

Stories of Success

Mental health service users' experiences of social inclusion in Aotearoa New Zealand:
Na pukorero rangatira: Na tangata waiora i whaiora i enei tuahuatana

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Original artwork: Rachel Kania

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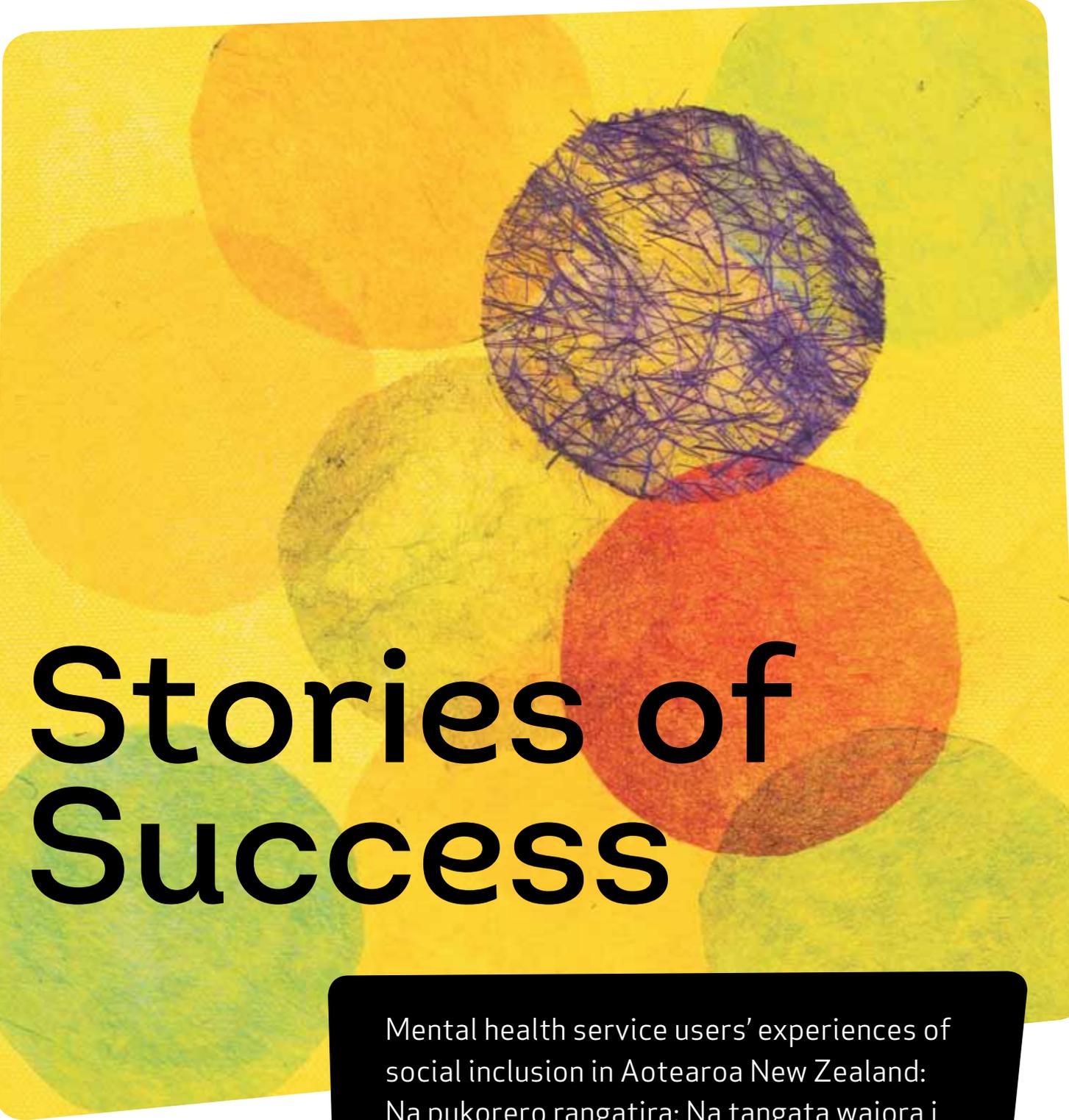
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Citation: Hamer HP, Clarke S, Butler R, Lampshire D, Kidd J. Stories of Success: Mental health service users' experiences of social inclusion in Aotearoa New Zealand: Na pukorero rangatira: Na tangata waiora i whaiora i enei tuahuatana. Auckland, New Zealand: The Mental Health Foundation of New Zealand; 2014.

ISBN 978-1-877318-87-0 (PDF)

ISBN 978-1-877318-88-7 (Hardcopy)

This document is available on the Mental Health Foundation website -
<http://www.mentalhealth.org.nz>



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Mihi

E whakakorōria ana i te ingoa o te Matua i te rangi

Praise and glory in the name of our Father in heaven

Ko ia te tīmatanga o ngā mea katoa

He is the beginning of all things

Ko ia te whakamutunga o ngā mea katoa

He is the ending of all things

Ko ia te kīngi o ngā kīngi katoa

He is the king of all kings

E whakapaitia ana tōna ingoa

We pay tribute to his name

E mihi ana ki ngā mātua tūpuna kua hoki atu ki Hawaiki nui, Hawaiki roa, Hawaiki pāmamao

Tributes continue to flow for our dearly departed ancestors who paved the early journey for us

Me ngā tini aituā o ngā marae maha o Aotearoa, me ngā iwi o te Moana nui a Kiwa

And those in Aotearoa New Zealand who have recently departed from life, and our extended families of the Pacific

Nō reira, e ngā iwi o ngā hau e whā, tēnei te mihi ki a koutou katoa, otirā ki a tātou te hunga ora

Therefore to the peoples of the four winds, salutations to you all nevertheless all living beings

Tēnā koutou, tēnā koutou, tēnā tātou katoa

My humble greetings and blessings to you all

Kotahi te kōhao o te ngīra e kuhuna ai te miro mā, te miro whero, me te miro pango

There is a single eye of the needle through which the white, black and red threads must pass

Mā te mahi tahi tahi me te whakaaro tahi, e anga whakamua

By working as one and thinking as one, we move forward

Ka whakakapi ake i runga i tēnei whakataukī;

Concluding with this proverbial saying;

He aha te mea nui o te ao?

What is the greatest thing of all?

Māku e kī atu: he tangata, he tangata, he tangata

My response is: tis people, tis people, tis people

Aroha nui ki a koutou katoa

Love to you all

Acknowledgements

There have been many people who have, in some way, contributed to making this study possible. Specifically we would like to acknowledge and thank wholeheartedly the participants for sharing their stories of success and for their ongoing encouragement and support to the researchers during the research process. We would also like to recognise those people who helped recruit participants for the focus groups: Bridget Greaney, consumer team leader, Capital Coast District Health Board; Graham Johnson and Richard Dick at Te Taitokerau Tangata Whai Ora Network, Whangarei; Sarah Williams (registered nurse) and mātua Te Awhimate Tawhai (taurawhiri) at Waitemata District Health Board; Manu Fotu, general manager of operations, Vaka Tautua, Auckland and Aaron Woolley at Te Korowai Hauora O Hauraki for his initial networking to recruit Māori participants.

Thanks also to the reference group who gave us guidance and assistance with the analysis and preparation of the final report. Thanks go to Professor Pete Ellis, Department of Psychological Medicine, University of Otago, Wellington who gave some very helpful insights and suggestions in his review of the final draft report. Thanks also go to Juan Jose Tellez for his help in the final drafting of the report. Finally we would like to thank both Kaumātua Hone Ahu (Centre for Mental Health Research) and Kaumātua Rawiri Wharemate (Mental Health Foundation of New Zealand) for their wisdom, awahi and spiritual guidance during the research process.



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Foreword

The Mental Health Foundation is proud to be part of *Like Minds, Like Mine*, a programme that challenges discrimination and promotes social justice. *Like Minds* has included a research component since its inception.

Stories of Success is the latest in a series of research projects that challenge discrimination and promote social justice. It adds to previous reports published by the Mental Health Foundation, including *Respect Costs Nothing* (2004), *I Haven't Told Them, They Haven't Asked* (2007), *Fighting Shadows* (2008) and *Walk a Mile in Our Shoes* (2010) which provide an in-depth look at the parts of our society that need to be challenged and changed.

Stories of Success focuses on the stories and experiences of services users who have experienced social inclusion, using them as a platform to further challenge stigma and discrimination. The people with lived experience who were participants in this project have described their starting place for social inclusion as a feeling or perception that it is a genuine possibility, and told of their increased sense of personal power and improved contribution to their relationships and communities.

The research takes a hopeful view of social inclusion, and reveals the powerful potential of friends, whānau, employers, health professionals and peers, who walk alongside service users to challenge the institutional structures that perpetuate stigma and discrimination towards those with experience of mental distress.

The people who took part in the project, including the researchers, participants, reference group, and those who have offered

support and feedback during the research journey are to be congratulated for their commitment to finding the stories of success that surround us every day. Those people whose stories appear in this document have forged a path that gives hope to those who follow, but more than that, they have generously shared their triumphs, mistakes and strategies. They are the leaders in the drive for social inclusion, and each person has my thanks and appreciation.



Judi Clements
Chief Executive

Mental Health Foundation of New Zealand

Executive Summary

This report gives an account of a study that explored successful stories of social inclusion experienced by people with mental illness in Aotearoa New Zealand. The objectives of the study were to:

- describe the external factors that support people's inclusion within society
- explore the internal factors that create a sense of social inclusion for people
- highlight the positive attitudes and behaviours, which participants encountered within their communities and government organisations, that foster social inclusion
- determine implications and recommendations to inform the *Like Minds, Like Mine* strategic direction, objectives and research programme in the future.

Definition of social inclusion

Social inclusion can be defined as the extent to which people are able and confident to exercise their rights and participate, by choice, in the ordinary activities of citizens. Social inclusion implies full participation in society, with no constraints or conditions placed on a citizen's status.

The literature acknowledges the complexity of social inclusion as a concept and its inherent connection with social exclusion, noting unclear boundaries between the two. Issues around a person's own perceptions and actions, poverty, social capital, deprivation and inequality add to this complexity.

Background to the study

The mental health system in Aotearoa New Zealand is informed by the recovery approach, and aligns with the principles of hope, personal agency, social connectedness and inclusion

within society. This research study was commissioned as an exploration of successful stories of social inclusion experienced by people with mental illness, and aims to contribute further knowledge to inform the *Like Minds, Like Mine* programme. The study is also informed by *Rising to the Challenge* (1) (service development plan), which sets the direction for mental health and addiction services in seeking to improve the mental health and wellbeing, physical health and social inclusion of people with mental illness.

One of the consistent barriers to social inclusion is the negative labelling and stereotyping of people diagnosed with mental illness, and their subsequent experience of overt stigma and discrimination. Similarly, coercion is still a current issue for service users in the context of mental health services, particularly for those subject to the Mental Health (Compulsory Assessment and Treatment) Act 1992. Of concern, is that mental health professionals continue to be reported as one of the many stigmatising groups that service users will encounter (2,3).

It is suggested that the reversal of stigma and discrimination experienced by mental health service users can be achieved through focusing on and increasing the options for social inclusion (4). Programmes such as *Like Minds, Like Mine* aim to increase the participation of service users in society, so they can become contributing and valued members. Since its inception, *Like Minds, Like Mine* has established a body of work to counter stigma and discrimination through a national media advertising campaign, and other programmes such as community development activities, training and education.

Research findings

This study adds to the scarce body of literature concerning social inclusion and stories of success for mental health service users in Aotearoa New Zealand. The key themes from the study are summarised below.

- Defining social inclusion – the findings confirm the complexity of social inclusion as a fluid and subjective experience and that social inclusion is not merely the absence of social exclusion. Social inclusion for participants was defined as the fundamental right to be recognised as an equal alongside others in society.
- The feeling of social inclusion – many participants described their experience of social inclusion as a two-stage process. The *before* stage represented the person moving beyond their self-stigma to a feeling that social inclusion was a possibility; the *after* stage represented an increased sense of participants' personal power, a deepening of social relationships and a belief that they have the right to contribute to society.
- What others did and said – stories of success around social inclusion centred on the actions and words of others who included participants in the activities of everyday life. Participants felt that they were no longer required to work harder to be included, leading to a reduction of self-stigma and an increased sense of personal power. Participants also placed importance on the idea of reciprocity, the give-and-take of social connection, which generated mutual positive regard between their co-citizens.
- Personal power – personal power was regarded by many of the participants as an integral part of social inclusion, which provided them with the self-confidence to

make decisions and choices in their daily lives. Personal power also related to the ability to challenge existing institutional structures that perpetuate stigma and discrimination towards service users.

- Finding the champions – the findings indicate that social inclusion is often linked to a particular person or event. Health professionals, peers, family members and cultural leaders were regarded by participants of the study as champions of social inclusion. The study found that social inclusion was seen to work both ways; including others also meant including oneself.
- The future – the majority of participants reported that progress has been made regarding social inclusion for those with mental illness in Aotearoa New Zealand. Participants suggested education, the media, access to information and resources, initiatives focussed on younger people and increased visibility of service users in leadership positions as areas of potential focus.

Recommendations

Though this is a small indicative study, with a limited sample, the study has generated the following recommendations, which could be further explored by the *Like Minds, Like Mine* programme.

Raise the visibility of services users as leaders in key roles in the mental health sector.

Increasing service user leadership, in partnership with providers and funders of mental health services, advocacy groups and other key stakeholder groups, will further foster inclusionary practices within mental health services. Strengthen service user involvement at a leadership level will stimulate debate on how to create innovative ways to increase social inclusion in Aotearoa New Zealand.

Develop more opportunities for service users to have meaningful and supportive employment in a wide range of industries and professions.

Meaningful employment increases people's sense of value, participation in, and contribution to, the society within which they live. Although transitional and supported employment is essential for people who have mental illness, placing the focus on how employers can provide safe and supportive workplaces outside of the mental health sector is important in increasing social inclusion.

Focus the *Like Minds, Like Mine* programme on younger adults and include their presence in future media advertising campaigns.

The majority of the participants in this study suggested that future media advertising campaigns need to increase the focus on younger people. Participants regarded this as an opportunity to break the cycle of stigma and discrimination, and to challenge early on ("starting young") negative attitudes and behaviours towards people with mental illness. This could also be considered as an example of a circuit breaker. Therefore, it is vital that younger people are given the opportunity to contribute to the planning of future *Like Minds, Like Mine* programmes, as well as increasing their visibility in media advertisements.

Share provider and government agency stories that support social inclusion in the *Like Minds, Like Mine* programme.

The participants in this study often reported that it was the actions of one person, or in one situation by a champion, that led to their stories of success of social inclusion. The actions of others not only increased the personal power of participants; these actions made a claim for the service users' basic right to be included. Examples of these actions are worthy of future exploration, to help staff in the mental health

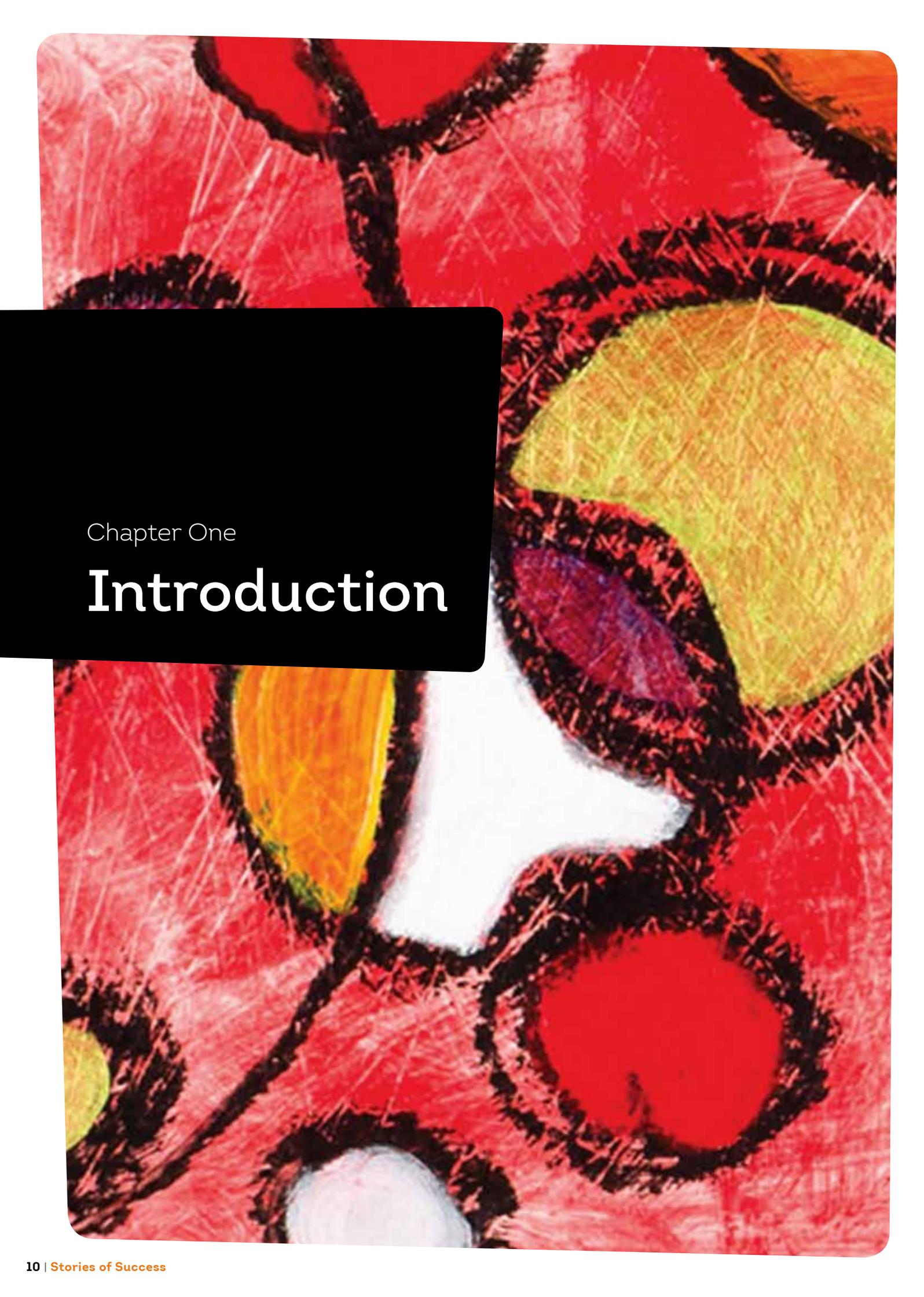
sector and other allied government agencies, such as housing and employment, to champion the social inclusion of service users.

Explore the use of wider-reaching face-to-face, media and virtual campaigns to support the understanding of the lived experience of mental illness.

It is recommended that *Like Minds, Like Mine* continues to explore the use of social media and web-based platforms, similar to what is being done elsewhere in innovative international initiatives, to inform future media advertising. Websites could also be considered as a medium to access narratives about mental illness and provide examples of how other service users have experienced successful social inclusion (see www.patientmemoirs.com as an example of such a platform). The *Like Minds, Like Mine* media advertising campaigns could also be used as teaching aids to promote discussion in schools and work settings, and with non-health agency staff.

Further develop and measure the Aotearoa New Zealand concept of social inclusion, inclusive of Te Ao Māori and Pasifika realities.

The need for valid and reliable measures of social exclusion and inclusion has been highlighted in the literature reviewed for this study. The *Measuring Social Inclusion* (5) report advocated for improved social inclusion for people with experience of mental illness, and highlighted the importance of cultural identity and the need for further examination of the lived experience of social inclusion from a qualitative perspective. However, it remains unclear what impact social inclusion policies have on ethnic minorities (6). Therefore, the role of culture in promoting the social inclusion of ethnic minorities continues to be a key policy area that needs to be further assessed and evaluated in Aotearoa New Zealand.

An abstract painting with a vibrant red background. A thick black outline defines a central shape. Inside this shape, there are several distinct areas: a large yellow section at the top right, a purple section below it, a white section at the bottom center, and a red section at the bottom right. The texture of the paint is visible, with some areas showing fine, radiating lines.

Chapter One

Introduction

This report gives an account of a research study that has explored the successful stories of social inclusion experienced by people with mental illness in Aotearoa New Zealand. This introductory chapter will present the background and theoretical positioning of the study. Social inclusion and social exclusion are explored as concepts, and the context of mental health in Aotearoa New Zealand is briefly discussed.

Background to the study

The United Nations Convention on the Rights of Persons with Disabilities (7) is one of many successive conventions that recognise the inherent right of people with disabilities¹ to have human rights protection (7,8). Article 19 of the convention states that people with disabilities have a right to “live in the community with choices equal to others... and their full inclusion and participation in the community” (7 p13). The convention also stipulates that all countries that have ratified the convention must take effective and appropriate measures to support the participation and inclusion of people with mental health problems through full physical, mental, social and vocational support.

New Zealand’s first report (9 p32) on the pathway it has taken to ratify the convention added, however, that social inclusion remains problematic due to people’s experiences of “loneliness, lack of participation and ability to develop social networks within local

communities”. Hence the importance of the New Zealand Government’s commitment in *Rising to the Challenge* (1) to increase social inclusion, to counter the impact of stigma and discrimination and the self-stigma (10) associated with having a mental illness.

Theoretical foundation of the study

The theoretical foundation for this study is guided by the understanding that social inclusion involves the extent to which people are able to exercise their rights and participate, by choice, in the ordinary activities of citizens (11). Our understanding of social inclusion, therefore, is based on the idea that people with mental illness will have full participation in society, and be able to exercise their rights and responsibilities as citizens without any constraints or conditions placed on their status (12). This theoretical foundation is grounded in the principles of the human rights and citizenship framework (7), and is consistent with the *Like Minds, Like Mine* programme to counter discrimination and with the social model of disability (13,14).

Social exclusion and social inclusion

There has been concern that the terms ‘social exclusion’ and ‘social inclusion’ have been poorly defined and researched, and that both terms require more conceptual and methodological work (15-17), specifically on what constitutes social inclusion (17).

The foundational work by Sayce (4,18-20) in 1998 to 2003 made an early contribution to the understanding of social inclusion. According to Sayce, social inclusion means having support and reasonable accommodation, so that people can be included in employment

¹ Article 1 states that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (7 p4).

and social networks, and have friendships, intimate relationships and participation in civic life. Sayce further suggests that social inclusion needs be given a greater emphasis in mental health policy and must become a therapeutic goal in the practice of mental health clinicians. This early work, along with additional explanations and the context of social inclusion are discussed further in Chapter 2. It is hoped that this report will contribute further to the understanding of what supports social inclusion in Aotearoa New Zealand.

The context of mental health and social inclusion in Aotearoa New Zealand

Mental health care in Aotearoa New Zealand is informed by the recovery approach (21). Central to recovery are the principles of hope, personal agency, social connectedness and inclusion within society (21-24). There are, however, concerns that one of the consistent barriers to social inclusion is the negative labelling and stereotyping of people with a diagnosis of mental illness, the results of which lead to people being regarded as the feared outsiders (25,26).

In response to these concerns, the *Like Minds, Like Mine* programme (27,28) was implemented in 1997 to promote de-stigmatisation of mental illness within Aotearoa New Zealand (3,10,29-31), and to build an infrastructure to deliver high-quality education and training about mental illness, in order to change public attitudes. This was to be achieved, primarily, through increasing the visibility and strengthening the public voice of people with experiences of mental illness.

However, coercion (32) is still an issue for service users of mental health services, particularly for those subject to the Mental Health (Compulsory Assessment and Treatment) Act (33), and can perpetuate their demoralisation and social exclusion. Likewise, social exclusion further increases stigma of the self (10) and by others, through covert and overt discrimination. Of particular concern is that mental health professionals continue to be reported as one of the stigmatising groups that service users will encounter (3,34).

In 2001, a report by the Social Exclusion Unit (35) in the United Kingdom suggested that the stigma and discrimination experienced by people with mental illness can be reduced by increasing the focus on social inclusion, with the aim of increasing the participation of service users as contributing and valued members of society (18,36,37).

As recently as 2011, the Mental Health Commission (5) noted that there was no established dataset that provided a picture of the nature and extent of social inclusion for people with mental illness² in Aotearoa New Zealand. Its report provided a framework for how social inclusion was experienced by individuals with mental health and addiction problems, based on the limited data that was currently available. Key findings were that “people with symptoms of mental distress feel less included in society than other New Zealanders at major cost to them and their communities” (5 pix). The life domains that were identified as being particularly affected for people with symptoms of (severe) mental distress included: relationships (e.g. feeling isolated from others); participation in civic

² This statement also included people with addiction problems in Aotearoa New Zealand.

life (e.g. voting); personal safety; cultural identity (e.g. how easily people were able to express their identity); leisure and recreation (e.g. difficulty in participating in free-time activities); knowledge and skills (e.g. attainment of educational qualifications); employment; and, standard of living (including housing satisfaction) (5).

This research study will specifically focus on the enablers of social inclusion. We have explored the positive experiences of inclusion by talking to people who have been diagnosed with a mental illness in Aotearoa New Zealand. Following in the footsteps of other influential research reports, for example, *Respect Costs Nothing* (31) and subsequent studies (3,10,30,38,39), this study aims to make a further contribution to the strategic direction and objectives of the *Like Minds, Like Mine* research programme.

A word on the terminology used

There is an ongoing debate about the best term to use when referring to people living with mental illness. The terms consumer, service user, psychiatric survivor and tangata whai i te ora are used interchangeably in many publications. The majority of the participants in this study used the term service user or consumer, and also described their experiences as mental illness. We have adopted the terms service user and mental illness within this document.

Summary

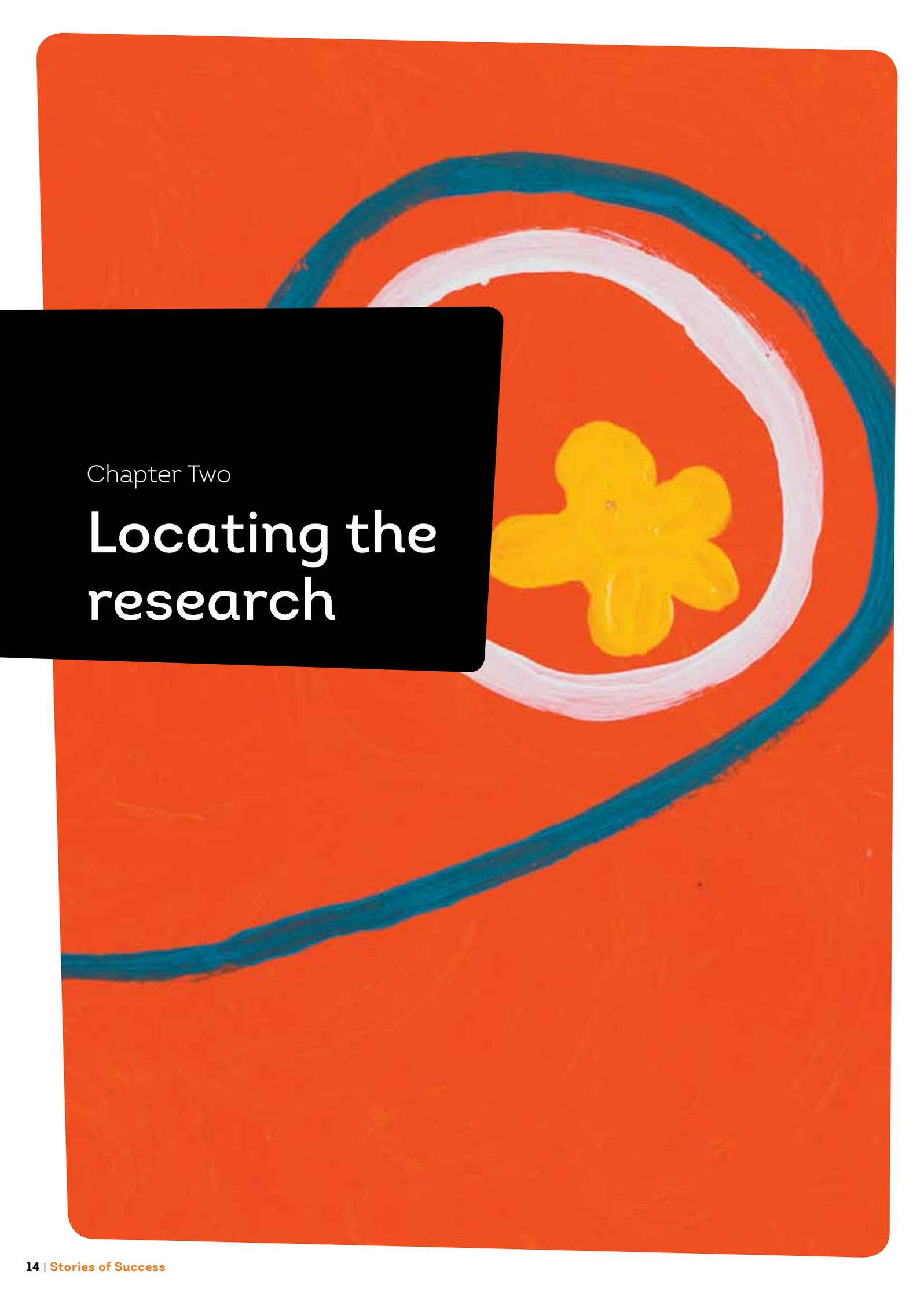
This chapter has provided contextual information on social inclusion within the mental health setting. It is anticipated that this project will be of interest to the wider

service user networks, family, whānau, mental health clinicians, policy makers, government departments and the broader community. The findings will lead to a better understanding of the factors that increase a sense of social inclusion for people with mental illness. The findings and implications of the study will contribute to the reduction of stigma and discrimination, particularly in settings such as mental health services, and the education, housing and employment arenas. It will also potentially contribute to the direction of the *Like Minds, Like Mine* programme.

Content of this report

This report is divided into five chapters.

- Chapter 1 is the introduction, giving the background and theoretical foundations of the study.
- Chapter 2 reviews the literature on social inclusion in the context of mental health.
- Chapter 3 describes the research aims, methodology and methods used to collect and analyse the data.
- Chapter 4 presents the research findings in the context of the interview questions outlined in Chapter 3.
- Chapter 5 discusses the key themes that emerged from the research findings, along with the strengths and limitations of the study. Research conclusions are outlined and recommendations are proposed for further consideration.

An abstract painting on a bright orange background. It features a thick blue brushstroke that forms a large, open circle. Inside this blue circle is a white brushstroke that forms a smaller, more defined circle. In the center of the white circle is a yellow, five-petaled flower. The brushstrokes are thick and expressive, suggesting a hand-painted style.

Chapter Two

Locating the research

This chapter reviews the literature on social inclusion in the context of mental health, and locates the research within the current national and international literature on the topic.

Social exclusion and mental health

It is widely recognised that people experiencing mental illness are more likely to be excluded from society (5,20,40-45). Similarly, people with serious mental illness and a combined alcohol and substance abuse problem are highly likely to experience social exclusion (46).

There are a variety of reasons for this occurring. Societal stigma in relation to having a mental illness has a key role to play (5,42,44,47-53). For example, people with mental illness are often regarded by others in society as strangers; this can result in social distancing and exclusion, leaving them unable to find their rightful place in society (26). As a result, many people with a diagnosis of mental illness may only socialise with those who have also had experience with mental health services (52), or choose to keep their diagnosis hidden from others, including employers and friends (41,54). Experiences of negative reactions, due to prejudice, towards people with serious mental illness may also result in people withdrawing from social and other networks (53,55).

Unemployment is a common experience for people with a mental illness (5,41,44,48,52,56,57), despite many wanting to work (44), yet few studies have explored employment for people with serious mental illness (30,58-60). In Australia and Aotearoa New Zealand, the employment rate for people

with mental illness is less than 25 per cent (61,62). In the United Kingdom, it has been reported that only 15 per cent of people with serious mental health problems are working (48). Lockett and Bensemman (61) suggested that the numbers of service users employed could rise to 45 per cent if evidence-based employment programmes (63) were a standard part of treatment in clinical settings. Nagle, Cook and Polatajko (52) also reported that the onset of a mental illness impacts on people's ability to retain employment when both the symptoms of the illness and the side-effects of their medication made it difficult to keep up with the occupational demands of the job.

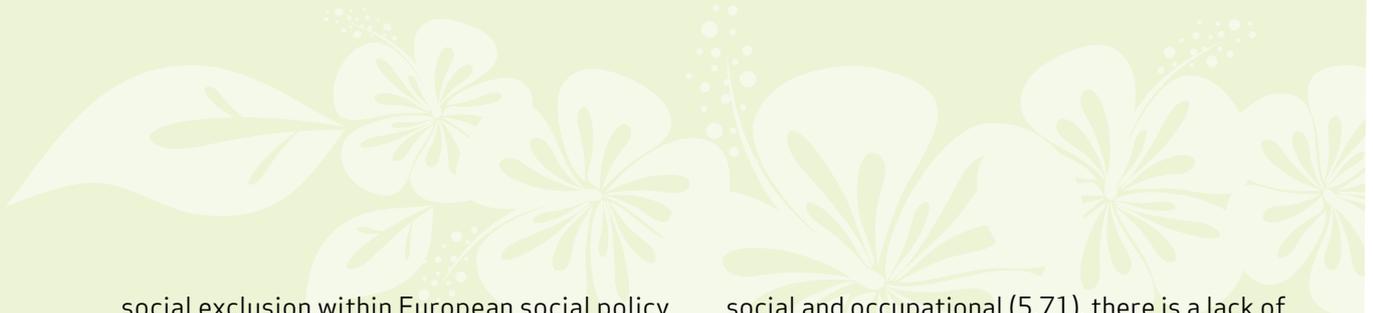
Other issues faced by service users include restricted access to their social rights and expectations, such as reasonable life insurance premiums (12,64,65), accessible health care, holidays and financial services (41,66), voting (5,50), transport (57) and (quality) housing (5,44,67).

In the United Kingdom, the Social Exclusion Unit identified five key reasons why mental health problems may lead to people experiencing social exclusion (44). These included: stigma and discrimination; low expectations of people with mental health problems (e.g. amongst health professionals); lack of clear responsibility for the promotion of vocational and social outcomes; a lack of support in relation to access to employment; and, barriers to community engagement (e.g. due to restricted access to transport and housing).

Social inclusion and mental health

History of social inclusion

In their review of social exclusion and mental health, Morgan et al (47) trace the origins of



social exclusion within European social policy to the work of Lenoir (68), and note that strategies to promote social inclusion were developing in France throughout the 1980s. Indeed, social inclusion has been on policy agendas, particularly in Europe, for a number of years (47,48,69). In the United Kingdom, for example, it was adopted as part of the government's policy agenda, with the Social Exclusion Unit established in 1997. Of note is that, in 2004, the Social Exclusion Unit focussed on social inclusion for people with mental health problems, which played a key role in shaping practice development in the following years³ (69).

Whilst it has been claimed that initiatives to promote social inclusion are ongoing (47), others are concerned that both social inclusion and exclusion have been dropped from recent United Kingdom mental health policy frameworks (69). The subsequent tension between a focus on social inclusion for people with mental health problems and contradictory policy developments (e.g. the Mental Health Bill in the United Kingdom) has also been discussed in the literature (70,71).

Defining social inclusion

A review of the literature identifies multiple definitions of social inclusion (71). It has been described as a complex concept (5,69) that overlaps⁴ with a number of other issues, such as poverty⁵, social capital, deprivation and inequality (11,47,69)⁶. Moreover, while it is generally accepted that social inclusion is multi-dimensional, that is, made up of a number of aspects such as physical, psychological,

social and occupational (5,71), there is a lack of consensus regarding which aspects are relevant or the most important (50). It has also been reported that social inclusion and exclusion are sometimes confused, with unclear boundaries between the two (69,73). As noted by Nash (50 p700) "it is difficult to write about social inclusion without referring to the concept of social exclusion". This is reflected within this summary of the literature, with some material referring to social exclusion, where appropriate.

The New Zealand Mental Health Commission (5 p1) has also highlighted the "complex, dynamic and multi-dimensional" nature of the concept. In its paper on the issue of social inclusion for service users (11), a number of key characteristics were identified, including:

- social exclusion is caused by an act (or omission) of an individual, institution or group
- a person may exclude themselves by choice, or they may be excluded as a result of the decisions of others
- social inclusion is relative to a given society (place and time)
- social exclusion is multi-dimensional and social inclusion is dynamic
- there are multi-level causes of exclusion.

The New Zealand Mental Health Commission (11 p6) defined social inclusion as "...the extent to which people are able to exercise their rights and participate, by choice, in the ordinary activities of citizens in the society in which they

³ Wright and Stickley (69) note that this work was overshadowed by competing political agendas (e.g. a draft Mental Health Act that increased powers to detain people against their will).

⁴ It has been argued, however, that social inclusion encompasses a broader remit (e.g. compared with poverty), given the additional experiences, such as stigma, likely to be faced by people with mental health problems (47).

⁵ It has been claimed that the term social exclusion was adopted by the British Government as a more acceptable phrase than poverty (51).

⁶ Social capital has been defined as "the features of social organization, such as civic participation, norms of reciprocity, and trust in others that facilitate cooperation for mutual benefit" (72 p1491).

Definition for social inclusion in the context of mental health

Inclusion may be defined in terms of a virtuous circle of improved rights of access to the social and economic world, new opportunities that users can choose to pursue, with support or adjustments where necessary; for example, education work, joining social cultural and religious groups, friendships and relationships, raising a family and participating in civic life (jury service, voting, political office) (20 p122).

reside". In a similar vein, the text box below displays a widely cited definition for social inclusion within the context of mental health.

The development of social relationships and networks is generally seen to be important in building a participatory and socially inclusive life (47,69,71). Croucher and Le Boutillier (71 p137) suggest that while many of the common understandings of social inclusion focus on basic socioeconomic needs, and social and psychological aspects, there is a need to ensure that the concept includes "personal meaning, a sense of involvement and social connectedness, rather than simplifying the concept to a person's hours of physical engagement with his or her community". If only a one-dimensional view of social inclusion is adopted, they argue, there is a risk of overlooking the individualistic and multi-dimensional nature of the experience (71). In line with this, others have discussed whether the experience of being socially included or excluded is an objective state that can be measured, or something that is subjectively felt (11). The potentially fluid nature of social inclusion has also been emphasised as an essential aspect of the concept (47,53,71).

The role of others, including at a broader societal level, has been emphasised in relation to mental health service users' experience of social exclusion (47,48,74,75), but the issue is less clear when considering social inclusion specifically. Schneider and Bramley (74 p133), for example, describe social exclusion as requiring an interaction or exchange between people; it therefore "cannot exist unless someone or something brings it about". Morgan et al (47) extend this further, and claim that the level of belonging and involvement experienced by service users in local networks and communities is determined by other individuals within these social settings. In their discussion of employment, social inclusion and mental health, Evans and Repper (48) note the high rates of unemployment amongst people with serious mental health problems in both the United Kingdom and the United States of America despite evidence that users of mental health services want to work.

Critics of social inclusion

As a result of their review of the literature on social inclusion and mental health, Wright and Stickley (69 p78) concluded that much of the evidence "accepts uncritically" that inclusion is a positive experience for people with mental illness. However, they were concerned that inclusion overlooks the political connotations of the term: that the excluded have to meet some expectations to be included. In other words, whilst not widespread, social inclusion in relation to mental health does have its critics (16,69,73).

A recent study on citizenship by Hamer et al (12) found that the notion of social inclusion was a contested concept by some participants who reported that they had to regulate their behaviour in order to follow the rules and norms of inclusion held by the dominant

group in society. Spandler (73) also notes that social inclusion assumes that being included in mainstream society is both desirable and unproblematic, which is not the case for everyone. Additionally, Spandler argues that the link between social inclusion and improved mental health is not clearly established.

Measuring social inclusion

The Mental Health Commission's occasional paper on *Mental Health and Social Inclusion Concepts and Measurements* (11) highlighted a number of potential benefits of measuring and reporting on social inclusion for people with mental health problems. These included increased understanding of the barriers to participation and systemic discrimination, improved policy coherence, and an increased focus on mental health issues. A number of possible risks were also reported, including further stigmatisation of people with mental illness and a range of data collection challenges (11).

Measuring the degree to which a person feels included cannot be discussed without first reviewing the measures of social exclusion, given that these are often used in relation to initiatives designed to promote social inclusion (47). A review of the tools used to measure this concept identified that the most common method was the use of lists containing multiple indicators of exclusion, which were usually drawn from pre-existing datasets (47). Morgan et al (47) identified a range of problems with this approach, including the interchangeable use of the terms poverty and social exclusion. Moreover, they noted that indicators are rarely linked to participation in social and cultural life, which does not set them apart from measures

of deprivation and poverty (47). The Mental Health Commission (5 p3) also noted that indicators are "big picture" measures and, while they are able to highlight areas requiring further investigation, they do not provide in-depth analyses of the causes or implications of an issue.

The measurement of social inclusion with regard to mental health service users raises a number of challenges, aside from those discussed above. As highlighted, the data used may have been originally collected to measure a different concept (47). Some researchers have highlighted that findings from some of the measurement studies undertaken are questionable due to the lack of validation of the tools used (69). Given that social inclusion may be measured subjectively (i.e. whether a person has experienced feeling excluded or included) or objectively (i.e. via rates of participation in activities and access to services) (11), the challenge of measuring a subjective and, a potentially fluid state has been noted (43,47,53). Due to these current limitations and challenges the need for valid and reliable measures of social exclusion and inclusion, has been highlighted (47).

Service users' views and experiences of social inclusion are important to emphasise within this discussion. Croucher and Le Boutillier (71) note that while some individuals may not be considered typically socially included by others, they may be quite content with their level of social inclusion; they, therefore, argue that a polarised or linear view of social exclusion⁷ and inclusion is not overly helpful in this regard.

Nagle et al (52) report that people with severe mental illness elected to limit their activities in

⁷ Croucher and Le Boutillier (71) suggest a personally defined middle-ground as an alternative view; whereby mental health service users locate themselves between the two polarised sets of circumstances (e.g. halfway between isolation and full participation).

order to maintain their health, and prioritised their occupations to allow them to do this (52). Other studies have also emphasised the notion of choice with regard to social exclusion or inclusion (11,73). Spandler (73) for example, highlights that those who are socially excluded may value this positioning in society, and form networks with others in similar situations. As noted previously, the potentially fluid nature of social inclusion has also been emphasised as an important aspect of the concept (47,53,71). These are all important considerations, given that traditional measures of social inclusion may not incorporate such factors.

Facilitating social inclusion for mental health service users

Much of the literature that discusses ways of facilitating social inclusion for service users is explored from the position of tackling social exclusion. This includes, for example, addressing financial and housing needs. In addition, while the following content outlines proposed strategies for addressing social exclusion, or facilitating inclusion, there is limited analysis of their effectiveness within the context of social inclusion and mental health.

Similar to the social model of disability (76,77), it has been argued that in order for people with mental health problems to experience social inclusion a societal change is required (20,44,47,74,78). In achieving this, a multi-faceted approach is often recommended as the best way forward. For example, Sayce and Measey (41) claim that a mix of legal reform, public education, and local initiatives is required. Similarly, Cobigo and Stuart (78) recommend four approaches, which incorporate legislation, community-based supports and services, anti-stigma and discrimination



initiatives, and further monitoring and evaluation data. In the development of its work, the Social Exclusion Unit in the United Kingdom highlighted a need for a sustained programme, comprising six key areas or categories, to challenge the attitudes of the general public towards people with mental health problems, and to promote awareness of people's rights (44) (see the text box below for an overview of this). It is clear, therefore, that future initiatives on social

The six categories to reduce social exclusion

A project undertaken by the Social Exclusion Unit in the United Kingdom (44) explored what needed to be done to enable adults with mental health problems to gain and retain employment, and what would facilitate them securing similar opportunities to the general population with regard to social participation and access to services. Data was collected via a range of methods, including literature reviews, a series of consultation exercises, local research, and visits to projects aimed at tackling social exclusion. The project resulted in an action plan to reduce social exclusion, which included six categories as follows.

- 1 Stigma and discrimination: a programme to challenge negative attitudes and promote awareness of people's rights.
- 2 The role of health and social care: evidence-based practice in vocational services; access to employment advisors and social support in primary care; redesigned mental health day services; training for health and social care professionals; closer working with the criminal justice system.
- 3 Employment: increased support for people with mental health problems to find and retain work (e.g. via training for employment providers).
- 4 Families and community participation: early support to families and early recognition of mental health problems in parents; access to education, training opportunities and community roles, such as jury service.
- 5 Access to basic facilities and services: guidance to housing authorities and improved access to financial and legal advice, and affordable transport.
- 6 Implementation of the programme: effective leadership and coordination at national and local levels (44).

inclusion must move from a solely health focus to incorporating more strongly a rights agenda.

Sayce and Measey (41 p66) further argue that legislation can help set a benchmark for "what society considers acceptable", and that current discourses on mental illness need to be reframed via the media and other educational avenues. Nash (50) also highlights the potential impact of adverse media reporting of mental health issues, and emphasises the need to redress this.

Community⁸ engagement has been suggested as an effective means of facilitating social inclusion, particularly given its potential to contribute to the development of social capital (51) and the value a person gains from their social networks. Schneider (51 p282) proposes fostering positive

interactions between service users and the wider community, and claims that "it is difficult, if not impossible, to sustain social exclusion when people are engaging voluntarily around meeting mutual needs, building trust and helping each other".

Others have suggested a range of community initiatives, including: supported employment schemes and voluntary organisations supporting people to get involved in sporting and other activities (41); specific programmes such as Healthy Living Centres and Health Action Zones⁹ (50); and community-based systems of care (78). The formation of partnerships between mental health services and community organisations (e.g. sports and art centres) has also been

⁸ Communities may be defined geographically, or they may be virtual and based on affiliations or selected memberships.

⁹ Health Action Zones were area-based initiatives established in England in the late 1990s to tackle health inequalities.

suggested as one way of promoting and fostering service users' community participation (45).

Research that explored service users' experience of social inclusion identified that it was facilitated by other people with positive attitudes, social support provided by mental health services, and a sense of belonging (e.g. to a job) (55). Participants indicated that positive day-to-day interactions with people on the street had resulted in them feeling more included, and experiencing a greater sense of personal safety (55). Similarly, a study undertaken in a rural community in Scotland found that mental health service users felt more involved in their local community, as a result of acts of kindness, and other demonstrations of acceptance and caring by community members (including family, friends and neighbours) (53). It is interesting to note, however, that such practices could also be upsetting for some, given that they were sometimes interpreted as intrusive and due to "community inquisitiveness", rather than a genuine sense of concern.

A search of the social inclusion literature retrieved an Aotearoa New Zealand unpublished qualitative study by Cheer (79), which explored the understanding of social inclusion by a small group of service users living together in supported accommodation. Cheer found that participants felt socially included through a number of factors, such as having honest and open communication with others; being supported to have choices and to make decisions; and having access to decent housing, employment and community resources. Having supportive employment was also important; specifically employers that kept service users' jobs open during periods of un-wellness. The

author concluded by recommending that mental health professionals can increase social inclusion for service users when they show confidence in service users' capacity to recover and support their optimism and hope for the future.

It has been suggested that the evidence base is strongest in relation to paid employment¹⁰, with regard to its potential to foster social inclusion for mental health service users (30,81,82). This is not only due to increased financial status (with availability of funds having a bearing on people's ability to engage with, and feel a part of, their communities) (5,40,52,55), as employment also contributes to the development of self-confidence and social acceptance (52). As reported previously, there are lower employment rates for people with serious mental illnesses (5,48). Being employed, however, is associated with improved mental health and wellbeing (30,44,82,83). Of note is that it has been reported that between 60 and 70 per cent of those with a mental illness would like to be in paid employment (40,45). Evans and Repper (48) argue that while service users may face barriers to work, services and communities have the ability to address service users' lack of employment opportunities and the discrimination that they face.

The contribution of mental health workers to service users' sense of social exclusion or inclusion has received much attention in the literature (44,45,48,55,74,84,85). For example, it has been reported that mental health workers may overlook service users' ability to work in mainstream, paid employment when considering their needs (48). Bradshaw et al (57) highlight the particular influence of this group, given that mental health service users may be especially

¹⁰ It is interesting to note that the relationship between participation in voluntary work and social inclusion is not clear, despite voluntary work being seen as a means of providing access to a meaningful activity and a possible step towards paid employment (80).

reliant on them, due to difficulties in making wider social connections. It has also been suggested that, whilst practitioners have a role to play in aiding inclusion, an association with mental health professionals may indeed further stigmatise clients (69).

However, it should be noted that research in Aotearoa New Zealand, undertaken with staff

from mental health services, identified that there had been a positive shift in the attitudes and practices of mental health professionals in addressing stigma and discrimination in recent years (85).

Lloyd et al (45) propose a range of actions¹¹ that mental health practitioners can undertake to promote social inclusion, as displayed in Table 1.

Table 1: Four key strategies to improve social inclusion for people with mental illness

SPECIFIC ACTIONS FOR MENTAL HEALTH PRACTITIONERS			
Addressing attitudes and beliefs	Promoting employment opportunities	Supporting families and community participation	Addressing housing, finance, transport and access issues
believe in service users' potential to recover	adopt social disability and access model	family members or care-givers need support to encourage service users' community participation	provision of supported housing
allow service users to take calculated risks to move forward	develop a range of training and employment options in the local area	psycho-education as evidence-based practice	links between housing, mental health services and support services
examine staff's own discrimination against people with mental illness	provide supported education	form partnership between mental health services and community organisations to develop joint social/recreational initiatives	developing memoranda of understanding between mental health services and services providing supported housing
set specific targets for employment, housing, education or engagement in social activities in local community	provide transitional and continuous supported employment	follow systematic process to plan and implement community-based programme	utilising practical strategies (e.g. paying rent and bills)
social integration must be set as priority goal from early stage of intervention planning	deal with the issue of disclosure of psychiatric disability		providing life skills training
	lobby changes in funding system to remove disincentive to work or offer paid jobs		advocacy
think laterally to create multiple options for service users	provide alternative option such as workers' cooperatives		linking in with social support networks
psychosocial programme must have strong relevancy to service users' community lives			developing money management skills
			providing opportunities for community access
			transport training

Lloyd et al (45). Reproduced with permission of e-Content Management Pty Ltd.

¹¹ These are positioned under four overarching principles: 1) involve multiple services providers; 2) form alliance with and educate public media; 3) develop community initiatives; 4) reform legal framework.



At a broader level, government policy and legislation that extends beyond mental health service users has a role to play in facilitating social inclusion. The passing of the recent Marriage (Definition of Marriage) Amendment Act 2013 (86) in Aotearoa New Zealand is an example of inclusionary legislation. The act will contribute to the overall levels of social inclusion experienced by a marginalised group of people with gender and sexual diversity, and subsequently decrease the significantly poorer mental health that this group enjoys, compared with other groups in Aotearoa New Zealand (87,88). Likewise, the development of inclusive legislation and policy agendas could also reduce service users' experiences of discrimination and social exclusion (12,89,90).

Examples of clinical interventions

A review of the current literature identifies a range of clinical interventions aimed at fostering social inclusion for service users. Much of this work has been developed within the field of occupational therapy, and is therefore targeted at meaningful occupation and increased social activity and connections. Moreover, no examples of work in this field within Aotearoa New Zealand were identified as part of this current review.

One example of an initiative established to enhance levels of social inclusion for people with mental health problems is the Active Advice pilot project (91). Described as a "leisure enhancement initiative", the project sought to assist people to overcome barriers to leisure participation by identifying and connecting

them with others with similar interests. An evaluation of the pilot found that just under half of all participants were still engaged in their chosen leisure pursuit at follow-up. Barriers to uptake of the leisure activity included a lack of confidence or motivation, and a lack of a companion (the evaluators noted that some participants did not feel comfortable pursuing their leisure interest alone) (91).

Arts-based projects have been identified as having the potential to provide opportunities for inclusion (42,44,45,92), and to improve communications skills and the development of relationships with others (42,45). While there is evidence of a range of arts and creative projects established for service users, many of these are undertaken within mental health settings, with less evidence of support for people participating in mainstream activities (45,74). A project that adopted drama-based teaching methods to stimulate discussion and learning about mental illness, and aimed to promote social inclusion of people with mental health problems, involved college students and mental health service users working together to develop a theatre performance. An evaluation of the project found that there was a positive shift in students' attitudes towards mental health issues following involvement in the project. For service users, key impacts included: increased optimism and sense of achievement; feelings of inclusion and integration in the local community; increased confidence and empowerment; and, a sense of value. Several of the service users also went on to further creative activities following their involvement in the project (42).

Therapeutic horticulture has featured in a number of initiatives aimed at fostering social inclusion for mental health service users (93-95); while it has been reported that much

of the evidence regarding positive impacts is anecdotal in nature, horticulture may present a range of learning and other opportunities for mental health service users (93). These include motor skills, learning around horticultural techniques and opportunities for social interaction (93). For example, a horticultural allotment group established with people who had been referred to a mental health team was found to have a positive impact on participants' interpersonal interactions (94). Similarly, members of an inner-city allotment group reported that the opportunity to engage in activities outside of the home and to make new friends were two key aspects that they liked about the group. They also reported that it had helped their communication skills and self-confidence (95).

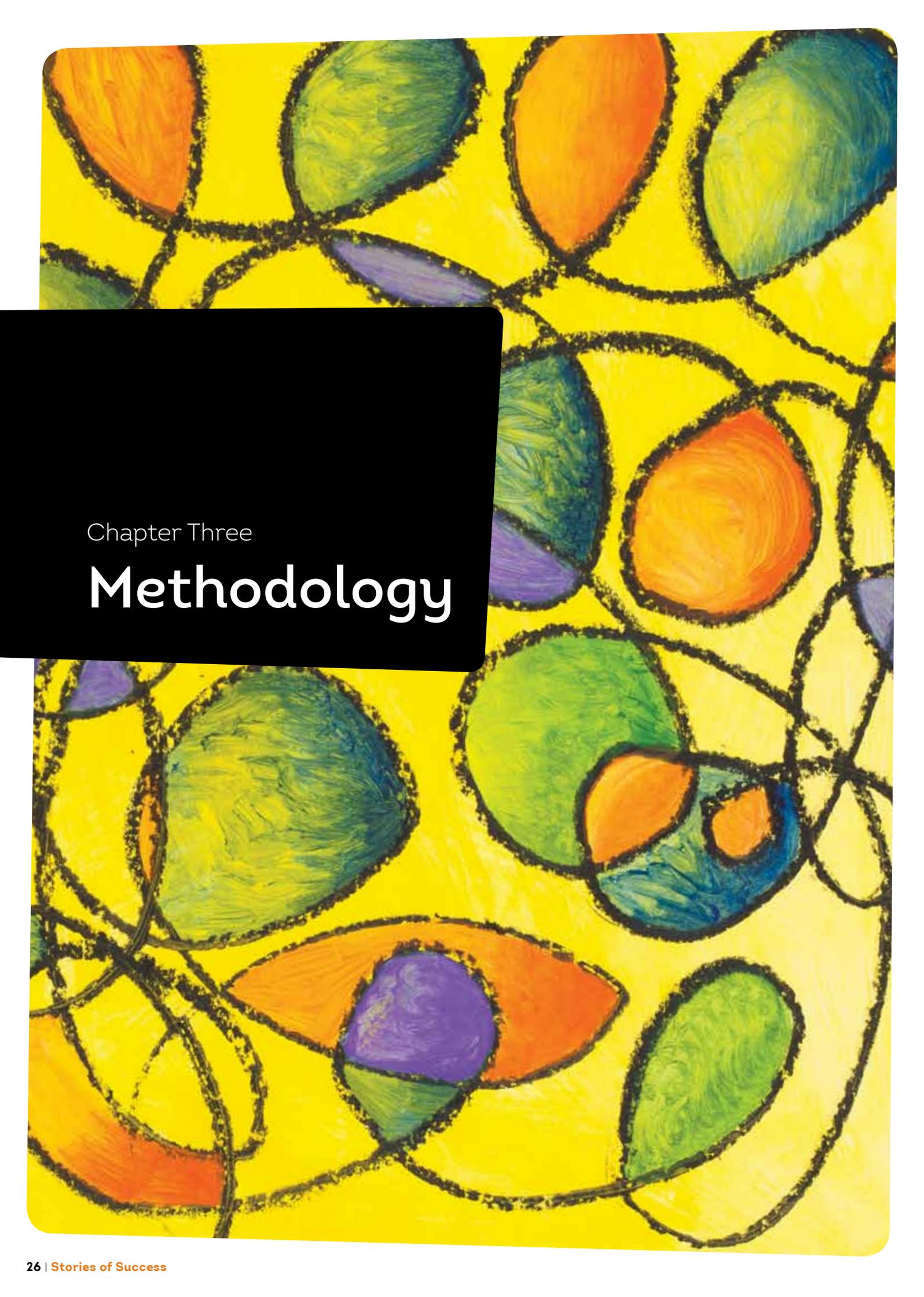
It is important to note that the robustness of some of the published intervention evaluations in this field has been questioned (81,93). Dorer et al (81) for example, claim that many evaluations are descriptive or anecdotal reports, due, in part, to a lack of suitable evaluation tools. Further, in evaluating these types of initiatives, Schneider and Bramley (74) highlight the need to consider the potential harm to other aspects of social inclusion (e.g. the provision of payments to service users may mean that they become dependent on benefits and result in unintended negative consequences). As highlighted previously, many of these interventions are designed to target one aspect of service users' lives, and may not take into account wider experiences of social inclusion or exclusion.

Summary

Much is known about the barriers to social inclusion (15,18) and how people with mental illness are treated unfairly and less favourably than others in society who face similar circumstances (29). Despite this, there is limited evidence in the area of social inclusion and mental health (69), and limited stories of success. Research to date has indicated that social inclusion is a multi-dimensional, subjective, and fluid construct, with an individual's sense of inclusion potentially varying across different time-points and contexts. Of note, less is known about the enablers to social inclusion, and what can facilitate people with a mental illness participating fully in society.

The following chapter will describe the research process undertaken to explore service users' experiences of successful social inclusion in Aotearoa New Zealand.



An abstract painting featuring a vibrant yellow background. Overlaid on this are several overlapping, teardrop-shaped forms in various colors: orange, green, blue, and purple. These shapes are outlined with thick, dark, textured strokes, giving the impression of leaves or petals. The overall style is expressive and colorful.

Chapter Three

Methodology

How the research was conducted

The following section briefly outlines the aims of the research and the methodology, and describes the methods employed for the data collection and data analysis. Demographic information and ethical aspects of the study are also presented.

The study's aim

The aim of this research study was to explore positive stories of social inclusion by people with a diagnosis of mental illness living in Aotearoa New Zealand. It was intended that the findings from this study will contribute to the robust body of research that underpins the strategic direction and objectives of the *Like Minds, Like Mine* research programme.

The study's methodology

One of the key philosophical debates in research is how to study people's experiences, beliefs and interpretations of their social world (96). To fully explore people's stories of social inclusion a qualitative approach was deemed appropriate.

The study's objectives

The objectives of the study were to:

- describe the external factors that support people's inclusion within society
- explore the internal factors that create a sense of social inclusion for people
- highlight the positive attitudes and behaviours, which participants encountered within their communities and government organisations, that fostered social inclusion
- determine implications and recommendations to inform the *Like Minds, Like Mine* strategic direction, objectives and research programme in the future.

Sample and recruitment

The first source of data was collected from 16 people who were recruited to take part in individual interviews as key informants. These key informants were people who held leadership positions, such as consumer advisors, peer support workers, managers and academics. They were purposively recruited because of their potential to share their own positive stories of inclusion, their role in fostering social inclusion, and their ability to share stories of success of other service users that they had worked with.

Each person was contacted (in person, by email or by phone) by an intermediary from the research reference group and invited to take part in the research. The interviews were conducted in people's homes or their workplaces in the greater Auckland and Wellington region and lasted for approximately 60 minutes. On completion of the individual interviews, we invited the key informants to recommend people who could help us recruit participants for the focus groups.

The second source of data was collected from people who participated in four focus groups. These participants were recruited because they had more recent involvement with mental health services. Participants were recruited using the following inclusion criteria: 18 to 65 years of age; have a diagnosis of mental illness; have received care in secondary mental health services; and are living in the community setting. Participants were not included if they were currently acutely unwell.

Two focus groups were convened with Māori, one in Auckland and one in Northland, one focus group with Pasifika in Auckland, and one focus group with young adults in Wellington. The duration of the focus group was approximately two hours.

Ethics approval was granted by The University of Auckland Human Ethics Committee (reference number 2012/8812) (Appendix A). Issues of informed consent and confidentiality (Appendices B and C) for the participants and their data were paramount. The individual participants were invited to choose a pseudonym at the beginning of the interviews; some opted for the researcher to choose the pseudonym, while a small number chose to use their real names. Due to the larger numbers of participants in the focus group we did not allocate individual pseudonyms. All participants were fully informed (Appendices D and E) and knowledgeable about the study, its confidentiality, risks and benefits, and storage of their data, and signed consent forms before the individual interviews and focus groups were undertaken. The geographical locations were chosen for practical reasons given the time frame for completion of the study. Thus the findings do not represent the experiences of those living in rural areas.

Demographics

Table 2: Key informants (n=16)

CHARACTERISTIC	NUMBER
Age (years)	
17	0
18-20	0
21-29	1
30-39	1
40-49	6
50-59	5
60-65	2
65+	1
Ethnicity¹²	
New Zealand European	12
New Zealand Māori	4
Pacific Islander	1
Other	1
Gender	
Male	4
Female	12

At the time of the research, most participants were employed in the mental health sector (in district health boards or non-government organisations), or were working for training providers or universities. A couple of participants were self-employed.

¹² Some participants identified with more than one ethnicity. One participant identified as Australian Aboriginal and pākehā.

Table 3: Young adult focus group (n=10)

CHARACTERISTIC	NUMBER
Age (years)	
17	1
18-20	3
21-29	6
30-39	0
40-49	0
50-59	0
60-65	0
65+	0
Ethnicity¹³	
New Zealand European	10
New Zealand Māori	0
Pacific Islander	0
Other	0
Gender	
Male	1
Female	9

Table 4: Pasifika focus group (n=9)

CHARACTERISTIC	NUMBER
Age (years)	
17	0
18-20	0
21-29	4
30-39	1
40-49	2
50-59	1
60-65	0
65+	0
Ethnicity	
New Zealand European	10
New Zealand Māori	0
Pacific Islander ¹⁴	0
Other	0
Unknown	1
Gender	
Male	6
Female	3



¹³ All participants who self-selected for the young adults group were New Zealand European.

¹⁴ One participant identified as Fijian, one identified as Tokelauan and one identified as Cook Islander.

Table 5: Māori focus group – Northland (n=7)

CHARACTERISTIC	NUMBER
Age (years)	
17	0
18-20	0
21-29	0
30-39	3
40-49	3
50-59	1
60-65	0
65+	0
Ethnicity¹⁵	
New Zealand European	2
New Zealand Māori	7
Pacific Islander	0
Other ¹⁶	3
Gender	
Male	4
Female	3

Table 6: Māori focus group – Auckland (n=11)

CHARACTERISTIC	NUMBER
Age (years)	
17	0
18-20	0
21-29	1
30-39	4
40-49	5
50-59	1
60-65	0
65+	0
Ethnicity¹⁷	
New Zealand European	1
New Zealand Māori	11
Pacific Islander ¹⁸	1
Other ¹⁹	1
Gender	
Male	8
Female	3



¹⁵ Some participants identified with more than one ethnicity.

¹⁶ Two participants identified as Australian and one as French.

¹⁷ Some participants identified with more than one ethnicity.

¹⁸ One participant identified as Cook Islander, Rarotongan and Dfulaki (Pasifika sub-tribe or village).

¹⁹ One participant identified as Indian.

Table 7: Total sample (n=53)

CHARACTERISTIC	NUMBER
Age (years)	
17	1
18-20	3
21-29	12
30-39	9
40-49	16
50-59	8
60-65	2
65+	1
Ethnicity	
New Zealand European	26
New Zealand Māori	22
Pacific Islander	9
Other	
Unknown	1
Gender	
Male	23
Female	30

Data collection

In order to answer the research question, a semi-structured question format was developed to guide the individual and focus group interviews. The interviewers asked questions that logically progressed from a general to a specific discussion, allowing flexibility for clarification and probing, and to create safety for participants to answer specific questions. All participants were sent a copy of the interview schedule prior to the interview, which assisted in warming-up them up to the topic (see text box below). The final question was prompted by participants' feedback during the data collection phase.

Interview questions

- What is your understanding (or definition) of social inclusion?
- Can you tell me how other people and/or situations that you encounter in your daily life have fostered your sense of social inclusion?
- How have such experiences created a personal or internal sense of inclusion and belonging in society?
- Can you describe encounters or situation/s in your daily life where you have fostered the social inclusion of other service users?
- Now that we have discussed at length your idea or definition of social inclusion, how might the future look?

Data analysis

A thematic analysis (97) was used to manage the data. This approach provided a systematic set of procedures for analysing and interpreting qualitative data in order to produce reliable and valid findings (98). Multiple readings of the transcripts by the research team, followed by several team meetings, enabled the identification of themes within the data.

The rigour of the study was ensured by a number of tasks, such as transcribing and sending participants a copy of the content of their interview. Member-checks were also undertaken with the participants to assist with the accuracy of the interpretations emerging from the analysis. This consisted of sending a brief overview of the key points from the initial findings to all participants via an email. One of the individual participants responded to say, “The themes are great! I think the process you guys are using in this research is awesome, and by far the most ‘inclusive’ research I have ever participated in...that makes it easy and safe for me to participate and feel valued”. This process increased the sense of reciprocity between the participants and the researchers, to enable a mutual construction of their stories.

Rigour was further ensured by the involvement of service-user researchers on the research team who took part in the data collection and analysis, interpreting the findings and writing the final report. We also conducted peer debriefing within the research team and had discussions with the kaumātua from the reference group. The research team also had an opportunity to further test the validity of the findings by presenting the data and emerging themes at the annual *Like Minds, Like Mine* seminar in Auckland, in May 2013.

The reference group

A research reference group was assembled to offer suggestions about the research process, data analysis and preparation of the final report. Due to the timeline of the research, the group was assembled after the design of the study was established and data analysis was underway. Membership of the group and its terms of reference can be found in Appendix F.

Summary

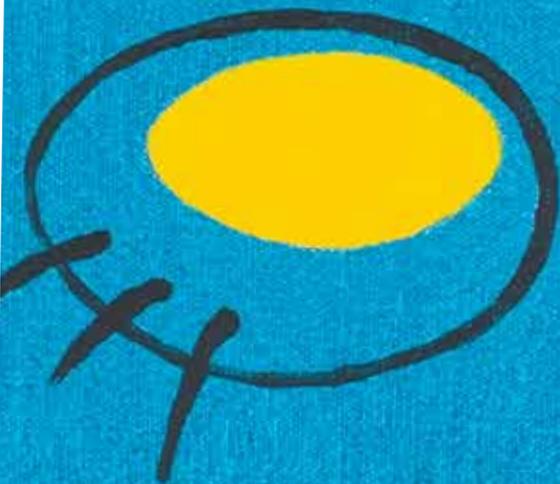
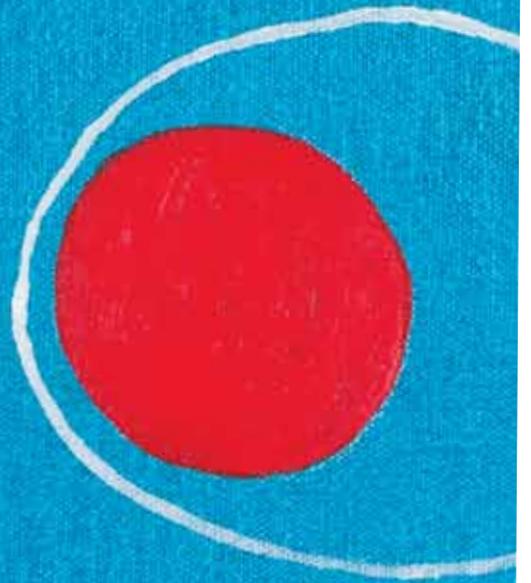
This section has briefly outlined the aims of the research and its methodology, and described the methods used for data collection and analysis, and the ethical aspects of the research study. Demographic information of the participants has also been presented.

The following chapter will present the research findings.



Chapter Four

Research findings



This chapter presents the research findings. It is divided into five parts, each devoted to one of the five interview questions. A description of each theme, with examples from the data, is presented within each part of the chapter.

The reader will also find a small number of vignettes within the sections. Each of these represents a synopsis of the individual's story of success, derived from their complete narrative, which could not be captured in the participant's data quotes. The vignettes were constructed by the service user researchers on the team, in conjunction with the participants.

Part 1: Defining social inclusion

The literature review on social inclusion clearly points to the concern that the terms social inclusion and social exclusion are poorly defined and understood. Therefore, it was important to hear what the participants' understanding of social inclusion was. In response to this first question, along with a number of other participants, Teresa, Debbie and Shelley explained that they could not begin to define their understanding of social inclusion without first talking about their understanding and experiences of social exclusion:

Social inclusion it's... You know I can't think about my own experience without it being a journey really, from exclusion to inclusion... you can't separate it out.

People come together in lots of different ways to share their experiences and attempt to, I think, heal and feel included and heal their feelings of exclusion, which have happened because of various experiences. (Teresa)

.....

I suppose when I think of social inclusion I do think of exclusion... And I think it's about you're either included or you're not. You can face discrimination and still be included and stuff. So there's this dichotomy within social inclusion which isn't there so much in discrimination. (Debbie)

.....

I guess conversely, inclusion always... it is also is a feeling of not being excluded. Because I think you sense exclusion a lot more than inclusion, I think that's a stronger feeling. (Shelley)

.....

The idea that moving from exclusion to inclusion is a journey was put forward by a number of participants. Some described having many years of experience of being socially excluded and discriminated against, and that transitioning to a place whereby they felt included required a shift in their understanding of the term social inclusion. Even though participants were familiar with the term social inclusion, they had not often given much thought as to how they might define it. On reflection, some participants described a variation between the accepted terms and their own understanding:

My perception of social inclusion, I thought perhaps I should look that up and I thought no that probably defeats the purpose because that's not necessarily my perception of it or my understanding... I've probably in some ways gone against some of those preconceptions anyway, because I've just assumed I had a right. (Reina)



When I saw 'social inclusion', straight away I thought 'I better Google it in case my interpretation is wrong'... It's really interesting because I actually thought 'Am I being negative?', but I saw it more from the term of social exclusion as opposed to social inclusion... I thought 'Oh, it's quite a negative word even as a positive word, social inclusion'. It really does stand people outside and it sits really funny with me. Because it says 'We have to do this because of who you are and not because you deserve it', or anything. Yeah. (Mercedes)



Both Reina and Mercedes questioned the standard definition of social inclusion, and had concerns that current definitions could imply that there are some pre-conceived ideas of who is socially included, or that the term can imply that there is an obligation on society to include others, rather than inclusion being a basic right. Debbie further supported this perspective:

I think inclusion is about power and I think it's about whether society has the power to include or exclude or whether the person with mental illness has the power to decide whether to be a part of that society or not. (Debbie)



Teresa also suggested that social inclusion need not be viewed as a fixed state of being:

The 'journey' of inclusion can be helped or hindered by a range of things, such as support and trust, opportunity for and access to education and information etc. I think some people work towards this... I think it's a really important part of inclusion... not just what it 'feels like' to be included but that it is not a 'static' feeling and can be very determined by the attitudes and opportunities we bump up against. (Teresa)



It appears that social inclusion is not perceived as a fixed state, rather, inclusion is a fluid experience that is determined by the attitudes and the opportunities made possible for participants within their everyday world. Fully participating in society was also part of the participants' understanding and definition of social inclusion.

Participation

For many participants, fully participating in society defined their sense of being socially included. For example, having full access to the same rights and privileges as others, without barriers, was important:

My perception of social inclusion is that, as an individual who is socially included that you have the ability to participate in everything else that anybody else in society would participate in, and that would be obviously in an overt way, because obviously people wouldn't necessarily know your experiences. Therefore they would treat you as not having what would be perceived as a social excluded identity or label. (Reina)



Total acceptance in society... So you're not just tolerated but you're embraced. It means just taking part in society without barriers really. (Jane)

.....

Really for me it's about that participation, not only participation by the individual but an acceptance by others of that participation. So you're not defined as the other but you are part and parcel of whatever is going on. (Dani)

.....

However, Dani further explained that for people who have addiction problems²⁰, participation can be curtailed when there are barriers, for example, due to their methadone treatment:

Someone rings on a Saturday morning and says, 'We're going out fishing for the day, do you want to come?' 'Oh I'd love to, I can't.' 'Why?' 'I've got to go to the chemist: it's only open between 9 and 12; can we go fishing at 2?' And you're only going to say that to someone you know and trust. Otherwise you are only going to be making up excuses all the time. Which is another irony because you having to lie a lot about why you can't do things. Wow. It's the ultimate surveillance kind of thing isn't it? It really, really is, that whole sense of monitoring, and people having to police their own behaviour, and the scheduling. You can't just have this free approach to whatever you do. (Dani)

.....

Dani suggested that some types of treatment can place restrictions on people's participation in society and therefore can be exclusionary.

Rights

Participants reported that when a person is able to fully participate in society then this increases their opportunities to have the same access and privileges as others:

For me, you know, the fundamental has been about the ability to enjoy the same opportunities as others in the community and society. Such as having access to education, housing and employment, and really importantly, the ability to access good healthcare and other supports that contribute to one's wellbeing. The real important thing is... employment, as the ability to be able to afford the things that are essential. (Agent A)

.....

It was reported that when participants felt that they had the same social, as well as civil and political rights as others, it increased their sense of inclusion. Being treated like everyone else maintained a person's status as an equal:

I was brought up thinking I've got a right to be here, I've got a right to say the things I think are true... I think the whole issue of that drop of status you get as you cross that threshold into psychiatric patient-hood; I think the whole thing eats into you. (Mary)

.....

Inclusion means to be part of something, to be connected with other people, in an equitable way I think. Right, so there's equality in inclusion. There's a right to be there, and a valuing; like you have a place there. (Shelley)

.....

²⁰ Some participants spoke about addiction issues associated with social inclusion and mental illness.

Identity

As well as having rights and status, social inclusion was also understood as being recognised as having an identity beyond that of being exclusively a service user:

I've thought a lot about how I would define social inclusion... Well on quite a few different levels, how I feel about where I am, that's kind of one level I suppose, or the group. How I feel about my place in the world. How I fit in it. The identity and the roles, the kind of roles that I have and what my roles are. (Teresa)

.....

What makes me feel important is because of my family background, my identity as a New Zealand Māori and the coming of our ancestors because I'm a descendant, that's something important about me, because I come off important ancestors... another thing that's important about me too it is all to do with family history... really my breakdown is when I lose someone in my family, like a close father or a brother or a sister, because that's why I'm important, because I'm important to my family and I'm important to my husband now. (Māori focus group)

.....

The older wahine Māori in the focus group above makes an important statement, not only about how her identity is shaped by her cultural heritage; she also described how her mental illness is strongly associated with her grief at the loss of the important connections with members of her current and past whānau, hapu and iwi²¹.

Frank also saw identity as being an important aspect of social inclusion:

This sense that social inclusion provides the recognition of who you are and where you come from, and therefore, having an identity. (Frank)

.....

Belonging

Social inclusion was understood to be about feeling that you belong to a range of groups within society, not just the sense of belonging to others who have a mental illness:

Social inclusion is also linked strongly to the sense of belonging... so I suppose a common definition would be feeling that you belong to society, that you're accepted by society, that you're valued, that you're respected and so on. (Frank)

.....

For Frank, being accepted and valued fostered a sense of belonging. Shelley also noted that being recognised as having the same experiences as others in society was an important aspect of social inclusion:

Social inclusion is subtle, if you're included, you're listened to, and you're heard. You contribute to whatever it is you are included in, and there is a sense of purpose about being within whatever it is. Like, you know, when you've just had a baby, and all of a sudden it's like, you may not think about this but... honestly it's weird, it's like you've suddenly joined this club, and strange women will talk to you about labour and babies! (Shelley)

.....

²¹ Whānau: extended family, family group, a familiar term of address to a number of people. Hapu: kinship group, clan, tribe, sub-tribe, section of a large kinship group. Iwi: extended kinship group, tribe, nation, people, and race; often refers to a large group of people descended from a common ancestor (see: <http://www.maoridictionary.co.nz>).

When Shelley was pregnant, her identity changed to that of mother and she felt included by other women through the shared language and everyday conversations that mothers have. This story of success was initially a surprise to Shelley, as she was used to maintaining her vigilance towards the rejections and social distancing that she had previously experienced.

A number of participants reported that social inclusion was understood as feeling valued through others' hospitality and sense of welcoming:

Social inclusion is simply where everyone in society feels welcome in public spaces and they feel welcome in communities. (Graham)

Such hospitality was seen to be an important part of social inclusion and sustained by the development and maintenance of social relationships that encompass respect and valuing of each other. By participating and feeling that they belonged, opportunities arose for some participants to make a contribution to society:

I get the opportunity to contribute to the greater good, now things that are about making this world a better place for people are the higher ideals that I aspire to, and I get a huge amount of satisfaction and reward from having the opportunity to do that. (Agent A)

Reciprocity and mutuality

For the majority of the participants social inclusion was also understood as "I give to you, you give to me" (Jane) and the mutuality of support and friendship.

I find that social inclusion to me means genuine kind of caring towards others... So my friendships... they actually really care about my week, they really care about how I'm doing whether it be my mental health, but actually, just in general... They will be real with me... I find it really good to have those relationships around me actually. I feel like we're actually both investing in each other's lives. (Young adult focus group)

So the people that I have in my life are the type of people that I pick and choose carefully and they come with the concept of reciprocity. Otherwise I just don't have them in my life, you know. That's taking back the control. (Agent A)

A number of participants explained that, contrary to the assumptions that others in society make about people who have mental illness, service users have a great deal to contribute to their communities. When participants discussed their reciprocal relationships with others in their community, this increased their sense of connection and commitment to the common good, and a sense of satisfaction and pride in their ability to be able to give back to their communities. This generated an increased sense of acceptance and belonging with others. Shelley suggested that not being able to give back to others can be exclusive:

You know a really good way of excluding people is to only give to them, to not let them give back, it's that reciprocity, that everybody brings something of value and you kind of share it, that there's... a flow between, whereas exclusion means that the gate is shut, and there's no flow. (Shelley)

Being able to give back to your community increased the participants' sense of being accepted as contributing members of society. Shelley suggested that the term social inclusion is "synonymous with acceptance". Likewise, Jane described what inclusion and acceptance meant to her:

[On a fishing trip] just the way we were treated, they didn't have to say anything. It was just the way we were treated. You know sometimes it's about not focusing on disability and all that was the issue. Just treat me like you're just one of the other customers going on and treat me with the same respect they would treat a non-disabled customer and that was the difference. It was good. (Jane)

.....

Part 2: The external factors that foster social inclusion

Participants reported that external factors were important for social inclusion, and that these actions and gestures led to them feeling that they were part of the community, and that they had a shared understanding and a commonality of experiences with others. The four main areas where this occurred were within family and friends, with other people in their communities, with their peers and with mental health professionals.



Family and friends

A number of the stories of success in relation to social inclusion involved the participants' family and friends. For example, during an episode of mental illness David spoke to his employer about having some time off; however, his employer was not helpful and David felt alienated and excluded. When he could no longer keep working, David expected that he would end up in full-time care in a mental health acute unit. His ex-wife, however, stepped in:

My ex-wife looked after me, she said, 'You're not going into hospital'. Because I was living on my own, 'You are going to be looked after by me. You are too good for hospital'... She got in touch with the DHB²², they did amazing stuff and my ex-wife gave up a year's work. That's my ex-wife. In fact we're still married. Still live together. So she looked after me, so she believed that had my employers been more responsible, I may not have got so unwell. (David)

David was emotionally moved when he recounted the above story of success. His ex-wife's gesture of care and compassion created an inclusionary place where he could be cared for while he recovered from his depression.

Johnny suggested that when mental health services keep the focus on including family this fosters his sense of inclusion:

I've learnt that each time I walk through that door [of the acute mental health unit] I'm leaving my family behind, but my security is with my babies. I need my babies with me. So each time I'm walking there I feel like I'm

getting further and further away from them. The knowledge that I'm picking up, I'm learning this without them, and we're not connecting. That is causing a lot of distress because we're a family that can't love each other if we don't know the thinking that the other one has been through... The challenge is for the services to walk to me. (Johnny)

Holly believed that by being open about her experience of mental illness with people she can trust is a form of normalising. Being open increases others' belief that being different is okay and creates a greater acceptance of people with mental illness. Holly felt socially included through her new relationship:

When I first disclosed to my husband when we were dating... I just kind of put a little bit of information out there and he was just like, 'Oh okay'. It was as if I'd just said I'm going to go to the park... I was really worried that knowing I had a history of mental health problems, that maybe my husband's family would get weird about it and they wouldn't want me around the kids or something and that's never, ever, been an issue. (Holly)

When Holly took the step to tell her husband-to-be and his family, their responses were such that she felt fully included by them. Participants' reported that when they disclosed and the response was supportive and inclusive, then this increased their confidence to keep disclosing.

²² District health board.

Community

A young adult in the focus group gave an example of how a situation in a community setting increased their sense of social inclusion. As can be observed from the excerpt below, this involved connecting with people outside of her mental health networks:

I think you can also get quite a lot of social inclusion from groups that aren't necessarily mental health related... like if you're accepted by this other group that might not be aware of mental illness or have personal experiences, then it's kind of a step back towards the normal life I guess... I've just joined a [craft group] which is basically a bunch of old ladies who do knitting and spinning and things and I find it's been really fantastic. You kind of really feel part of something bigger than yourself. This is something that women have been doing for centuries. They don't know about my mental health status or anything and it's not something that I'm probably going to bring up, but it's still kind of an inclusion. (Young adult focus group)

This example prompted discussion within the group about their sense that society has become "split up" and that keeping the intergenerational links such as "wise granddad-young teenager" was important as this further supports the reciprocity and mutuality between people:

Yeah they were so excited to see a young person. They were like, 'Oh there's so much we can teach you'. I was doing some kind of more creative interpretive stuff and they were like, 'Oh I want to try that'. It was definitely going both ways... It can break down barriers. (Young adult focus group)

For two men in the Māori focus group, their sense of being included was increased by their spiritual and cultural connections within their communities:

At the Salvation Army, they're beautiful people, eh? The first time I was there, 'Come in, come in, and meet everybody. Come down for a cup of tea'. I didn't know anyone there but now I go there and I sing and pray. And we're one big family, and here even with the nurses. And spiritually, the Bible is my strength, so all I've got to do is just quote the Bible. (Māori focus group)

The elders [kaumātua] in Māoridom they look at you as a good citizen. They don't say anything; they just give you a nod and look you in the eye. They know what we are up against from around the rest of the world, [and] they know that we struggle in the neighbourhood... [Kaumātua] seem to be like body-guards in a way. (Māori focus group)

Teresa explained that once she and her husband got a job within their local community this increased her sense of inclusion:

I kind of separate out the inclusion that I feel within my work in mental health, I kind of want to say it's not the real community; it's not the real world. It's the mental health world... I've moved towards my own kind of community... and we got a cleaning contract to clean the school. My husband runs a little coffee machine out in [suburb], so we're quite kind of important really. To the local community, we're the school cleaners, 'Oh yeah there's the cleaners, 'Hi cleaners. [It's] Feeling included and being included. (Teresa)

Teresa further explained that she also had regular contact with a local community member who is now a friend. She suggested that her Facebook page is also a space where she can post information about mental illness to increase people's understanding. These mutual actions that deepen participants' social networks serve to further normalise the experiences of mental illness, particularly where there is a focus on a common interest.

Other participants' stories of success that occurred within their community were associated with being in high school or a tertiary education setting. In the following example, Holly described how her thesis research supervisor responded to her disclosure that she has had an eating disorder:

I was really nervous... I was kind of like, 'I just think that you should know that I've had an eating disorder' and he was like 'I know because I've seen your application for the programme, because you have to disclose.' I guess just him clarifying that was kind of a signal, 'Oh this is okay,' and I didn't need to go into it anymore. Yeah, but it was that feeling that I can come back to this. Like, I guess he didn't cut the topic off and he didn't kind of go all quiet, and he said, 'But thank you for letting me know.' And I think when people acknowledge that it's been difficult, and I've had that a few times when I've had to talk to employers, where they've just said, 'Okay, thanks.' (Holly)

.....

At [alternative school] like they're very focused on kind of group participation and kind of getting people to contribute even when they're feeling crap and the kind of sharing of you know, mutual experiences. It kind of makes you feel a lot more socially connected. That's what I found before, I was like totally isolated and no one understood. Then I went into this school and now I'm just like yeah, there are some people out there who do get it. You know? And that really fostered a sense of belonging, you know? I think it's really important to feel like you belong, otherwise you just feel like what's the point. (Young adult focus group)

.....

When the participants' disclosure of their experience of mental illness was met with a supportive and understanding response then this increased their sense of social inclusion. Holly explained that the "gentleness" in the way people reacted opened the door to keep talking about the experiences as necessary, and that people are willing to support you.

Relationships with professionals

Meaningful relationships with professionals in health and education settings also increased participants' sense of inclusion. Several participants explained that it was having a significant conversation that facilitated their sense of social inclusion:

Well I remember my counsellor saying to me 'Dani, you can stay outside the boat and get wet or you can get in the boat and actually shake it up. The choice is yours.' You know, and that again stuck with me because here I was learning Marxist theory and you know Foucault and thinking actually if I stayed out here [on the margins] no one is going to listen to me. So there was always that sense of social justice and wanting to kind of do the right thing... By being outside it was much difficult to be heard. That was the thing about getting into university, getting the education, being able to articulate those arguments. (Dani)

.....

And finding the champions who supported me I think I've found one who is an important one. Social justice! We talk about poverty, we talk about the disadvantage of certain areas and the champion totally gets it... and it was really cool because we had some conversations and it makes me feel... That I and they have influence, then they have the ability to support me when I start asking questions and they have a level of mana²³ within this organisation... I'm not a lone voice. (Reina)

.....

It was lovely, it felt fantastic. I think I really realised that at my poroporoaki²⁴ when a number of people stood up and spoke. I thought actually they have really included me and my manager said, 'Look, I'd like to keep in contact with you.' (Nina)

.....

A number of participants described the relationships and conversations with health professionals that made them feel safe and validated, which increased their sense of inclusion:

The social worker... It felt inclusionary... he put my sense of self back together a bit, he was incredibly kind, and he said things like 'I can hear that you're in a lot of pain, and that you're struggling a bit'. And all of a sudden I was a person again. He heard me, he'd seen my soul... he not only saw the distress and the mess, but he saw my strength with it... And he validated that... Such a relief... it feels valued and safe, it's not being judged harshly. (Shelley)

.....



²³ Mana: prestige, authority, control, power, influence, status, spiritual power or charisma (see: <http://www.maoridictionary.co.nz>).

²⁴ Poroporoaki: to take leave of, to farewell (see: <http://www.maoridictionary.co.nz>).

Sometimes social inclusion doesn't have to be named or articulated, you know it when it's there. I've got a new psychiatrist... he's not of New Zealand nationality, we have stimulating discussions about various concepts... And he said, 'Why is it that when someone is distressed we don't just go, "oh it's really hard" and hold that person?'. I remember at one point, he leant over and kind of rubbed my arm and he said, 'Now I shouldn't have done that should I?' and I went 'Yes, you should have.' You know, it's kind of a freedom to be a human [and] caring without some sort of fear of overt censure because of inappropriateness, you know, 'this is okay.'
(Penny)

.....

Penny explained that when her psychiatrist showed his "human" side she experienced increased trust in him and felt the human connection. Penny believed that such engaging and meaningful conversations that are not focused solely on her mental illness increase her internal sense of social inclusion. A younger woman and older man in the Pasifika group also described how their relationship with a social worker and a peer support worker helped them become more involved and participating in their community:

For example, my social worker takes me to the exercise. Like Zumba, or walking. I wake up in the morning and I walk around with my friend. I go to Zumba because my dream is to lose weight. I want my future and my life to start.
(Pasifika focus group)

.....

It's very important, the support worker or a social worker too. They give love and kindness to us. So do the priests and the nuns, the reverend, and the church. Yes and my neighbours... love your neighbour as yourself.
(Pasifika focus group)

.....

Peers

Participants reported that having relationships and conversations with people who are non-judgmental and validating creates safety and therefore increased their sense of inclusion. An older man in the Pasifika group described how community peer groups have helped him feel included:

I feel included when I attend community groups and connect with other peers and it has helped me connect to my culture, my hobbies and interests. I participated in the literacy programme and I wrote a little story about myself and I have participated in the music group. I am connected in that way because I have a lot of opportunities to socialise. I am not isolated.
(Pasifika focus group)

.....

In the follow example, members of the Māori focus groups described how being with their peers has increased their sense of social inclusion:



My peer group has become my family because my family still have their stigmas and labels around me and find it hard to accept... we do things together like a family would here. So I know I belong here. I've got my counsellor and my psych[iatrist]. I know when I come here I can be me, and being accepted. Even though I am a bit different, because I get treated as an equal, I don't get looked down on or spoken down to and that's just helped me grow so much and helped me be a better person, a better mother and just have a better life, because I feel okay at being me... I know that if I come here I feel safe and I feel safe with the people and that's a huge thing. (Māori focus group)



Yeah because in a religious status, we're all spiritual brothers, having spiritual experiences. And our sisters, yeah! Our wairua is our spiritual thinking in the spirit world, and our tinana is our physical body in the physical world, and we are bonded to that every day, kia ora. (Māori focus group)



The above participants in the Māori and Pasifika focus groups explained that being with your peers in the first instance helped to generate the social connection and the confidence to move out into the community. They regarded the group as a place where they can share their experiences, feel safe and accepted, and not hide their difference, which in turn decreased their internal stigma.

David – a powerful experience of social inclusion

David talked about having good friends who had supported him, and listened to him without trying to solve things during difficult periods. He described how some friends, however, who were quite social, would ask him along to events, but David often turned down these invitations. He was then told that he could lose these friends if he did not take up their offers to socialise on a regular basis.

David shared one of the most powerful experiences for him, about two specific friends of his whom he describes as “garden variety kiwis” who didn’t have any special knowledge about mental illness, yet could understand what David was going through. They acknowledged what his other friends had said and responded by saying to him “We won’t stop asking you”. David emotionally described how powerful those few words were to him; they made him feel like he mattered. He knew that their caring came from their heart and “it just turns me into tears”. David has recently stopped cancelling things and says these two friends are some of the most treasured people in his life; he invites them to dinner and is actively involved in their families in a supportive way.

Nina – being in control of her own life

A survivor of childhood trauma, which had ongoing negative effects on her mental health for many years, Nina tended to keep her past hidden knowing she would experience negative responses from people and be treated differently. Nina struggled with relationships, study and employment as a young adult, but over time and with self-reflection and support, emerged a stronger and, she believes, more tolerant person due to her experiences. In her mid-30s she completed a tertiary certificate in adult education and found employment in the mental health sector. Employment gave her a sense of purpose and value. Open about her experiences, first by choice and then in a designated “consumer” role, she acquired respect and acceptance from her co-workers. This was not an automatic reaction, rather gained over time through her commitment and her competency in the role. She struggled with identity issues. Was she a service user or was she really no different to anyone else? It was a dilemma: due to the profound effect trauma and the consequent diagnoses had on her, it was hard to deny or discount her experiences as they had shaped the person and the life she had created for herself; but they did not define her whole life.

Nina reached a point where she felt she had succeeded in merging all the various aspects of her life and her personality, allowing her to be content with who she was and able to acknowledge and reflect on her own achievements. She no longer wore a mantle of shame associated with having a diagnosis and continued to progress in her chosen field. Open in the workplace about her diagnoses, she was conscious that some of her health professional co-workers and managers were at times unsure whether she was a colleague or more of a potential patient. She came to realise that she was not responsible for others’ opinions; she could only be responsible for how she conducted herself.

Employment proved to be pivotal in liberating her from diagnostic labels and in gaining a strong sense of who she was as an individual. She was no longer confined to the stereotypical ideas of what it was to be a service user, such as having problems seeking employment and not being in control of her own life, when in fact, her life experiences enabled her to contribute in significant ways to society. Through her work she has found financial stability, career choices, personal and professional satisfaction, and lasting friendships. Her involvement within the community, both socially and professionally, has provided a welcome outlet to build a stable network of support, and given her the confidence to pursue creative endeavours.



Part 3: The internal sense of social inclusion

This section presents the participants' experiences of their personal or internal sense of social inclusion. Many participants described their internal experiences as a two-stage process: the *before*, an internal shift or sense that inclusion is possible, and the *after* and what it feels like to be socially included.

The *before* stage appeared to be linked to the definition of self-stigma reported in the *Fighting Shadows: Self-Stigma and Mental Illness* report (10), where it is described as the process of experiencing a degree of inferiority and remaining secret about having a mental illness. This can also be described as a sense of hyper-vigilance, in order to reduce the impact of the distressing experiences of social exclusion.

Identity

Many of the participants suggested that the *before* stage also related to a process of moving beyond a sense of living on the margins of their

communities, feeling isolated and excluded. For example, Graham explained that his exclusion was linked to his entire identity being defined by others' perceptions of "mad" and "crazy". Graham's shift from this *before* stage occurred when he had a conversation with his friend who talked about his process of moving away from the self-stigma of being a gay man:

He was talking about how there is a model for gay identity that can kind of be applied [to inclusion]... Your first stage is confusion... Then suddenly everything is about that experience of yours. You define yourself entirely by that and I've so been there. I defined everything in terms of not only am I mad but I thought about madness differently to the way that the system suggests I should. Now the final stage is synthesis where it just becomes one other thing about me, I feel I'm moving there but I keep coming up against situations in which society doesn't like that fact, so it's like for society there's only two options: 'you're crazy' and you talk about it... Or you're sane. And then you

move through to a sort of acceptance and you get to this point where it's like pride you know? (Graham)

.....

Graham's suggested framework begins with confusion and isolation. From there, he developed ways of thinking about his "madness" that were not necessarily consistent with the way the mental health system viewed it. Finally, he developed an image of himself where madness was one facet of his whole person. Importantly, although Graham notes that he still experiences situations where he is not accepted by society, his self-acceptance is not challenged by this.

A participant in the Māori focus group described the spiritual conflict associated with having a mental illness:

I was an outgoing and cheerful person, and then about 6 years ago I started getting spiritually attacked by the voices. I deal with that all day and half the night. I developed the strategy of internal thinking; of strengthening myself. I've developed this strategy of manipulating these voices into positive aspects and strategies of positive morale hygiene, thoughts and desires... So I don't see myself as a mental person. I see society being mental themselves, and as an invalid, by their prejudice judgments based on me. (Māori focus group)

.....

The prejudicial judgements of others in society had a profound impact on his spirituality and his inner defences to deal with the stigma and discrimination from others. His strong sense of spirituality was restored once he was able to develop a more positive and validating sense of self, while at the same time externalising the invalidating messages held by society about people with mental illness.

The power of the external factors discussed previously, increased the internal sense of social inclusion for many participants. Dani explained that her sense of separateness declined once she was encouraged to engage with others in the community:

Once you get talking to people, people are just people... and engaging with other people outside the drug and treatment culture was another catalyst for realising that actually I don't have to feel this separateness. (Dani)

.....

For many participants, moving from the stage of exclusion and separateness to developing a stronger internal sense of inclusion happened when they felt they were able to express the different parts of themselves:

So inclusion has to include the total me, including the 'me' who busks on the street, it's also the 'me' who writes... So those things people are quite attracted to but the other part of me, the diagnosed part of me, people are still wary of. (Penny)

.....

Having to deny your true self, playing the part, seeking approval from others, driven by depression and anxiety, the need to be liked, to be included created a number of different persona[s] which is impossible to maintain. Learning to accept yourself is paramount especially when trying to cultivate and sustain meaningful relationships. (Frank)

.....

The after stage: the feeling of being valued

Some participants explained that the *after* stage was concerned with the feeling of being valued and was a significant indicator of social inclusion through making connections with other people:

It's amazingly powerful. I think that feeling that you matter to somebody. It's not ego, you feel like you matter, that you have some importance. You can do something. You can contribute. (David)

.....

When others are saying 'We value your humanity, we value what you're saying, we know what you are saying is of great relevance and importance to you'... it means that they were present for you. (Penny)

.....

Being valued by others restores an internal sense of power and self-importance and this positive self-regard increases the person's momentum towards the *after* or *action* stage of being socially included.

Having the right to be included

Holding the belief that you have a right to be included, and are therefore entitled to participate more fully in society is important for social inclusion:

I feel I have a right. Feeling like I have the right changes the external influences on me. No one is better than me. (Reina)

.....

I guess... saying I have the right to be here... is about confidence. Any inclusion anywhere is confidence isn't it? I thought about your citizenship presentation and I thought, 'Ah, this is very similar to that'. How do you fit in and where do you feel included, so yeah, it's good. (Mercedes)

.....

By being connected participants felt that they had the right to participate and even the right to have the life they want, or to support others to have the right to hold those same aspirations:

Just helping and supporting each other is what we do, and to have that recognition of the value of that. And being able to sit and talk with peer support workers from around the country [and hearing that they are] trying to set up something with their local play centre because some of the women were really keen to do childhood development... so it wasn't just about staying within the addiction sector, but having a right to move out into other areas where people's needs and dreams and inspirations were. To stand and listen to all of that was fantastic, because you wouldn't have heard that 10 years ago. (Dani)

.....

Having paid employment and social networks that were meaningful increased the participants' sense of the right to be included:

Some of [my friends are] more work based, and we might have a coffee or a lunch date within work time and a reasonable amount of the

conversation will be work-based conversation, but there's certainly one person in particular from that DHB²⁵ role who has become a really close personal friend and we'll have girls' nights out, we'll go to each other's homes, we know each other's children. She's just a friend. (Nina)



Nina described feeling an internal sense of inclusion when she was fully included, both as the consumer advisor in her work place and in being regarded as a friend.

Personal power

It was evident that the *after* stage involved participants' experiencing an internal shift towards believing that they had a right to be included, which increased their sense of personal power:

[Social inclusion means] your sense of self starts to come together, you start feeling that you have got some power and control over your life. And you've got choices. You know, when you've got no money, no nothing, no job, what are your choices? So, you know, having choices in life is really important, having a sense of power in your life, cause you know, that's often the most significant impact of a mental illness, you have this sense of hopelessness and powerlessness around anything to do with you and your life and your opportunities. Personal power! (Agent A)



A sense of power is also restored when participants felt they could act politically to change the system for themselves and their peers:

That's what gave me that sense of power because although we've wanted change there was always that sense of banging your head against a brick wall. They're not listening. 'You're nothing but junkies, you're manipulative, and this is all about your own self-interest'... Our arguments could be undermined because of that. And we were trying even way back then, gosh probably about 27 years ago I would have written my first letter to the Minister of Justice saying how wrong it was people get imprisoned for drug use when they actually needed treatment. (Dani)



I wrote to the prime minister about a concern and I was happy to have a response from her. It feels good, I feel like I am an important person. (Pasifika focus group)



Taking back power and increasing their capacity for action as a citizen engenders a sense of social inclusion:

I saw people around me, in my family, who were seen to be making a valued contribution to the community... so when I struck the world of having mental health problems... I was quite well equipped to deal with that drop of status... For lots of different reasons, I was able to just say 'Well, stuff you.' Part of it is about your social position before it happens and part of it is about the sort of person you are and the confidence you have. You know, that sense that I have a right to be in the world and you know it doesn't matter what happens to me I'm still a roughly okay person. (Mary)



²⁵ District health board.

Frank – being an active participant

Growing up, Frank had always thought he was different. He felt like he didn't quite belong, never truly fitting in. He developed a number of different strategies to assist him to navigate his way through his adolescence and adulthood. He did this by adopting a number of different personas, each designed to fit with whatever social circle he found himself in. He craved companionship and acceptance, and developed behaviours he believed would give him the approval and validation he so desired. In so doing, Frank never saw himself as acceptable in any way, and felt he had no great personal view of himself to lose sight of. He began to loathe the 'fake' personas he presented to the world. Aware that he was not being genuine, any flattery or compliments were dismissed immediately, as those comments bore no connection to the person who he believed himself to truly be.

Such self-loathing led to a deep sadness, anxiety and anger that almost disabled him at times as he struggled to function in his everyday

life. He saw himself as a failure in all areas of his life: his work, his marriage, his parenting. The demise of his marriage and the dissolution of a long-term relationship brought him to the depths of despair and he attempted to take his own life. He was now forced to confront these long-held beliefs and opinions, which had served to sustain such damaging views, and allowed the opportunity to address his destructive and harsh judgements of himself. Given the opportunity to talk about the issues that plagued him, he was able to emerge from this self-imposed tyranny and began to feel more relaxed about who he was. When he felt more comfortable in his own skin, those around him responded accordingly and liked this warm approachable person and welcomed him into their lives. He developed a loving relationship and healthy and reciprocal friendships. No longer combating deep-seated insecurities, Frank now revels in the pleasure of true inclusion, acceptance and active participation in the community.

Dani – no less than anybody else

Dani reflects that her time as a university student was a catalyst for her epiphany that she wasn't that different to everyone else. Initially she felt like she was walking around with a neon sign on her head, because she felt and looked different to everyone else. She described feeling like a fraud walking around the university; putting everyone else on a pedestal. Then one day she felt like a light had gone on; her actual sense of difference was hers, not other people's. Dani considered that maybe her realisation may have been due to being in a university environment in which you learn to critique, analyse and consider your opinions. She realised people were interested in the things that she said, particularly a couple of lecturers who encouraged her to do further study and

saw the value in her experiences. These experiences made her realise that she was no less than anybody else; not special, just like everybody else. When other students reacted negatively to her, she realised the problem was theirs, not hers. Dani realised she was not that different and once you talk to people, people are just people. Dani also found that the education she gained from university meant she became better able to articulate herself. Her strong sense of social justice, combined with her developing ability to articulate her arguments, meant Dani could advocate for changes in her workplace so that others like her would get a fair chance, because they too, were no less than anybody else.

Part 4: Fostering social inclusion

This section reports the participants' examples of how they have fostered the social inclusion of other service users. Fostering occurred in a range of environments, including within the workplace, and in family and other social networks.

Role modelling

Role modelling took place within participants' daily lives, including at work and in their day-to-day interactions with other people in their communities. When speaking about this, they generally described situations where their own behaviours and actions helped to normalise other service users' experiences of mental illness:

I mean that's what I spend most of my time doing really, trying to support people with, you know, more than the limited information and resources than they seem to have... Trying to role model that you can aspire to more than living on the dole, in a crappy house. (Teresa)

Within the workplace, role modelling was seen as creating a safe, supportive and inclusive environment:

I think I role model positive consumer participation really well, and I do it for the people in my team, that gives them a sense of focus and leadership and confidence in me and a sense of security and safety for them because they understand their values and the ethics that I work with and that I don't, you know I mean I don't, I try not to be unfair at anything I do. (Agent A)

That's the beauty of the peer worker role, the peer and I have an instant connection. To see eye-to-eye, they look up to us and see that I've had [the same] experience. (Pasifika focus group)

Participants explained that mentoring others is part of role modelling, and usually occurred in the work setting or within family networks. One participant, for example, reported that she "made a point" of assisting people with experience of mental illness working in her field. Another described how she would "awhi"²⁶ students, whilst also mentoring a young niece with mental illness who was frequently coming into contact with the law. One participant said that "staying well" on a personal level was an important part of fostering the social inclusion of others.

Initiating social interactions

Asking other people out to social events, and engaging in social activities with others, was identified as one pathway for fostering social inclusion. In particular, this was spoken about within the young adult's focus group. One focus group participant noted that it had been an "epiphany" to realise that he could be the one to instigate social events, rather than being on the receiving end of social invitations:

You can actually be the leader in social interactions, which sort of occurred to me sort of later on, that it was somewhat an epiphany, that you didn't have to be the person that someone would be like, 'Alright mentally ill guy, you can come into our group and sort of test your worthiness.' You can just be like, 'Do you want to come out for drinks or something?' and see how things go. You can actually initiate. (Young adult focus group)

²⁶ Awahi: to embrace, cherish (see: <http://www.maoridictionary.co.nz>).

This young man was not only fostering a sense of inclusion for others, he was also facilitating his own sense of inclusion, and consequently deepening his social networks and relationships.

Other participants spoke about a range of situations where they felt that they had fostered a sense of inclusion for others, for example invitations to go for coffee, initiating new friendships at school or including people in an existing group of friends. Including people socially was sometimes as simple as making introductions, and ensuring that they were not left out of social group interactions:

Where I work now, part of my role is managing a community centre and we have one or two volunteers who come to help at the community centre and one or two of those have experience of mental illness... So you might be having a conversation with them or one of those volunteers might be around when somebody comes in and you might need to do a bit of business or something and I always introduce people if they are there and I always try to speak inclusively so that they're an equal part of the conversation. (Frank)



It is interesting to note that participants sometimes spoke about drawing on their own experiences or feelings in trying to anticipate the needs of others. One young adult, for example, stated: "I think for me it's sort of looking at myself and thinking if I was that person, I would probably want to be talked to and included, so it sort of makes me go and include them". Another stated that via his recovery he'd become "more perceptive to the way that people are feeling".

Participants noted that initiating social interactions with others was not always easy, and could pose a number of challenges. This included a perception that socialising was something that you were either good or bad at; similarly, some acknowledged that they needed to "work" at it, and others felt that they were only able to do it when "feeling better". The reactions of the invitee(s) were also a consideration, with one participant claiming that they didn't want to be seen to be "too forward".

Being open

Some participants spoke about being open about their mental illness as one way of fostering social inclusion for others in similar situations. This included talking about it within their families (including with children) as well as in public forums or work-based settings. Holly, for example, explained that she was able to do this via her work, where she spent time talking to students about her own mental health experiences as a teenager. Holly discussed the impact that she felt this had for the young people:

So going and talking to those students about what it's like being young and having a mental illness and how to deal with your peers and the reactions you might get from people, I think that helps... because I had time out of school because I had mental health problems and of course had all the normal teenage worries about people talking about me behind my back and all those worries... So I guess that hopefully talking to people in that way, about my own experiences and my own successes in life since, makes a difference in some ways. (Holly)



Similarly, Mercedes, who worked in the mental health setting talked about how she shared her

own experiences of mental illness with people in the inpatient unit, and the impact that this had in terms of modelling future life possibilities, as well as breaking down the barriers between health professionals and service users:

And that's part of that inclusion thing too because it gives them that link back into society, because when you are in there, there's a very us-and-them and even with the really good nurses there is still an us-and-them... when you're in a disempowering environment, like an inpatient unit, it can only be reinforced that you really are different and you can't do this. So even a really good nurse, you're different, you're lovely, you're really nice... You've got this perfect, wonderful life and you don't have to go back to what I have to go back to. So you still don't feel included but when you meet someone that's a fellow peer, like they never had peers around in my last experiences. It's hugely different. (Mercedes)



As highlighted above, having someone with first-hand experience of mental illness as a role model is a powerful experience of normalising and signals to other service users in similar situations that they were not alone in that experience. In other examples, the research identified examples of participants being open with people who may not be personally affected by mental illness, but who may have some influence over the levels of social inclusion subsequently experienced by service users:

Because certainly for the last four to five years I've been heavily involved in training people around mental health and disclosing my consumer status or label within the context. For example, down at the DHB²⁷ the training

programme we developed with the staff. So I would use stories of my experience... to illustrate some of the approaches to things we wanted the staff to take on board. (Nina)



Employment

Some participants had facilitated employment opportunities for service users. This included new roles that they encouraged people to take up, introductions to people “with influence”, and provision of support within the workplace to ensure the ongoing employment of colleagues. One participant, for example, explained how he accommodated a staff member’s mental illness, when they required additional leave and kept another employee’s job open after she had a “breakdown”. Another participant explained that she employed service users in her workplace, and believed that this gave them an employment opportunity that they previously would not have expected to have access to. She also described how she provided ongoing support in this setting:

I don't just train them in things to do with the job; I'm a bit of a life coach... I have been for years. I have to talk to them about, 'Goodness me, could you go and ask for some sensory modulation if you don't want to take the medication.' (Agent A)



A number of participants had held jobs in employment settings outside of the mental health sector at the time of their first episode of mental illness. Some were discouraged to return to their original job by their employer, or they felt that they could not return due to a sense of shame or loss of self-confidence.

The idea of an apprenticeship to bring people

²⁷ District health board.

Agent A – making the world an inclusive place

At the time that her world began to unravel, Agent A was stressed and worried constantly as things began to spiral out of control. Diagnosed with a mental illness, she watched all she had worked for slide from her grasp. As she descended into madness, friends abandoned her and she battled to overcome feelings of hopelessness and powerlessness. Five years of unemployment and near poverty ensued. But she refused to believe that this was her future forever, she would not allow her identity to be constructed around a mental disorder. With purpose and determination she actively began to rebuild her life, determined to create her own place in society. By reclaiming her own personal power, Agent A worked persistently to establish herself in a prominent position within mental health services at a senior management level.

Now in a position of influence to foster social inclusion, Agent A has drawn on her own experiences to educate and better inform clinical teams while endeavouring to demystify the experience of mental distress. The resourcefulness and resilience she mustered to endure and overcome the challenges she faced in her life spoke of her courage, which equipped her to embark on bringing changes to mental health services to ensure people received the very best. It was her wish that people should not have to go through this profound experience alone. Making this world an inclusive place for people is one of the higher ideals that she aspires to, and in doing so she enhances not only others worlds, but also her own.

into roles within mental health settings, which included “connecting” people in the sector, was a way of facilitating service users’ return to study or employment opportunities.

It was highlighted by one participant that the number of people in paid positions in the sector had grown significantly in recent years, and while she did not claim it as a personal achievement, it was acknowledged that this was, in part, due to the level of support provided by others with more experience in the field:

It’s not a job, it’s just helping and supporting each other, is what we do, and to have that recognition of the value of that, and being able to sit and talk with people in decision-making positions and funding positions about the value of these roles and actually seeing it happen and seeing those people in a room altogether from maybe two or three of us. (Dani)



Not all participants were employed within the mental health sector. For example, two Māori men in the focus group were self-employed:

I make crafts, create things and I’ve got them on display on the front lawn for the neighbours. I showed a few people, especially nurses, and they come in and see what I am doing in my shed. (Māori focus group)



I try and look for work, anything, like picking up rubbish, anything that builds the land. Mowing lawns; I feel that I’m wanted with some people that I mow lawns for. There’s a few that are like family... I’ve got some customers that I don’t charge money for mowing their lawns, but they give me a meal. (Māori focus group)



Other participants who were employed outside of the mental health sector worked in a range of jobs, such as community development for the local city council, as an office worker, serving in a fast food outlet, a check-out operator in a supermarket and as part-time students in the tertiary education setting.

Advocating for others

While not always explicitly described as advocacy, the participants spoke about things they did to foster social inclusion that involved advocating on the behalf of others. This was sometimes undertaken at a higher level (e.g. via seeking change to policy or organisational processes). At other times, it was carried out on behalf of individuals.

Nina, for example, had acted as a referee for one of her colleagues in support of their application for study. When completing the form she perceived some of the questions to be inappropriate, and went on to challenge the education provider on behalf of her co-worker:

There is a question about... how would you rate this person's mental stability... and I just thought this question is badly worded and potentially stigmatising and I'm not sure what it is you are trying to ask. So some of the comments I gave back were 'You know I really object to this question'. (Nina)

.....

A number of participants indicated their membership of different networks and organisations as having a role to play in facilitating social inclusion at a policy level. For example, this included representation of service users on senior management teams. One person noted that much of this work was “really invisible” in that they took a backseat role and instead endeavoured to facilitate others working together and developing connections: “I’m much more interested in getting other voices or people than myself”.

Others indicated that they were more vocal in their advocacy or lobbying work:

Reina – social inclusion is worth fighting for

Reina had been raised to embrace her identity as an empowered Māori woman and took as a given her prerogative to be treated with respect and dignity. She never permitted imposed labels to detract from her fundamental rights as a human being. When she felt that she was being discriminated against she openly challenged the source. Reina actively promoted a work environment of open dialogue and transparency, which encouraged total honesty and allowed any adverse judgments to be examined and critically analysed. She works to establish conditions that actively welcome diversity and celebrate innovation and multiple approaches within the addiction field. She constantly has to address the negative stereotypes associated with addiction, to ensure that people can transcend any negative prejudicial views they hold, so that service users can experience positive interactions when receiving services that should offer humane and effective treatment. Reina never held to the belief that people are inherently bad; rather that situations and circumstances can lead people to act in ways that can be detrimental to them and create harsh and divisive impressions within the community. Reina has long appreciated the value of support from peers, family and community, and is acutely aware that this support has motivated people to make positive changes in their lives. She holds high expectations of services and service users, knowing that nothing beneficial is acquired without commitment, integrity and the self-belief that your existence is worth fighting for.

So a fair bit of advocating and I guess whinging to management for them to put their money where their mouth is, around you know, you say you've got these designated roles, you say you value this stuff, actually in practice you're not doing it. (Nina)

.....

Reina also felt that talking about her experiences of both mental illness and addiction, as a participant in this study, was a form of advocacy:

[Research] looks exciting and obviously I'm sort of biased in the sense that it's cool to also include people from an addiction background. Given where I come from, I hold a wee flag for that. (Reina)

Part 5: The future

Participants explored their views of the future work required in the social inclusion area, including what they felt was needed to take the *Like Minds, Like Mine* programme forward in Aotearoa New Zealand.

Several participants highlighted the progress that had been made already with regard to the social inclusion of people with a mental illness. This was often spoken about in relation to stigma or discrimination, with a number of participants stating that they felt this had been reduced over recent years, in part due to the awareness-raising work that had been undertaken, for example, the “John Kirwan ads”²⁸. Others highlighted the number of mental health service users in paid employment as an indicator of progress:

I think one of the really cool things about being in this role and watching over the last, gosh 11 years, the growth in the number of people involved in one way or another but now in paid positions. A lot of the work people are doing, I'm thinking particularly around peer support, has been done voluntarily or people do it because it's what we do. (Dani)

.....

Despite this, it was acknowledged that there was still some way to go with tackling social exclusion for people with mental illness, as evident in the wide range of personal experiences reported in the research.

A number of comments were also made about the media portrayal of mental illness. In particular, the reporting of crimes, where undue emphasis was placed on the mental health of those involved, was further proof of the work still to be done. Indeed, a number of participants

also spoke about the long-term nature of efforts required in addressing this, “And that’s a 10, 20 year cycle. It won’t happen overnight”; and the multi-tiered approach that will be necessary:

I think social inclusion is a good concept, how we get to social inclusion is going to be the difficulty. Because we need the top levels of society, the ones in management, government, in the influence level, that influence the legislative, judiciary and the executive. We need them to understand. To influence businesses, to influence policy. We need management to understand. We need the front-liners to understand and we need to be teaching from age five. (Jane)

.....

Graham suggested that it would require a paradigm shift within society to increase the success of the *Like Minds, Like Mine* programme in the future. Graham identified a “fascinating phenomenon” whereby people can disavow their friendships of many years on hearing a disclosure from a close friend:

A friend of mine has a long-term friend who only just found out that he's got a diagnosis. Suddenly everything has changed. This friend is basically completely wary of him now, and the friend of mine is hopeful that this won't last... What's happening there is that the person that's decided suddenly 'Oh my God this person's got a diagnosis', they are completely disavowing their own personal experience of day-in and day-out knowing that person. So it's not just that we disavow mad experience, we disavow everyone's experience of people as people and we put it all onto the expert. (Graham)

.....

²⁸ The John Kirwan advertisements and aligned website are part of the National Depression Initiative.

Here, Graham reflects on how easily friends can forget everything they know about a friend as a person, in favour of society's dominant views of the mentally ill and the expert's medical-model understanding of mental illness.

The following section reports a number of key ideas generated by the participants, relating to social inclusion education in multiple settings; Like Minds, Like Mine and the media; information; young people; and service user leadership.

Social inclusion education in multiple settings

The *Like Minds, Like Mine* education programmes, such as workshops on a marae, have the key objective of replacing the myths about mental illness with "correct" (99) or less stigmatising information.

Some participants felt strongly that any education programmes should commence at an early stage; for example, within schools. Whilst not all specified a particular age or life stage, there was a general sense that in "starting young", there was a greater chance of shifting attitudes and facilitating change, as well as ensuring support was available for youth who required it:

To help people get treatment sometimes or people who, like me as a young person. Feeling like shit and wanting to commit suicide. My first clumsy attempt was at age 13 and so you know there are lots of kids and there are more kids now probably than there were in my day that often feel that way. So having lots of people in schools talking about that would be great. (Frank)

.....

In contrast, one member of the young adult focus group had concerns about how soon students should learn about mental illness and the way it was taught, favouring the role of a guest speaker with experience of a mental illness, rather than teaching signs and symptoms, which can unwittingly reinforce stigma and exclusion:

Yeah, I think also, I mean if you're in school and you're having to manage the mental illness, it may be hard to get up in front of a class and tell what it was like, but to give the students a bit more knowledge so that they're more understanding of you... but if it's introduced as part of an education system - 'Let's learn about bi-polar and how to recognise the symptoms' you know you are going to have a whole pile of people who are self-diagnosing themselves as bi-polar and that really is not helpful. (Young adult focus group)

.....

It was also mentioned in the young adult focus group that some more alternative schools may be better at fostering social inclusion than larger mainstream environments. Others highlighted the need for tertiary education providers to focus on social inclusion:

I think we've got to run social inclusion courses. I think we've got to teach it at tertiary level... At Polytech level, to everyone. I mean lawyers aren't trained in disability and yet they presume themselves to be experts on mental health and welfare guardianship. (Jane)

.....

Education of employers and employees was considered important by some participants, due to stigmatising attitudes still evident in the workplace. As noted by one participant, “Most employers are shocking in their understanding of the impact of mental illnesses”. Suggested approaches included tailored courses for management and frontline staff, focused on bringing mental illness “out into the open”.

Participants suggested the emphasis should be on the connection between optimal mental health and physical wellbeing and associated inclusion and diversity, rather than on signs and symptoms of a diagnosis:

Government departments need social inclusion training, particularly Work and Income, Housing New Zealand, those places you know?... Well I think you'd train them in social inclusion and difference, because they need to know what to do if someone is struggling in their mental health. (Jane)

Nina also highlighted the need for systemic changes to support this type of work:

You can't just put people through this course and then just throw them back into the workplace that hasn't actually changed... You could look at some organisations and diagnose them. (Nina)

Some participants highlighted that the education initiatives do educate the general public about mental illness, normalise people's experiences, and thus help to facilitate social inclusion for those with mental illness, particularly the Like Minds, Like Mine advertisements on television. It was felt by some that this work needed to continue:

I kind of think we've got to keep on with these campaigns of raising understanding, increasing people's understanding of it and getting it into much more normalised. 'This is a normal part of human experience. It's not the end of your life.' In fact it can be the beginning of something really amazing... For yourself, or for others. (Nina)

Some participants explained that educating people in a workshop about mental illness does not necessarily guarantee that this will lead to changes in their behaviour or increase their understanding and empathy towards people with mental illness:

If the emphasis on education and public awareness doesn't happen then the incidence of external discrimination will continue and that of course will be damaging to the people. It will become internalised. (Frank)

Some kind of education as to what a certain mental illness is like would maybe give them some more insight as to what it feels like and then they wouldn't be so harsh with everyone and they'd definitely be more accepting... People just need to have more empathy and insight as to what it's like for people who have mental illness. Because otherwise they're just completely oblivious and they're just like, 'You're weird; go away, you're not like the rest of us.' (Young adult focus group)

Like Minds, Like Mine and the media

When considering the future developments that are required, some participants spoke about amendments or changes to current media strategies. For some participants, there was a sense that the current messages in the *Like Minds, Like Mine* media advertising campaign did not need to be significantly altered, but could instead be extended to include a wider or slightly different scope and material, such as social media and web-based platforms, to highlight stories of successful social inclusion:

Social media is like anything, it's incredibly powerful... it can be very exclusionary or it can be inclusive... [The] Big White Wall for instance, it's a mental health specific social media platform from the UK, it made a pretty big splash... they are in league with the NHS now and there are tendrils to other countries. The idea that we can have something in common and we can have a working relationship of value based on our personal shared experience... Facebook can do that as well. (Graham)

Feeling included and being included ... Facebook is where sometimes those worlds interact. There's a structure... [I can be out] carefully, in a considered way, because I know who all my friends are. (Teresa)

Stories [of success], two amazing movies I've seen recently are Beaver and Take Shelter and they're both about mental illness but in a really awesome way... I'm glad that there are movies out there like this... Film makers really make the balance that talk about the person that is



affected by mental illness and not talk about, I don't know, not do a horror film in an institution. (Young adult focus group)

One participant spoke about the need to ensure that the focus of the *Like Minds, Like Mine* programme is not just on the negative experience of having a mental illness; others felt that the use of “celebrities”, “heroes” and “charismatic leaders” could be extended further. Additional suggestions included further work in relation to encouraging people to support someone with a mental illness and an increased focus on young people:

I think it would be awesome to have like the All Blacks or someone really famous saying 'I am supporting a person with a mental illness. I challenge you to do that'. (Holly)

I think there's a place still for the Like Minds advertisements and the campaigns but I think they need to take them to a different level now... The last lot was sort of okay, and here's an idea. Young people! Is there one on young people that's on TV? That's my focus. (Agent A)

.....

We need a few pin-ups... in some ways when you look at Like Minds it almost went too quickly to the normalising and 'Wow let's be like a star and have bipolar!' I think we still need some believable people that have warmth and charisma. (Shelley)

.....

Some participants spoke more generally about using different types of media (including social media) to have conversations and keep issues related to mental health salient in people's minds:

Well, put millions more into Like Minds, Like Mine. I mean in the end it is about media and you know it is about public awareness and the only way the public becomes aware and the institutions which are part of the public become aware is by having the discourse going on all the time, and causing them to think. (Frank)

.....

There should be penalties for the media... they should be made to jump through hoops if they want to report on mental health that's not positive, because that is the biggest damaging thing that is being done. (Mercedes)

.....

Information

Access to information was considered important by a number of participants. This included information about accessing help in relation to mental illness (where and how), access to community resources, and early intervention information. As can be seen in the following interview extracts, this was felt to be necessary across a range of population groups, including families and affected others, as well as for service users themselves:

But I think at the same time you've also got to be giving people a sense of 'How do I prevent myself from being susceptible to mental illness?' There's also messages about early intervention... there's this massive gap in people's understanding between their home and all they are aware of is there is home and then there is hospital. They're not really aware of the NGO²⁹ options, the online options, the help lines, peer support. (Nina)

.....

There are all these conflicting messages about where things fit and we kind of assume that people know what's out there and they know who to go to... It's not just young people, it's their parents as well and adults and you actually don't know where to go for help until you've reached crisis point. (Holly)

.....

The contact I have with things like the [name of support group] just general groups in the community that people come to... people just don't seem to have the resources and information. (Teresa)

.....

²⁹ Non-government organisation.

Service user leadership

In discussing the future, a number of participants highlighted the important role of service users in leading the way with social inclusion:

I mean we are supposedly a civilised society and I mean education is always the key and so at the kind of sharp end if you like, Like Minds, Like Mine are doing great work, but always needs to be sharpening its act as well and I think it always needed to be driven a bit more by consumers rather than having non-consumers instead. (Frank)

.....

The current lack of a service user voice was commented on by some. Of note was that, while it was acknowledged that there had been some strong service user leadership at the New Zealand Mental Health Commission in the past, it was felt that this had diminished and was an existing gap:

So I think the fact that the ministry still doesn't have a consumer voice; the fact that the consumer movement doesn't have a voice itself. A piece in the paper I read a day or two ago, about the use of Tasers. Thirty something per cent of the use of them have been on people with mental health issues, compared with 20 something on criminals and who was making the point about that? It was [public figure] who is a wonderful spokesperson for consumers but really she is a default spokesperson, it needs to be a consumer voice that has the credibility. (Frank)

.....



Other comments regarding service user involvement included people holding senior management positions. Shelley hoped that in the future, such roles would be taken for granted, and may not even need to be named as such:

It is kind of that thing I was talking about things being innate where there isn't a single senior leadership or executive management or team that doesn't include that viewpoint as just a matter of course. That doesn't seek response and experiential knowledge from people that use services or experience things... they wouldn't necessarily even be named roles anymore. (Shelley)

.....

One of the benefits of increased service user involvement in the future of social inclusion was seen to be the level of expertise that this would provide: “Ideally, it would just be that if you’ve got a question about bipolar, you ask someone who is experienced in it” (Graham). Graham also spoke about peer support workers potentially fulfilling other visible roles in the community, particularly within non-mental health settings:

I love the idea of focussing more on offering a community resource that isn’t even necessarily through a mental health pathway. That would be fantastic... Imagine a sort of Citizens Advice Bureau run by peer support workers that isn’t a health pathway, which I think could be awesome. (Graham)

.....

Other participants talked about service user leadership in terms of service delivery, particularly around service users having more control and choice in their treatment and therapy, including alternative therapies:

So what would improve services would be having more choices. Would be reversing... I am going to be radical and say we should get rid of compulsory treatment. It would be giving the consumer the choice rather than still leaving the choice in the system’s hands... so there needs to be much more choice, and prevention [and] early intervention. (Frank)

.....

Leadership and role modelling by peer support workers was also regarded as important:

There is so much great stuff happening to challenge that with Peer Support and Like Minds but I feel like currently the paradigm shift hasn’t yet occurred so those things are still balancing-weights, rather than the

mainstream views... and it goes back to the thing I said at the beginning, judging behaviour not judging people and disentangling our judgment of behaviour from the labels we put on each other. (Graham)

.....

Young people

Whilst young people were sometimes discussed in relation to the future work outlined above, it is worth highlighting that this population group were often pinpointed as an important focus for future developments. This was due to the potential that they held in breaking down current barriers to social inclusion, their vulnerability with regard to their mental health, being a captured audience to begin to learn how to be socially inclusive, and because, some felt, that they had been overlooked in work to date:

But I said for a long time all the money is going into adult services and if we really want to make a difference to the future, we need to make something happen for our young, because they are the most under resourced services in the country. (Agent A)

.....

I suppose when you said we were going to talk about the future, my instant thought was I’ve got a 13 year old daughter and at some point I hope she’ll have kids and I can be a grandmother. And I just think of how normalising this stuff [is] for her and hopefully giving her some protective and preventative factors and strategies that she can draw on; and that I can do that for my grandchildren as well and my nieces and nephews. (Nina)

.....

One participant commented that work should be undertaken at the very early stages in life:

How can we change that life course that they're on into something that will lead them into some other place, other than mental health services, CYFS³⁰ residences, prisons... even babies and children? (Agent A)

.....

The importance of consulting with young people, and ensuring that any education or awareness-raising activities were appropriately tailored, that is, youth-centric, was highlighted by Holly and Jane:

I would be consulting a lot with young people and it would be tying things together so that it's not... because there's this big view of education and health are separate but for a young person things don't separate out like that and physical health and mental health don't separate out. We are saying all these things are part of life but then we are categorising them for funding purposes. (Holly)

.....

There's always going to be an ignorant part of society but I believe if you teach children from the age that they start school, the age of 5, about social inclusion, you are going to change a generation, but it will take a generation to change that generation. (Jane)

.....

It is interesting to note that not all participants felt that young people should be prioritised, with regard to future work in this field. One participant for example, felt that there was an "awful lot" being targeted at youth currently, and she felt that other issues (e.g. employment initiatives) should take precedence.

Graham – creating inclusive communities

Graham described an occasion where he felt he fostered mutual social inclusion for two groups of people in a local community. He spoke of a community organically certified garden in his local area, which a number of clients of a non-government organisation had been tending until the point when the garden was going to revert to council land. A group of keen local gardeners wanted to open the garden to the public and make use of the resource, but they didn't know how to work with the 'ex-clients' of the organisation who had put years of work into the garden and who all had allotments. At the same time, the local gardeners didn't have enough people resource to maintain the gardens by themselves.

The solution was obvious to Graham who was asked by a friend to assist with the situation. There was a community meeting in which he spoke, disclosing his experience of 'madness' and articulated that both the groups of people who had been using the garden and those who were going to be, were the same; they were all gardeners and had the mutual goal of wanting to keep the garden working. The new gardeners were worried that since they didn't have any knowledge about mental illness users, they may do or say the wrong thing and wouldn't know how to work with the service users. Graham communicated to the service users that they were welcome to keep gardening; they were experts and their skills, knowledge and people power were highly valued and needed in order to keep the garden going. With the community at large, Graham gently dissuaded the local community members from their fears that they needed any specialist expertise to work alongside the clients. Over time the two groups of people became indistinguishable and the people with experience of mental illness were no longer referred to as the 'ex-clients'. This community garden was a lovely example of mutuality and acknowledging the value of all people, which could be replicated in other community and non-mental health settings in the future.

³⁰ A government agency that provides child, youth and family services.

Mary – working towards equality and human rights

Mary decided she would talk less about her own experiences, as she felt they were too long ago, and that she was no longer directly affected by social inclusion or exclusion issues; however she thinks about it a lot and advocates for inclusion in her life.

She described an upbringing where she knew that she had a right to be here and knew she was of value. Mary described this as being a buffer for her when her mental health problems began; she still thought she was a roughly okay person. She acknowledged that other people may not have these buffers and when they experience the drop in status that comes with having a mental illness it can lead to social exclusion.

Mary spoke much more about the various ways she was trying to create equality and human rights for other service users through her work. She is vehemently opposed to legislation that coerces and controls people and takes away their liberty, particularly when decisions around this are based on predicting people's behaviour. She argues that mental health legislation does more harm than healing and that we need to find better ways to protect people. Mary wants there to be an underlying message that people diagnosed with mental illnesses are full human beings, not on a lower hierarchy of the human order locked in hospitals and in seclusion for days on end. Mary described previous legislation that has made a huge difference to other minority and discriminated groups of people and that repealing New Zealand's mental health act could do the same.

Mary believes in the power of peer support to convey the message for people that there's hope, if they see people who have similar experiences and go to on to have a life they want. She also argues that valuing people, and even valuing the experience of mental illness, challenges dominant knowledge about it. Valuing people will improve people's social inclusion and the quality of their life.

Focus group facilitators' reflections

We have included these brief reflective accounts by the group facilitators, in order to capture some of the points of difference in the discussions with the participants in the focus groups who have had more recent contact with the mental health services. The reflections also include the aspects of service users' experiences of social inclusion that relate to their ethnicity or culture, as Māori, Pasifika or as a younger adult.

Pasifika focus group: Helen Hamer

I was warmly welcomed into the service where the focus group was being held. After the opening prayer and introductions we commenced the discussion. One major point of difference from the individual interviews was the strong sense of the spiritual aspects of their lives, and the role of the church and their elders in promoting a sense of inclusion for the participants. One group member summed this up by saying that inclusion is about 'faith, hope and love'. Another group member talked about the importance of physical activity, such as Zumba for her physical and mental health. This young woman also promoted social inclusion for her peers by encouraging them to join her at the local gym. The role of the peer support workers was praised as being an important aspect of their increased sense of social inclusion, particularly one man who said that his peer support worker was a role model to him; a role that he plans to take on in the future. Overall there was a sense of fun within the group; at one point one of the younger men said, 'This is the most interesting conversation that I have had in a long time'. We closed the group with a prayer and posed for a couple of group photographs before we ate food together.

Young adult focus group: Shona Clarke

Before the focus group, I got the opportunity to sit in on one of the young adults' regular groups. I got an exciting glimpse of their passion and motivation to make positive changes in the mental health and illness area. Already warmed to conversation and discussion, this bunch of young adults began to impress me even more with their insight, positivity, articulateness and ability to hook right into the research topic, not an easy one, and leave my jaw dropping, both in shared laughter and by what these young adults were saying.

At the end of the focus group I fed back to everyone how blown away I was by what they had been talking about. Most of the key stakeholder interviewees had needed to discuss social exclusion before moving into success stories. Every single young adult in that group dived fully into stories of success and social inclusion, while only alluding to having experienced discrimination or stigma. These young adults had many stories of success, both in terms of what they experienced and the things they had been doing for others. No story was too small: a text to a potential university mate, cooking dinner for someone who had become isolated, and a first sharing of mental illness experience over drinks. Their stories were vast and ranged from single conversations that changed relationships, to an inclusive school environment that embraced diversity rather than ostracised it.

Their biggest success story was one they shared. They talked extensively of being involved in their group, which mental health services and others consult for advice. As one young adult stated, she thought the best example of social inclusion was their group. I watched the room light up and there was much smiling, nodding, agreement, appreciation and compassion in the room that the digital recorder was never going to pick up! As others talked about their participation in this group, they admitted to an element of peer support, but for them they felt it was more important to belong to the group in terms of what they did. They were using their mental illness experience for good. They were giving back to the service that had helped them, to help develop better services, and to put out information and a metaphorical hand for other struggling young people. Belonging to this group was important as it gave their experience value, and gave themselves a sense of worth and value, which consequently increased their confidence to do other things.

As an older young adult, I was warmed by their suggestions and their passion to change the way people treat each other. Their words really suggested that they got that they have, as every other human being has, the responsibility to foster and create social inclusion. It was less about what other people should do, and it was about what we all could do. Their group embodied social inclusion and my wish is that everyone will get to feel this sense of inclusion that I was privileged to experience in this focus group.

Northland Māori focus group: Helen and Shona

We were graciously welcomed into the space where we were going to have the focus group, which was visibly a welcoming place for people who visit. We relished the time before the group began to appreciate the beautiful art on the walls, to whakawhanaungatanga, have a blessing for the rest of our time there and for waiata.

Reflecting on this focus group, the most significant thing for us was the collective socially included environment that they had created. Some had moved from other cities; some spoke of the stigma, discrimination and the feeling of being an outcast in both the city and their families of origin. A number of people spoke of how moving to this, more rural, area had been life changing, in particular by having involvement in the host organisation through which they had met each other. They discussed living near to each other, of being whānau and looking out for each other. Having this whānau with similar life experiences gave them confidence to venture out into the world. Most importantly, they articulated a sense of social inclusion, a success story. Their lives may not represent a governmental definition of social inclusion, such as everyone being employed, but essentially we don't think it mattered; they had each found this collective success story of social inclusion.

After the group, we shared kai and got to know more about some of the group members and their lives. One of the hosts came back to us and told us that a couple of the participants had said to him that we had been tika and pono. As pākehā, we felt incredibly humbled and grateful for this feedback. They felt like the greatest compliments and we hope that we have represented their truth in this report.

Auckland Māori focus group: Debra Lampshire

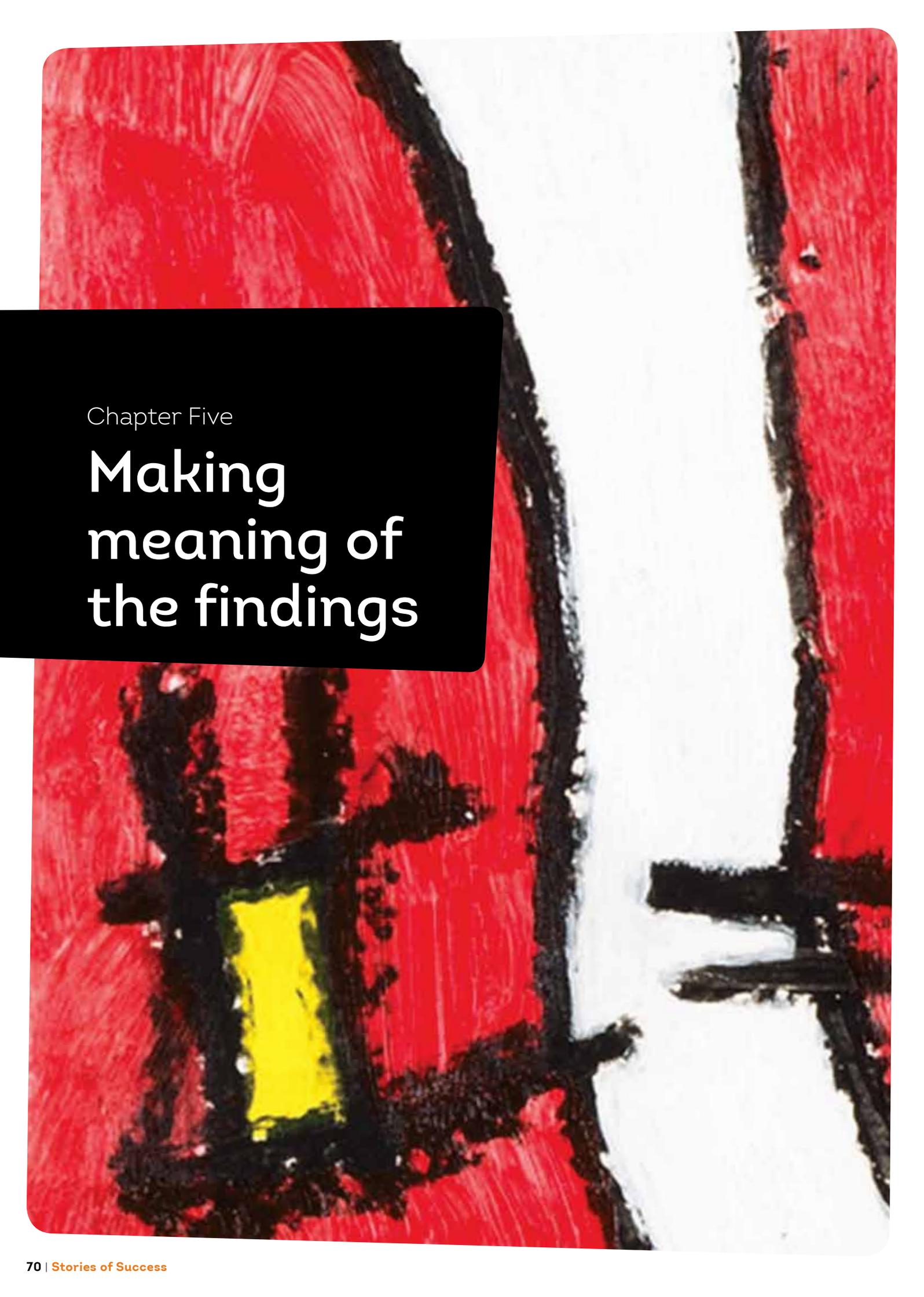
What struck me most was how welcome I was made to feel. Mātua set the scene for a safe, respectful, lively and informative discussion. When people spoke individually there was a sense of collective agreement amongst the group, and each participant's view was considered, then the next person would add to their wisdom.

The group spoke of the value of connecting and, for some, reconnecting to their Māori culture. Others had never been exposed to their culture and this sense of familiarity and of 'coming home' instilled feelings of deep pride and mana within the participants. The group members also spoke of straddling the two worlds: the Māori and the pākehā, not only in the wider community, but the within the different approaches from the mental health services.

There was a deep sense of the spiritual aspects of social inclusion within this group, and the importance of their connection and support for each other as they faced some adversity within society. At one point, I was profoundly moved when one of the older men moved forward and hugged a younger man who was describing his experiences of social exclusion. His soothing words and empathy were evidence of the acceptance and shared understanding within this group. The participants felt understood and better served within the Māori cultural services and spoke with great fondness about the staff and also their peers.

The participants truly embodied their sense of whānau. They had found their way back to where they wanted to be. They were accepted and embraced. This was the greatest gift from the services and I personally felt very humbled and slightly envious of the strong sense of belonging that came from that group. I left after the interview feeling like I had been in the presence of aroha. Shortly after the group a staff member who was a supporter for some of the group members emailed to say that she was 'blown away' by the depth of the discussion that tāngata whāiora generated in the group.



An abstract painting with bold, expressive brushstrokes. The composition is dominated by vibrant red and stark black, with a central white vertical band. A bright yellow rectangular shape is visible in the lower-left quadrant, partially obscured by black strokes. The overall effect is one of dynamic energy and contrast.

Chapter Five

Making meaning of the findings

Introduction

The aim of this research study was to explore positive stories of social inclusion from people with a diagnosis of mental illness living in Aotearoa New Zealand. To gain a deeper understanding of the participants' worlds, a qualitative approach was adopted for the study. The study's objectives were to report on the internal factors that created a sense of social inclusion and participants' perceptions of the external factors that further supported inclusion within society. A further objective was to highlight the attitudes, beliefs and actions of others that participants saw as fostering their sense of social inclusion.

Defining social inclusion

The participants in this study described social inclusion as a fluid concept (47,50); a journey of moving in and out of inclusion and exclusion, depending on the internal and external factors in their personal lives and the situations they encountered. This was illustrated when many of the participants noted that they could not talk about social inclusion without also talking about social exclusion. This finding is in contrast to the theoretical concept of inclusion, which describes a dichotomy between the two states, and the perception that a person is either in-or-out of their communities. An example of this was provided by David, who was excluded by his employer when he disclosed his mental illness, yet was simultaneously included by his ex-wife.

For the participants in this study, social inclusion was defined as having the fundamental right to be a fully participating member of the community with the same access to rights and responsibilities that the majority of others in society enjoy (20). Being recognised as an equal was also an important aspect of social inclusion, as a way of creating a sense of belonging and connection with others. Being a fully participating member led to participants making a valued contribution, for example, within their friendships, in their workplaces and within their families and whānau. Making a valued contribution, in turn, created a sense of personal value. Finding meaning in the experience of mental illness also created a sense of value, particularly when participants actively used the wealth of knowledge they had gained through these experiences in their employment settings and in their service user advisor roles.

The feeling of social inclusion

The participants' stories of success have helped us to understand the more subjective or personal feeling of what it means to be socially included. Many participants described their feeling of inclusion as a two-stage process; the *before*, described as an internal shift or sense that inclusion is possible, and the *after* and what it feels like to be socially included.

The *Fighting Shadows* report (10) offered a new model of self-stigma and discrimination, including a definition of self-stigma and the notion of the 'circuit breakers' (see Table 8) to show how self-stigma could be combatted. It is proposed that the participants' description of the *before* stage is strongly linked to self-stigma. Further, participants' descriptions of how they journeyed towards social inclusion demonstrated how the internal and external factors activated the 'circuit breakers'. Such factors included participants' being open about

their mental illness, accepting and celebrating their difference, being positive role models, having a sense of power and confidence, being leaders and keeping their focus on their right to be included. This in turn fostered the social inclusion of their peers.

These findings point to the idea that the participants have moved out of the shadows

of self or externally generated exclusion, to the *after* stage, and the internal sense of being socially included. In sum, the *after* stage of inclusion was also determined by the deepening of participants' social relationships and a belief that they have a right to make a contribution to society.

Table 8: Circuit breakers (actions) that can interrupt the cycle of self-stigma

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

Source: Peterson, Barnes and Duncan (10 p63).

What others did and said

Participants' stories of success of being socially included generally involved the actions and words of others, such as their family and friends, their peers, employers, colleagues and professionals. Firstly, a sense of inclusion was generated for participants when others included them in the activities of everyday life, such as extending an invitation to a social event, being welcomed into a community craft group and, importantly, offering friendship, which fostered a deeper sense of connection. Such gestures of inclusion by others relayed to participants that they were no different from others. This was a profoundly normalising and validating experience, which reduced their self-stigma (10,31) and increased their power to act.

On a subjective level, feeling included was also evident in the attitudes of others, conveyed in words and sentiments that affirmed the participants' belief that they have a right to be included and make a genuine contribution to society. In other words, participants felt that they were important and mattered to others.

The deepening of these social connections was centred on the importance that participants placed on the principle of reciprocity; the give-and-take of social connection, which generated mutual positive regard for each other. Social inclusion was also fostered when others demonstrated empathy that, for example, followed a personal disclosure of having a mental illness. These supportive responses increased the person's trust and confidence in themselves, and in the people in their social and professional encounters. Demonstrations

of concern towards participants led them to conclude that they were being recognised for their humanness, rather than being defined by their diagnosis.

Nussbaum (100) has described the importance of having participatory imagination, a concept that moves beyond empathy to a morally informed perception of the other. Nussbaum suggests that we can develop our inner eyes to see the full human being by looking beyond the negative stereotypes, which are often based on our innate fear of those who are different from ourselves.

For the participants in the Māori focus groups, their positive stories of inclusion were based on the principles of whanaungatanga³¹ and manaakitanga, which was described as the hospitality and kindness extended to them by others. For Māori, such stories of success highlighted how these experiences had restored their mana³² and their wairua or spirit.

For the people in the Pasifika focus group, their sense of inclusion was equally related to the spiritual and religious realm, specifically the role that the church plays in their lives. For both these groups, kaumātua, kuia, their elders, pastors and whānau were important people who fostered their deeper sense of inclusion.

Possibly, because members of the focus groups had had recent experiences with mental health services, their peer support workers were rated highly as important people who increase their sense of social inclusion. Peer support workers were important as role models and also as people who could navigate the complexity of

³¹ Whanaungatanga: a relationship or kinship; a sense of family connection through shared experiences and working together, which provides people with a sense of belonging. The relationship develops as a result of kinship rights and obligations, which also serve to strengthen each member of the kin group. It also extends to others who one develops a close familial, friendship or reciprocal relationship with (see: <http://www.maoridictionary.co.nz>).

³² Mana: prestige, authority, control, power, influence, status, spiritual power or charisma.

the mental health system in order to reduce the participants' sense of exclusion.

A note about personal power

Personal power was regarded by the participants as an integral part of social inclusion; indeed many stories of success were centred on the person's sense of having the power and self-confidence to make decisions and choices in their daily lives. Personal power also related to challenging the institutional structures that sustain stigma and discrimination, and resulted in exclusionary practices for themselves and their peers.

Link and Phelan (101 p367) have argued that the interrelated elements of stigma, such as labelling, stereotyping, separation, status loss and discrimination co-occur "in a power situation that allows the components of stigma to unfold". These power situations can be within the social, economic and political arenas.

For many of the participants in this study, personal power was an important circuit breaker that increased their sense of social inclusion. In sum, for a number of participants, once treated with deference and recognised as having something of value to contribute, they were able to realise the ideal of functioning as "fully participating members, with the same rights and opportunities as other citizens" (102 p8).

Other marginalised groups have journeyed towards fuller inclusion in society. For example, adopting a social model of disability within the government's disability strategy (13) has reduced many physical, psychological and institutional barriers, and further increased disabled people's full participation within society (1). Further, social inclusion needs to be

regarded as a human rights issue (69,73,103), rather than primarily a health issue, in order to secure fuller participation for people with mental illness within Aotearoa New Zealand (Sayce L, Chief Executive, Disability Rights UK 2013, oral personal communication, 2 May). This can be achieved by pursuing the recommendations in the *Mental Health and Social Inclusion Concepts and Measurements* (11) report to: further explore the barriers to participation, and continued systemic discrimination; and to improve policy coherence to enable social inclusion.

Full inclusion and participation in society increases a person's power through the generation of human capital (12,104,105): for example, employment, meaningful social relationships with others, social welfare and the recognition of one's social status by others. This has been demonstrated by the number of participants in the research who were involved in consumer or service user advisor roles. These employment experiences were reported as having a positive key role to play in relation to individuals' experience of social inclusion. This was both in terms of the financial gains they provided, as well as the wider effects they had of making participants feel valued and equal with others. Human capital increases one's ability to flourish (106) and to live life to the full. Complementing the current focus on a health agenda to increase social inclusion, with concepts such as human capital and a rights-based approach, can further secure service users' civic identity and recognition as equals.

Finding the champions

For the majority of the participants, social inclusion was often linked to a particular person or event. Health professionals, peers, family

members and cultural elders were regarded as champions of social inclusion. Service-user involvement or representation in policy development, and in educating the community about mental health and illness, was presented as further evidence of championing social inclusion. Interestingly, being a champion for social inclusion could also be seen as not only a means to foster others' social inclusion, but a means to include oneself.

The future

While not an original objective of the research, the discussion of the future of the *Like Minds, Like Mine* programme was prompted by participants' feedback during the data collection phase.

Overall, the majority of participants reported

that progress had been made with regard to the social inclusion of people with a mental illness within Aotearoa New Zealand. This was often spoken about in relation to stigma or discrimination, with a number of participants stating that they felt this had been reduced over recent years. It should be noted, however, that this could be related to the nature of the sample of participants, many of whom were in leadership roles.

A number of key ideas were generated by the participants, such as: providing education to increase social inclusion; revisiting the role of *Like Minds, Like Mine* and the media; increasing service user leadership; and placing a greater focus within the *Like Minds, Like Mine* programme on younger people.



Education was widely discussed as a tool for working towards social inclusion. This included, for example, increasing public health literacy, with the aim of increasing people's knowledge and understanding of mental health and addiction issues in our communities. Raising the community's understanding of discriminatory practices could also be a catalyst for making changes to social norms and increasing acceptance of diversity and difference. Participants consistently talked about the need for education, with a focus on the depth of understanding that can be generated by first-hand accounts of mental illness and its consequences. It was evident that participants thought that education to increase social inclusion needed to occur within multiple settings including schools, tertiary establishments, employment and governmental departments, emphasising that empathy towards service users by the public was important.

Effectively using education as a strategy towards social inclusion is complex and needs to be part of initiatives that are multi-phased and address policies and local issues, which if not otherwise addressed, may foster social exclusion and render any educational programmes ineffectual (107). A multi-faceted approach is also needed to ensure sustainability, which will increase the likelihood that education will facilitate long-term attitude and behaviour change (107). This is particularly the case when educational content focusses solely on psychiatric diagnosis and symptoms, or makes parallels with a physical illness, as this can unwittingly perpetuate stigma and discrimination (18,108,109). Pursuing strategic, multi-level and multi-faceted approaches, will ensure education is effective to further normalise people's experiences, and thus help to

facilitate social inclusion for those with mental illness (107).

Media images and narrative accounts that promote greater empathy and understanding, and are not limited to the negative experience of having a mental illness, were important to participants. Images of younger people were also regarded as the way of future programmes. A resource centre modelled on the philosophy of the Citizens Advice Bureau could assist service users and their loved ones to be cognisant of their rights and obligations to help them get the best outcomes.

Of importance, participants gave high priority to focussing the *Like Minds, Like Mine* programmes on the younger population. Participants believed that young people have significant potential to break the cycle of stigma and discrimination that perpetuates social exclusion. By breaking down the current barriers that impede social inclusion it was deemed possible to reduce the young person's vulnerability and increase their resourcefulness with regard to their mental health. The prime minister's Youth Mental Health package of initiatives will also make a significant contribution (110). Helping the next generation of young people to increase their ability to accept difference within society, and develop the skills of cooperation and reciprocity is also a circuit breaker (10). In sum, the participants concurred that the future *Like Minds, Like Mine* programme needs "freshening up" (1 p23).

Strengths and limitations of the research

The key strength of this research is its high level of engagement with service users, including their involvement in the overall development and running of the project, and the contribution

of the research participants in the analysis and interpretation of the findings. A qualitative methodology, while enabling the inclusion of rich, in-depth data, presents a limitation in terms of the generalisability of the findings. As this was a smaller study (and due to its timeframe) the majority of the participants were recruited from metropolitan areas; therefore, the experiences of service users living in rural areas are not represented in this study. Likewise, the research study did not explore the experiences of people who are not engaged with mental health services.

Recommendations

Though this is a small indicative study, with a limited sample, the study has generated the following recommendations, which could be further explored by the *Like Minds, Like Mine* programme.

Raise the visibility of services users as leaders in key roles in the mental health sector.

Increasing service user leadership, in partnership with providers and funders of mental health services, advocacy groups and other key stakeholder groups, will further foster inclusionary practices within mental health services. Strengthening service user involvement at a leadership level will stimulate debate on innovative ways to increase social inclusion in Aotearoa New Zealand.

Develop more opportunities for service users to have meaningful and supportive employment in a wide range of industries and professions.

Meaningful employment increases people's sense of value, participation in, and contribution to, the society within which they live. Although transitional and supported employment is

essential for people who have mental illness, placing the focus on how employers can provide safe and supportive workplaces outside of the mental health sector is important in increasing social inclusion.

Focus the *Like Minds, Like Mine* programme on younger adults and include their presence in future media advertising campaigns.

The majority of the participants in this study suggested that future media advertising campaigns need to increase the focus on younger people. Participants regarded this as an opportunity to break the cycle of stigma and discrimination, and to challenge early on ("starting young") negative attitudes and behaviours towards people with mental illness. This could also be considered as an example of a circuit breaker. Therefore, it is vital that younger people are given the opportunity to contribute to the planning of future *Like Minds, Like Mine* programmes, as well as increasing their visibility in media advertisements.

Share provider and government agency stories that support social inclusion in the *Like Minds, Like Mine* programme.

The participants in this study often reported that it was the actions of one person, or in one situation by a champion, that led to their stories of success of social inclusion. The actions of others not only increased the personal power of participants; these actions made a claim for the service users' basic right to be included. Examples of these actions are worthy of future exploration to help staff in the mental health sector and other allied government agencies, such as housing and employment, to champion the social inclusion of service users.

Explore the use of wider-reaching face-to-face, media and virtual campaigns to support the understanding of the lived experience of mental illness.

It is recommended that *Like Minds, Like Mine* continues to explore the use of social media and web-based platforms, similar to what is being done elsewhere in innovative international initiatives, to inform future media advertising. Websites could also be considered as a medium to access narratives about mental illness and provide examples of how other service users have experienced successful social inclusion (see www.patientmemoirs.com as an example of such a platform). The *Like Minds, Like Mine* media advertising campaigns could also be used as teaching aids to promote discussion in schools and work settings, and with non-health agency staff.

Further develop and measure the Aotearoa New Zealand concept of social inclusion, inclusive of Te Ao Māori and Pasifika realities.

The need for valid and reliable measures of social exclusion and inclusion has been highlighted in the literature reviewed for this study. *The Measuring Social Inclusion* (5) report advocated for improved social inclusion for people with experience of mental illness, and highlighted the importance of cultural identity and the need for further examination of the lived experience of social inclusion from a qualitative perspective. However, it remains unclear what impact social inclusion policies have on ethnic minorities (6). Therefore, the role of culture in promoting the social inclusion of ethnic minorities continues to be a key policy area that needs to be further assessed and evaluated in Aotearoa New Zealand.

Conclusion

This research study has added to the somewhat scant body of literature regarding social inclusion, and in particular, the stories of success for mental health service users in Aotearoa New Zealand. This study set out to explore the internal and external factors that created a sense of social inclusion and to give examples of the attitudes and behaviours of others that fostered participants' sense of social inclusion. The report has also presented the recommendations that will inform the future aims and objectives of the *Like Minds, Like Mine* programme.

The findings support the premise that social inclusion is a complex concept, and have highlighted the fluid and subjective nature of what it feels like to be included. For the participants in this study, social inclusion was not simply about having a job, or belonging to a club – it incorporated dimensions such as feeling a sense of belonging and acceptance, having meaningful participation (i.e. without conditions or barriers), having a sense of value, and feeling a sense of entitlement to the same civil, political and social rights as others in society.

The stories of success, which have increased the sense of social inclusion for people with mental illness, help us all, as citizens, employers, whānau, family, friends, workmates and health workers to understand how we can foster, respect and uphold the rights of people with mental illness to be fully included in society. In conclusion, it is indeed an honour to be able to share in this research report the many success stories from people who have found their inherent value, despite their experiences of social exclusion.

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Appendices

- Appendix A: Ethics committee approval letter
- Appendix B: Consent form: individual interviews
- Appendix C: Consent form: focus group participants
- Appendix D: Participant information sheet: individual interviews
- Appendix E: Participant information sheet: focus group participants
- Appendix F: Reference group membership



Appendix A: Ethics committee approval letter



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UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE

19-Nov-2012

MEMORANDUM TO:

Dr Helen Hamer
Nursing

Re: Application for Ethics Approval (Our Ref. 8812)

The Committee considered your application for ethics approval for your project entitled Stories of success: mental health service users' experiences of social inclusion in Aotearoa New Zealand.

Ethics approval was given for a period of three years with the following comment(s):

The Committee thank you for a thoughtful and well-constructed application.

1. The demographic information collected from Focus Group participants is labelled "CONFIDENTIAL", but it is not clear how the information is to be used if the information is in fact confidential. It would be good to clarify the distinction between the demographic information and the remainder of the focus group information on the PIS and CF.
2. The PIS for the focus group says "I understand the confidential nature of my participation: that all information gathered will be stored in the strictest confidence..." This may be misleading since neither the participant's identity nor the information collected during the focus group are confidential, due to the nature of focus groups. Please state that information will be stored securely, rather than in strictest confidence.
3. PIS: Please remove all references to anonymity from the paragraph about the focus groups. As noted in Point 2, information provided in the focus group cannot be made anonymously because it is a group setting. Please amend this by stating that participants in the focus group will be asked to keep information shared within the focus groups confidential among themselves.
4. Please include the information about support that was given in section H6 in the PIS.
The expiry date for this approval is 19-Nov-2015.

If the project changes significantly you are required to resubmit a new application to UAHPEC for further consideration.

In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. Contact should be made through the UAHPEC ethics administrators at humanethics@auckland.ac.nz in the first instance.

All communication with the UAHPEC regarding this application should include this reference number: **8812**.

(This is a computer generated letter. No signature required.)

Secretary
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Nursing
Dr Gary Bellamy
Dr Jacqueline Kidd

Additional information:

1. Should you need to make any changes to the project, write to the Committee giving full details including revised documentation.
2. Should you require an extension, write to the Committee before the expiry date giving full details along with revised documentation. An extension can be granted for up to three years, after which time you must make a new application.
3. At the end of three years, or if the project is completed before the expiry, you are requested to advise the Committee of its completion.
4. Do not forget to fill in the 'approval wording' on the Participant Information Sheets and Consent Forms, giving the dates of approval and the reference number, before you send them out to your participants.
5. Send a copy of this approval letter to the Manager - Funding Processes, Research Office if you have obtained funding other than from UniServices. For UniServices contract, send a copy of the approval letter to: Contract Manager, UniServices.
6. Please note that the Committee may from time to time conduct audits of approved projects to ensure that the research has been carried out according to the approval that was given.

Appendix B: Consent form: individual interviews



THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

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Consent Form: Individual interviews

Research title: Stories of Success: Mental health service users' experiences of social inclusion in Aotearoa New Zealand

- I agree to take part in this research.
- I understand the confidential nature of my participation; that all information gathered will be stored in strictest confidence and that no material which could identify me will be used in any reports on this study.
- I understand that I will be sent a copy of the transcript to check for accuracy and to make any necessary amendments of my details. I also understand that I can request that my digital recording be returned to me.
- I understand that taking part in the research is voluntary and I am free to withdraw my participation at any time. However I understand that I cannot withdraw any of my data after 1st February 2013.
- I understand that if I experience any distress during the interview I have the details of who I need to contact for support.
- I understand that if I have any conflict of interest with a member of the research team then that person will not have contact with me, or my data, during the research process.
- I understand that data will be kept in a password protected computer for 6 years, after which they will be destroyed.
- I understand that I will receive a final report of the findings at the completion of the study in August 2013.

Full name of participant:

Signature:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19th November for 3 years from 19 November 2012 to 19 November 2015 Reference Number 2012/8812.

Appendix C: Consent form: focus group participants



THE UNIVERSITY OF AUCKLAND
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Consent form for focus group participants

Research title: Stories of success: Mental health service users' experiences of social inclusion in Aotearoa New Zealand

I have read the Participant Information Sheet. I have understood the nature of the research and why I have been asked to participate. I have had the opportunity to ask questions and have had them answered to my satisfaction.

- I agree to take part in this research.
- I understand the confidential nature of my participation; that all information gathered will be stored securely and that no material which could identify me will be used in any reports on this study.
- I understand that taking part in the research is voluntary, that I am free to withdraw participation at any time, and if I experience any distress during the group interview I have the details of who I need to contact for support.
- I understand that I will not be able to withdraw any data from the focus group after I have participated.
- I understand that attending the focus group will take approximately two hours
- I understand that the focus group will be digitally recorded and transcribed by a third party who has signed a confidentiality agreement.
- I agree not to disclose anything that was discussed in the focus group

PTO

- I understand that data will be kept for 6 years, after which they will be destroyed.
- I understand that whilst every effort will be made by the researchers to maintain anonymity and confidentiality, this cannot be guaranteed due to the nature of the discussion group as participants will be aware of each other's presence.
- I understand that the recording of any demographic information, such as my age and ethnicity, is subject to my agreement, will be stored securely and will not identify me when included in any reports on this study.
- I understand that if I have any conflict of interest with a member of the research team then that person will not have contact with me, or my data, during the research process.
- I understand that I will receive a final report of the findings at the completion of the study in August 2013.

Full name of participant:

Signature:

**APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON
19th November for 3 years from 19 November 2012 to 19 November 2015 Reference Number 2012/8812.**

Appendix D: Participant information sheet: individual interviews



THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

Helen P Hamer, RN, PhD FNZCMHN
Senior Lecturer/Nurse Consultant (Mental Health)
SCHOOL OF NURSING
Faculty of Medical & Health Sciences

Private Bag 92019
Auckland
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PARTICIPANT INFORMATION SHEET: INDIVIDUAL INTERVIEW

Stories of Success: Mental health service users' experiences of social inclusion in Aotearoa New Zealand

You are invited to participate in a research study conducted by a small team of researchers. The study is being coordinated through the School of Nursing at the University of Auckland and funded by the Mental Health Foundation of New Zealand. You are invited to participate because we would like to explore your stories and examples of your experiences of a sense of connection and belonging and how that contributes to feeling included in society.

Your participation in this study is entirely voluntary. If you do agree to take part in the study, you are free to withdraw from the study at any time, without giving a reason. To help you make your decision about participating please read this information sheet carefully.

What is the purpose of the study?

The purpose of the study is to explore mental health service users' experiences of social inclusion in order to highlight the factors which facilitate their full participation within society. The findings from this study will help us understand how the stigma and discrimination programme may have had positive impact on society thereby increasing a sense of social inclusion for service users.

What will it involve?

It will involve taking part in a face-to-face interview. The interview will take place in a setting that is convenient for you and at a time that suits you. You will be interviewed once, and then there may be a follow up discussion once you have read the transcripts. The interview time is 1 hour.

What happens if I decide to take part?

If you decide that you would like to take part, we will ask you to reflect upon your experiences and views of social inclusion. For demographic purposes, we would also like to record some simple information, such as your age and ethnicity (subject to your agreement). Individual interviews will take place in a setting convenient to you. You will be sent a petrol voucher as an appreciation of your participation in the study.

Will the discussion be recorded?

With your permission we will record the interview using a digital voice recorder. You can ask for the recorder to be turned off at any stage during the interview. The interview will last approximately one hour. The interview will be transcribed by a third party who has signed a confidentiality agreement, and then we will send you the written transcript to you to review. This will enable you to amend the information you have provided, or withdraw your data, before Feb 1 2013.

For the purposes of confidentiality pseudonyms will be used in the transcripts and you will not be identified in any reports or publications resulting from this research. We will guarantee safe storage of all digital tapes and written information in a password-protected computer and a locked cabinet within the University of Auckland premises. Only the research team will have access to the data. After the study is completed all digital recordings can be returned to you or stored by the researcher for six years, then all written and recorded material will be destroyed.

What is the time-span for the study?

The study is expected to start in November 2012 and will conclude in June 2013. You will be sent a final report of the findings at the completion of the study in August 2013.

The risks and benefits of the study

There are no specific risks associated with your participation in this study. The aim of the study is to explore your stories of success and taking part in this study will give you the opportunity to share your ideas and knowledge about social inclusion. In the unlikely event that you may experience distress I will arrange further help or counselling through an external contact.

The researcher will ensure that all identifying information will remain confidential. If the information provided is included in a report or published, this will be done in a way that does not identify you. A member of the research team holds a professional position as a mental health promoter which could create a conflict of interest for you. If this occurs, this person will not have any contact with you and your transcript will remain confidential to Dr Helen P. Hamer, the Principal Investigator.

What will happen to the results of the study?

The researchers would like to report the findings from this project in a range of professional and academic journals and at conferences to inform health professionals and other relevant people of what enables the social inclusion of service users in society.

Who is organizing the research?

Dr Helen P. Hamer is a Senior Lecturer and the Principal Investigator of the research study which is being conducted through the School of Nursing at the University of Auckland.

Contact for further information

If you require any further information, please contact:

Principal Investigator: Dr Helen P. Hamer +649 9237441 or h.hamer@auckland.ac.nz

Head of School: Associate Professor Judy Kilpatrick +649 373 2897 j.kilpatrick@auckland.ac.nz

Ethics Chair: For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1143. Telephone 09 373 7599, Ext. 83711.

If you have any further questions or concerns about this project you can also contact the Health and Disability Advocate, telephone 0800 555 050

Thank you for taking the time to read this information sheet.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19th November for 3 years from 19 November 2012 to 19 November 2015 Reference Number 2012/8812.

Appendix E: Participant information sheet: focus group participants



THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

Helen P Hamer, RN, PhD FNZCMHN
Senior Lecturer/Nurse Consultant (Mental Health)
SCHOOL OF NURSING
Faculty of Medical & Health Sciences

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Fax: 64-9-367 7158
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PARTICIPANT INFORMATION SHEET: FOCUS GROUP

Stories of Success: Mental health service users' experiences of social inclusion in Aotearoa New Zealand

You are invited to participate in a research study conducted by a small team of researchers. The study is being coordinated through the School of Nursing at the University of Auckland. You are invited to participate because we would like to explore your stories and examples of your experiences of a sense of connection and belonging and how that contributes to feeling included in society.

Your participation in this study is entirely voluntary. If you do agree to take part in the study, you are free to withdraw from the study at any time, without giving a reason. To help you make your decision about participating please read this information sheet carefully.

What is the purpose of the study?

The purpose of the study is to explore mental health service users' experiences of social inclusion in order to highlight the factors which facilitate their full participation within society. The findings from this study will help us understand how reducing stigma and discrimination in New Zealand has increased a sense of social inclusion for mental health service users.

What will it involve?

It will involve participating in one focus group discussion with approximately six other service users. A focus group is a form of research in which individuals are asked their thoughts and feelings about something. Questions are asked in a group setting where individuals are free to talk with other group members. You do not have to answer any questions that you are asked in the group. The focus group will take place on a convenient date and time and will take approximately 90 to 120 minutes. Refreshments will be provided.

Information provided in the focus group will be made anonymous. If the information provided is included in a report or published, this will be done in a way that does not identify you. The participants in the focus group will be asked to keep all the information shared within the group confidential amongst themselves. This means that once the focus group has commenced, you will not be able to withdraw any information you have provided. Should you decide to, you will be free to leave the focus group at any time.

What happens if I decide to take part?

If you decide that you would like to take part, we will ask you to reflect upon your experiences and views of social inclusion. We would also like to record and include some simple demographic information such as your age and ethnicity (subject to your agreement) to use in any reports on this study. I will keep this information confidential to the research team and you will be sent a petrol voucher to reimburse your travel to the focus group venue and as an appreciation of the time you give to the study.

PTO

Will the discussion be recorded?

Yes, the focus group will be digitally recorded. Each recording will be downloaded onto a password protected computer and only members of the research team will have access to them. They will be transcribed by a third party who has signed a confidentiality agreement. You will be asked to read the written copy of the transcript but you cannot change or withdraw any of the content. No material that could personally identify you will be used in any reports on this study. Following the completion of the study, all transcripts and other information will be stored in a locked cupboard and password protected computer at the University of Auckland for 6 years.

What is the time-span for the study?

The study is expected to start in November 2012 and will conclude in June 2013.

The risks and benefits of the study

There are no specific risks associated with your participation in this study. The aim of the study is to explore your stories of success and taking part in this study will give you the opportunity to share your ideas and knowledge about social inclusion. In the unlikely event that members of the focus group may experience distress I will advise the group who to contact at the beginning of the focus group. If you require further help or counselling I will arrange an external contact to offer you support.

The researcher will ensure that all identifying information will remain confidential. If the information provided is included in a report or published, this will be done in a way that does not identify you. A member of the research team holds a professional position as a mental health promoter which could create a conflict of interest for you. If this occurs, this person will not have any contact with you and your transcript will remain confidential to Dr Helen P. Hamer, the Principal Investigator.

What will happen to the results of the study?

The researchers would like to report the findings from this project in a range of professional and academic journals and at conferences. Our findings will also be reported in a range of professional and academic journals and conferences to inform health professionals and other relevant people of what enables the social inclusion of service users in society.

Who is organizing the research?

Dr Helen P. Hamer is a Senior Lecturer and the Principal Investigator of the research study which is being conducted through the School of Nursing at the University of Auckland.

PTO



Contact for further information

If you require any further information, please contact:

Principal Investigator: Dr Helen P. Hamer +649 9237441 or h.hamer@auckland.ac.nz

Head of School: Associate Professor Judy Kilpatrick +649 373 2897 j.kilpatrick@auckland.ac.nz

Ethics Chair: For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1143. Telephone 09 373 7599 Extension 83711.

If you have any further questions or concerns about this project you can also contact the Health and Disability Advocate, telephone 0800 555 050

Thank you for taking the time to read this information sheet.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 19th November for 3 years from 19 November 2012 to 19 November 2015 Reference Number 2012/8812.

Appendix F: Reference group membership



Stories of Success: Mental Health Service Users' Experiences of Social Inclusion in Aotearoa New Zealand

Reference Group Membership:

Matua Hone Ahu, Kāumātua, Centre for Mental Health Research

Debra Lampshire (Chairperson) Centre for Mental Health Research

Dr Helen P Hamer (Principal investigator)

Huka Williams, member Te Roopu Arahi (Like Minds, Like Mine Māori leadership group)

Corrinne Oliver, *Like Minds, Like Mine* Reference Group

Sione Vaka Pacific peoples' perspective

Dr Allan Wylie, Research Director, Phoenix Research

Judi Clements, Chief Executive, Mental Health Foundation and commissioner of research

Dr Jacquie Kidd, co-researcher

Shona Clarke (co-researcher & observer)

Terms of Reference

- Represent stakeholders within the Like Minds, Like Mine national programme and the broader mental health sector
- Have oversight of the project to ensure that the project meets the objectives, intentions and vision of the Like Minds, Like Mine programme
- Have oversight of the progress and processes of the research
- Advise and have input into the data analysis, findings, implications and the recommendations of the research
- Read and respond to draft documents generated by the research process as required
- Contribute to the drafting of the final research report

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