crisis, a quiet space to allow time out, and assistance transitioning between classrooms were also recommended. The implementation of a model similar to the National Heart Foundation's Cardiac Rehabilitation Model, involving weekly support meetings, was recommended as a way of supporting students who are experiencing mental illness and/or reintegrating after an absence from school.

Targeting Schools

- School wide education
- Targeted education for students
- Targeted education for senior staff and counsellors
- Reintegration processes
- Resources for students who experience mental illness

5. Utilising community leaders, communication and traditional values

Utilising leaders and those in positions of authority within Māori and Pacific communities was regarded as an effective strategy to increase awareness about mental illness and to counter discrimination. Participants regarded kaumatua and kuia, and Pacific church leaders, as having the influence necessary to promote education and change community attitudes about mental illness. Likewise, utilising other community leaders or public figures was recommended as an effective strategy for educating communities. The leaders approach would require support from appropriate cultural advisors who possess sufficient knowledge of mental illness and discrimination.

Marae and churches were identified as key sites where education could appropriately take place. Community leaders were also regarded as having a responsibility to counter discrimination. Some Christian Pacific

participants believed that because God is in everyone, discriminating against consumers was discrimination against God. It therefore seemed likely that if religious leaders promoted beliefs of this kind, congregations would be less likely to discriminate against consumers and their families.

Promoting communication within and across whānau, hapū and iwi, and amongst Pacific families and communities, was regarded as an important way to stimulate discussion and increase knowledge and awareness of mental illness, and thus to reduce fear and discrimination.

Several Māori participants spoke of the importance of manaakitanga and a return to traditional Māori values of inclusiveness, spending time with one another and talking together as a way of healing. This approach goes hand in hand with Whānau Ora and a holistic understanding of wellbeing. Drawing upon traditional knowledge and concepts was also regarded as beneficial in terms of removing the label of mental illness and returning mana to tāngata whai ora and their whānau. Traditionally, people who heard voices, for example, may have been tohunga and were usually highly respected in their communities. Participants indicated that by embracing these traditional concepts, tāngata whai ora could once again take up their rightful place in the whānau, hapū and iwi. Some suggestions were made that Māori need to go back to the marae and learn from the old people about tikanga, and how to behave towards one another, as this knowledge had sometimes been lost in the whānau.

Community Leadership & Communication

- Utilising Māori and Pacific leaders
- Communication across whānau, hapū and iwi
- Communication across Pacific families
- Promoting manaakitanga and traditional Māori values

6. Modelling other successful campaigns

Several participants recommended modelling other successful campaigns as a way to promote greater awareness, understanding and acceptance of mental illness. The general consensus was that it is important to shift public attitudes so that mental illness is perceived as 'an ordinary part of life.'

Postnatal depression initiatives and the National Depression Campaign were identified as successful strategies for increasing public awareness and education about depression. Participants suggested that various aspects of these campaigns could be utilised as part of the broader programme to increase awareness and education about mental illness.

Many participants commented on the success of the Like Minds, Like Mine campaign in positively changing attitudes and behaviours about mental illness, especially in relation to 'depression' and 'bipolar'. There was widespread discussion that the Like Minds campaign now needs to target 'schizophrenia', as this remained one of the most stigmatised and feared labels. The use of comedians to 'lighten' the Like Minds, Like Mines advertising campaign was recommended. A suggestion was also made for the Like Minds programme to facilitate the establishment and maintenance of peer support groups for families and whānau. Participants strongly indicated that when families felt educated and supported, they felt less stressed and more empowered, and were therefore more likely to treat family members who experience mental illness in a supportive manner.

A minority of participants spoke of the importance of linking the existing Like Minds, Like Mine programme with the Whānau Ora strategy. This approach would ensure a more strongly whānau centred approach to mental illness and discrimination, and locate the family at the centre of wellbeing.

Successful Social Marketing Campaigns

- Postnatal depression initiatives
- National Depression campaign
- Extend Like Minds, Like Mine advertising campaign
- Link Whānau Ora and Like Minds, Like Mine Campaign

7. Media and social networking

Although participants did not identify the media as one of the top strategic priorities, the media was mentioned by almost all participants at some stage throughout the research. Ongoing media education and training were identified as extremely important for facilitating and maintaining awareness of mental illness amongst media personnel. Some participants suggested the establishment of more rigorous guidelines and sanctions when media organisations transgress boundaries in terms of perpetuating discriminatory messages. The media and education were often spoken of simultaneously as participants discussed ways to educate the public. Participants widely believed that ensuring an enlightened media was critical to facilitating a shift in public awareness of mental illness.

Some participants discussed language use and the use of nouns, such as 's/he is a schizophrenic', as powerful reinforcers of myths and stereotypes about particular diagnoses. The general consensus was that there is a need for continued media and public education about the use of appropriate language in relation to mental illness. An analogy was drawn between mental illness, and physical and intellectual disabilities. Participants noted that it is now considered completely unacceptable for the media to use terms such as 'spastic' or 'Mongol' in relation to people who experience physical or intellectual disabilities. However, language of this kind remained commonplace in media references to mental illness. Participants recommended that language use is in significant need of targeting as a strategy to reduce discrimination.

The establishment of a primetime television programme dedicated to mental illness, family and whānau stories about mental illness and discrimination was also recommended. Some participants identified use of social networking sites, such as Bebo and Facebook, as an effective strategy for increasing awareness about mental illness and reducing discrimination.

Media and Social Networking

- Target media
- Target language use
- TV programme
- Social networking sites

Summary

Participants from across focus groups, and those who attended the discussion forum, identified a range of strategies that they believed would be effective in reducing discrimination both within and towards families and whānau. These strategies encapsulate diverse content areas and multiple mediums of delivery. They cohere around seven key target areas:

- ✓ Mental health services
- ✓ Public education
- ✓ Peer support and other support groups
- ✓ Primary and secondary schools
- ✓ Utilising cultural leaders, communication and traditional values
- ✓ Modelling other successful campaigns and initiatives
- ✓ Media and social networking sites.

While the strategies which participants recommended may sometimes appear to have little to do with discrimination, they all reflect solutions to issues identified by participants as fostering discrimination within and/or towards families and whānau. The diversity of strategies is commensurate with the broad and varied interpretation of 'discrimination' used by participants throughout the research, and reflects approaches that are relevant for particular groups.

The final chapter provides a discussion of a broader framework for understanding and addressing family related discrimination. Strategies to reduce discrimination are proposed which involve building on the strengths of families and whānau, extended families and whānau, mental health services, social networks and organisations, and local communities.



chapter 8

Concluding Comments



Ko te kai a te Rangatira, he kōrero. Collective discussion is the sustenance of chiefs.⁷¹

The purpose of this research was to explore discrimination within and towards families and whānau of people who experience mental illness, and to identify strategies to overcome family related discrimination.

The research began with the assumption that understanding discrimination within families and whānau can be achieved only by also understanding the discrimination that families and whānau themselves experience. In this sense, the link between discrimination within and towards families and whānau is implicit. The research was informed by a significant body of literature that suggests a connection between the discrimination families are subjected to, and the presence of discrimination within families.

Many consumers and tāngata whai ora spoke of a lack of knowledge about mental illness in their families and whānau. They regarded this as critical to discrimination within the family context. They also asserted that what they saw as a narrow biomedical approach to mental illness, conveyed by mental health services, perpetuated discrimination. Moreover, the plethora of negative societal meanings about mental illness, reinforced by the media and popular culture, meant families and whānau had little real understanding of mental illness. Many participants acknowledged the power of the Like Minds, Like Mine advertisements in raising their own and others' awareness of mental illness. However, a lack of mental health literacy education or alternative sources of information about mental illness (other than those based on a biomedical model) contributed to their lack of understanding. Consumers and tāngata whai ora believed that a lack of understanding of the experience of mental illness resulted in families and whānau behaving in ways that were discriminatory.

This research also highlighted the ways in which discrimination towards families and whānau, from mental health services and extended families in particular, impacted on relationships within the family or whānau. In many instances, the discrimination families and whānau experienced, and the pressures associated with providing primary support, adversely affected relationships within the family. These factors impacted on the family's ability to meaningfully support the recovery of a family member who experiences mental illness.

Discrimination towards families and whānau in no way justifies discrimination within families and whānau. However, recognising the discrimination that may exist in these different settings provides a broader context for understanding the power dynamics and nature of relationships that may exacerbate discriminatory attitudes and behaviours.

In this concluding chapter, the following key topics are discussed:

1. The unique nature of families and whānau
2. The five D's – derogatory, disrespectful, dismissive, demeaning, degrading
3. Power dynamics, relationships and communication
4. Whānau ora
5. Human rights
6. Mental health services
7. Dialogue forums
8. Current initiatives to reduce discrimination

The chapter ends with a discussion of future research, and a closing comment.

⁷¹This whakatauki [proverb or saying] acknowledges that discussion, sharing of ideas and opinions, sharing of korero generally is what brings life to us all...is what brings growth to us all, and is what aids us all to be 'Chiefs'. Personal communication, Egan Bidois, Deputy Chair Like Minds, Like Mine Māori Caucus, 30 April 2010.

1. The unique nature of families and whānau

Families and whānau occupy a unique position in society, are a typically complex and dynamic entity, have unique relationships, share particular histories and have changing roles over a lifetime. Families and whānau are also clearly important in their member's lives, and are critical to healthy social, cultural and emotional development (Seigel, 2001). However, many families and whānau in this research reported challenging and even hostile relationships. Some family and whānau relationships were so adverse that children grew up experiencing serious mental health challenges that resulted in a diagnosis of mental illness in later life. However, most people remained or wished to remain connected to their families or whānau of origin.

Recognising and understanding this uniqueness is critical to developing effective strategies for countering discrimination within and towards families. Further, recognition of the ways intimate family and whānau relationships differ from those in the public domain is necessary to capture the fluid understanding of discrimination, as its meaning may change according to social distance.

2. The five D's

Another overarching conclusion that can be drawn from this research is that 'discrimination' in relation to families and whānau is highly complex. Families and whānau often indicated that it is difficult to identify whether their attitudes or behaviours were discriminatory. It is likely that extended families, staff working in mental health services and others also experience similar difficulties. 'Discrimination' may therefore be more readily recognised by specifying a range of behaviours deemed to be discriminatory. In this research, five common ways of behaving or treating people were identified as discriminatory. These behaviours, the 'five Ds', include behaving in ways that are derogatory, disrespectful, dismissive, demeaning and/or degrading.

Explicitly naming the kinds of behaviours that participants identified as discriminatory may lead to a better understanding of discrimination. Moreover, incorporating 'the five Ds' approach into strategies designed to reduce

discrimination may improve recognition of discriminatory behaviours and practices. This approach can be applied to work to reduce discrimination across different spheres of society, such as families, whānau, extended families, mental health services, government agencies and the media.

3. Power dynamics, relationships and communication

One of the most significant, although covert, themes throughout this research relates to power dynamics, relationships and communication. When families and whānau spoke of discrimination from mental health services, extended families and others, they were primarily talking about power dynamics, the quality of relationships and the nature of communication. When consumers and tāngata whai ora spoke of discrimination within families and whānau, they too were primarily talking about power dynamics, the quality of relationships and the nature of communication. Put simply, power, relationships and communication underpin discriminatory behaviour.

Participants widely recognised that a lack of information, education and knowledge about mental illness led to discrimination. However, there was little recognition of discrimination as a function of power imbalances, the quality of relationships and the nature of communication. It is widely known that healthy, respectful and empowering relationships are critical to healthy family functioning (Ministry of Social Development, 2009), as well as to recovery (Mental Health Advocacy Coalition, 2008). It therefore seems likely that facilitating a more equal balance of power, improving the quality of relationships and facilitating effective communication are likely to lead to a reduction in discrimination.

Effective communication is critical to ensuring that families and whānau have the skills, resources and capacity to enhance healthy family functioning. Families also need to have well developed communication in the face of life challenges. There was wide acknowledgement in this research that when a family member experienced mental illness, this could be a time of great pressure for all the family or whānau, and especially those providing primary support. The challenges associated with mental illness, and the family's responses to these

challenges, often adversely affected communication and relationships. In attempting to avoid the 'five Ds', healthy communication, across all relationships, needs to be fostered.

The New Zealand Campaign for Action on Family Violence ('It's Not Okay - Are You Okay') offers a useful analytical framework for understanding discrimination in relation to families and whānau. It also provides a positive approach for addressing power dynamics and promoting healthy relationships that are applicable across relationships of all types. The New Zealand Family Violence Prevention Taskforce notes that in healthy relationships, people feel 'loved, trusted, respected and safe'.⁷² Key elements of healthy relationships proposed in the family violence prevention campaign include:

- ✓ Saying more positive things than negative things (giving each other encouragement; not undermining each other with constant criticism)
- ✓ Telling each other when things are going well
- ✓ Making room for each other's views even when you disagree
- ✓ Expressing affection (spending time together, having fun, hugs).⁷³

The principles of effective communication and the promotion of healthy relationships (within and beyond the family or whānau) are also promoted by New Zealand Relationships Services⁷⁴ and other initiatives designed to improve the way family members relate to one another (e.g. positive parenting, communicating with teenagers). There is an ample body of research linking effective communication and respectful relationships within families to healthy child development and family functioning (Soloman & Seigel, 2003). Communication and healthy relationships also lie at the heart of Whānau Ora.

4. Whānau Ora

Whānau Ora provides a holistic and overarching framework that locates the whānau at the heart of health and wellbeing. By enhancing relationships and collective strengths, whānau are better placed to ensure the integrity of the whānau, to support the recovery of an individual family member, and to lessen discrimination. The Whānau Ora framework, recently endorsed by the New Zealand government, offers an integrated approach to supporting whānau. The concept of whānau ora embodies the principles necessary to create thriving relationships, to generate empathy, to behave correctly, and to nurture relationships within families and whānau. This approach aims to maximise the strengths and capacity of whānau, to encourage whānau to take responsibility and be accountable for the way the whānau functions (both in the past and present), and to foster empathy and self determination.

Whānau Ora relates specifically to whānau and reflects a Te Ao Māori standpoint. However, many of the concepts and principles underpinning Whānau Ora can be applied to other family types, and to relationships across communities, including those related to mental health services. In this sense, Whānau Ora has universal relevance in terms of providing a framework to address discrimination that is society wide.

5. Human rights

A human rights approach informs the Like Minds, Like Mine strategy to reduce discrimination (Ministry of Health, 2007). This approach recognises that human rights are fundamental to recovery; a stance endorsed by both the New Zealand Human Rights Commission and the New Zealand Mental Health Commission (Mental Health Commission, 2007). In this research, the adoption of a human rights framework has been integral to understanding discrimination within and towards families and whānau. Consumer and tāngata whai ora experiences have highlighted the importance of self determination, the right to citizenship and the right to active agency.

While human rights are legally protected under the Human Rights Act 1993, these rights extend only to the

⁷² http://www.areyouok.org.nz/about_the_campaign.php. Retrieved 27 April 2010.

⁷³ http://www.areyouok.org.nz/family_violence.php. Retrieved 27 April 2010.

⁷⁴ <http://www.relate.org.nz/Family/Familieswithteenagers.aspx>. Retrieved 27 April 2010.

public domain. The Code of Health and Disability Services Consumers' Rights (Health and Disability Commission, 1996), also accords consumers and tāngata whai ora 10 key rights, including the right to:

- ✓ Be treated with respect
- ✓ Be free from discrimination or exploitation
- ✓ Dignity and independence
- ✓ Services of an appropriate standard
- ✓ Give informed consent
- ✓ Complain about any perceived breach of these rights.

The Code is applicable to all health and disability services, including public and private services, paid or unpaid, and extends to 'people who care for family members' (Mental Health Commission, 2007a:185).

New Zealand has a comparatively high rate of community treatment orders (Lawton-Smith, 2005), forced treatment, seclusion and use of Electro Convulsive Therapy (Ministry of Health, 2009). The Mental Health Commission has sponsored work to address these issues, and has called for a reduction in compulsory treatment (Mental Health Commission, 2007a). It is imperative that consumer and tāngata whai ora rights remain fundamental to any efforts to reduce discrimination in relation to families and whānau. This is most important in the area of forced treatment, as the rights and roles of consumer and tāngata whai ora, and of family and whānau, come under challenge.

6. Mental health services

An overwhelming conclusion from this research is that mental health services require a radical shift in thinking, practice, power relations and delivery. The majority of participants spoke of the need for a holistic approach to understanding mental illness and the multi-faceted requirements for healing and wellbeing. In brief, participants called for a theoretical shift beyond the biomedical model. This stance is endorsed by leaders in the field of childhood trauma and family adversity, and by other individual practitioners working in New Zealand mental health services (see Codyre, 2006; Read, Mosher

et al, 2004). A framework that facilitates clinicians' understanding of the diverse experiences, beliefs and worldviews of consumers, tāngata whai ora, families and whānau is needed.

There was a strong call amongst participants for family inclusive practice. In the existing mainstream mental health service framework, much work has been undertaken to promote and explore family inclusive practice ((Lumb, 2007; Boyd & Sigglekow, 2010). Family inclusive practice is endorsed by the Mental Health Commission (Mental Health Commission, 2009a; 2009b). District Health Boards fund family advisor positions. However, family inclusive practice needs to ensure the consent of consumers and tāngata whai ora. The use of Wellness Recovery Action Plans, or Advance Directives, which provide mechanisms for ensuring informed consent, can be instrumental in facilitating family inclusion, while also ensuring that consumer rights are protected.

Māori have long championed holistic, intersectoral approaches to health and wellbeing, including mental health (Durie, 2001). Many kaupapa Māori mental health services embody what is needed to facilitate recovery and provide a model for service provision that could be beneficial to people across ethnic and cultural groups. This is currently exemplified in Whānau Ora.

The benefits of recovery defined and peer led services, and alternatives to acute mental health services, have long been advocated generally (Mental Health Advocacy Coalition, 2008; Mental Health Commission, 2004b; 2007a; O'Hagan, 2005; 2006; Onken, 2007). While there is much rhetoric about recovery in mainstream mental health services, participants' feedback suggests there is some way to go in terms of delivering services that are genuinely grounded in a recovery philosophy, and recovery defined concepts and practices.

7. Dialogue forums

In this research, the multi-region discussion forum provided a powerful mechanism for creating trust, respect, compassion and appreciation of diverse positions (e.g. among consumers, tāngata whai ora, families, whānau, Māori, Pacific, Chinese, Pākehā, younger, older, mother, husband, adult child of a parent consumer, sibling of a sibling consumer, consumer and tāngata whai ora parents).

The process of dialogue and engagement led to insights, self awareness and acknowledgement of discriminatory attitudes and behaviours that had not previously been recognised. The dialogue approach inadvertently revealed imbalances of power and facilitated awareness of patterns of communication and quality of relationships that may impede recovery and/or exacerbate mental illness.

The dialogue also revealed that some of those who were part of the families or whānau groups also experienced mental illness. This realisation challenged people's assumptions about 'us' (families or whānau) and 'them' (consumers or tāngata whai ora), and revealed that these assumptions can sometimes have little validity in relation to families and whānau.

It seems likely that a series of carefully planned and well facilitated dialogue forums could provide a highly effective mechanism for facilitating a shift in understanding amongst those from diverse standpoints, thereby reducing discrimination within and towards families and whānau. The provision of dialogue forums – involving staff from mental health services, families and whānau, extended families and whānau, consumers and tāngata whai ora – has the potential for multiple beneficial outcomes. These include: (implicitly) challenging negative assumptions; facilitating better understanding of one another's different positions and contexts; allowing the identification of one another's needs; promoting more effective communication and greater harmony in relationships; and ultimately enhancing the family or whānau member's recovery process. The use of dialogue methodology based on the 'Most Significant Change' technique is likely to provide an innovative approach to complex challenges in a way that captures multiple standpoints.⁷⁵

8. Current initiatives to reduce discrimination

Participants in this research recommended the implementation of a range of strategies that they believed would reduce discrimination in relation to families and whānau (as reported in Chapter Seven).

Many of the strategies identified by participants are currently provided through the Like Minds, Like Mine programme (e.g. education, training, advocacy and resources). Participants often reported having not received information about these services. Sometimes a lack of access reflected the absence of services tailored to particular demographic groups, barriers relating to geographical location (e.g. living in a rural area), and/or other logistical barriers (e.g. not having any transport, not having English as a first language, being young). It often seemed that there was a need for greater advertising and marketing of available services. However, participants emphasised a strong demand for the range of services and initiatives that currently exist. It seems that an increase in access to information about available Like Minds services, and a broader reach and access to resources such as Mental Health 101: recognise-relate-respond, would address some of the issues raised. Participants recommended that information about education, training and resources be provided as part of routine practice by mental health services, in primary health care and in other public domains.

Future research

Healthy functioning families and whānau, even under extreme stress, are better able to enhance the health and wellbeing of families and individual family members than those characterised by poor family or whānau functioning ((Seigel, 2001; Soloman & Siegel, 2003; Durie, 2001). There is also ample evidence linking family adversity to poor cognitive, social and emotional development (Briere & Scott, 2006; Seigel, 2001) and psychological distress or mental illness in later life (Barnett & Lapsley, 2006; Read, van Os et al, 2005; Read, Goodman et al, 2004; Soloman & Seigel, 2003). With the implementation of Whānau Ora, it seems timely to consider further research to explore the ways in which a new approach which incorporates Whānau Ora, and moves beyond a biomedical model of mental illness, can be instrumental in reducing discrimination and increasing family and whānau capacity and wellbeing.

⁷⁵ Anne Patillo, Extending the policy paradigm to complex problems.

http://www.patillo.co.nz/files/patillo_doc_2.pdf?PHPSESSID=46e1b2c25e498ea9859b393a83e0319c

Retrieved 30 April 2010.

Closing comment

By better understanding the nature of discrimination in the context of families and whānau, this research offers insights about ways to change discriminatory attitudes and behaviour as they relate to families and whānau. It also affirms the need for a human rights approach when addressing discrimination, and for continuing to challenge organisations, communities and individuals not to discriminate.

By locating strategies to reduce discrimination within a broader analytical framework which incorporates the 'five Ds', attention to power, communication and relationships, and Whānau Ora, there is immense potential to reduce discrimination as it relates to families and whānau. An important and unintended consequence of this broader framework is that it may very well lead to a reduction in mental illness (by reducing family adversity and dysfunction) and enhance the wellbeing of the whole family and whānau.

Finally, the process of listening to participants' accounts of their experiences revealed an intensity of emotion that is difficult to convey in a conventional research report. It is hoped that the quotes from participants throughout the report voice the range of feelings and emotions they expressed. These quotes offer insights into some of the complexities and tensions of understanding discrimination in relation to families and whānau. The report concludes with two quotes that eloquently capture the sentiments typically conveyed, and offer hope for mutually respectful relationships that can enhance the recovery journey:

[Y]ou want every dignity...you want the best care possible and all the rights to be given to your loved one... but sometimes that can overshadow the needs...of [other] family members...people don't know how to balance that. People don't know how to give to both.

(Family focus group)

[T]here's tremendous value in...sharing knowledge [with your family]...who knows you better generally than the people that you live with day in, day out? Who can support you more than anybody? Who can screw you up more than anybody is generally your family, but, also who can actually support your recovery more than anybody else.

(Consumer focus group)



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Appendix One

Terms Used in this Report

Terms used in this report have typically been adopted to reflect language that is in common usage within specific interest groups and/or to be consistent with the Like Minds, Like Mine programme.

While acknowledging the contestability of the term 'mental illness', this term is used in accordance with the Like Minds, Like Mine programme. Much contemporary research reflects a social constructionist notion of 'mental illness' (for example Ussher, 2000; Durie, 2001). Within a social constructionist framework, meaning is derived from and shaped by social, cultural, spiritual, economic, environmental, biological, political and discursive contexts.

The term 'consumer' is used to mean people with experience of mental illness. 'Consumer' is used to refer to people who attended the consumer focus groups and includes Pacific consumers. At times 'consumer' is used in a more general sense to include all people with experience of mental illness.

The term 'tāngata whai ora' means Māori who have experienced mental illness and are on the pathway towards wellbeing (Ministry of Health, 2008:14). This term is used in this report.

In the report, consumer and tāngata whai ora are typically used to distinguish participants who attended the consumer and tāngata whai ora focus groups.⁷⁸ These terms are adopted in this research as they have the most legitimacy in mainstream and Māori Like Minds, Like Mine and mental health networks.

In the interests of brevity, and due to a lack of appropriate language, terms specifically applicable to different Pacific and Chinese communities have not been included.⁷⁹

The term 'mainstream mental health services' or 'mental health services' is used to refer to inpatient, community adult mental health services, and community child and adolescent services, provided through District Health

Boards. Use of this term reflects participants' strong focus on these particular services. Other services are specifically referred to as appropriate.

The term 'carer' has often been used to refer to the informal support provided by families to a family member who experiences mental illness (Collings, 2009:7). In this report, the terms 'primary support' and 'support person/people' are used to align with a recovery paradigm and recognise the agency of the family member who experiences mental illness.

⁷⁸ It is noted that not all people who attended the consumer focus groups were Pākehā, and not all the people who attended the tāngata whai ora focus group were Māori. Some people who attended the families' and whānau focus groups subsequently disclosed that they too experienced mental illness.

⁷⁹ The term Te Ānau Tamārangi is now a respected term used in Rarotongan communities (Samuel, 2007).



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