SOCIAL INCLUSION AND EXCLUSION, STIGMA AND DISCRIMINATION, AND THE EXPERIENCE OF MENTAL DISTRESS

AOTEAROA/NEW ZEALAND

GORDON, S., DAVEY, S., WAA, A., TIATIA, R., & WAAKA, T.

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ACKNOWLEDGEMENTS

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PREFACE

I recently presented on the latest evidence base underpinning our efforts to counter stigma and discrimination associated with mental distress and reflected on how much had changed since I began my involvement with this work in 1998.

In terms of the introduction of the concepts of social exclusion and social inclusion into our thinking on the subject, I know Liz Sayce's 2000 book titled *From Psychiatric Patient to Citizen* was seminal for me personally.

Our national mental health policy, and particularly the 2014-2019 *Like Minds, Like Mine National Plan* (Ministry of Health and Health Promotion Agency 2014), now abound with these terms.

This work addresses the significant gap in understanding these concepts from the perspective of service users themselves. The more I undertake qualitative investigations into the experiences of service users, the more I come to appreciate the depth and richness of insight that can only be gleaned through this type of research. That appreciation also makes me anxious in terms of being responsible for ensuring that those insights are identified and conveyed in a manner that is commensurate with their significance and the trust that has been placed in us by the very act of people sharing such personal and often sensitive experiences with us. I hope that those of you who participated in the focus groups are happy with what we have produced based on your insights.

At times the experiences shared through the focus groups reflected the depth of ignorance and intolerance that exists in our society but, although not as pervasively experienced, there were also glimpses of how our society could be different, and the significance of that not only for us as people who experience mental distress, but for everyone.

This work was the collaborative undertaking of all the named authors, coming from various personal and professional experience and knowledge bases. I believe this has served to enhance the scope of the work, particularly in terms of enabling the investigation of cross-cultural perspectives in a manner that is most appropriate for each; and I acknowledge every one of the team for their respective contribution.
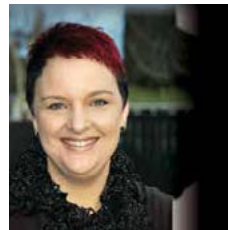
Dr Sarah Gordon

FOREWORD

The Like Minds, Like Mine programme celebrates its 20th anniversary in 2017 and over the past two decades has taken a lead in researching issues associated with mental health discrimination in Aotearoa/New Zealand.

It is my privilege to introduce the most recent research project, which builds on the knowledge gained from Stories of Success (2014) by delving deeper into the concepts of social inclusion and exclusion, and exploring how these affect the lives of people who experience mental distress, including young people, Māori and Pasifika people.

Social inclusion is elusive to define, yet its antithesis – social exclusion – can have a lasting, negative impact on people's wellbeing. Being excluded prevents people from participating in the normal activities of life, and also denies people the rights that are available to others.

From the mouths of those who live with mental illness every day, the experience of inclusion is described as feeling "you are where you should be, with the people you should be with, and as the person you really are". Exclusion, on the other hand, is described as feeling isolated, embarrassed, humiliated and ashamed, of being discriminated against and feeling that they don't belong and never will.

The results from this qualitative research offers further important insights into how the Like Minds, Like Mine programme might significantly impact the vicious and virtuous cycles of social exclusion and inclusion.

Why do people feel included in some situations and excluded in others? How can employment and sport support participation and engagement? What steps must we consider taking to change the culture of discrimination? Does public education and the power of contact counter social exclusion and promote social inclusion?

These are some of the many questions this research uncovers as it endeavours to find ways to continue reducing discrimination associated with mental distress, so that those with personal experience can exercise their rights to fully participate in the activities of their choosing.

We thank Dr Sarah Gordon, Steven Davey, Anaru Waa, Ramona Tiatia and Toa Waaka sincerely for their commitment to this research.

The results and recommendations from their work will inform and strengthen the Like Minds, Like Mine programme over the coming decade.

Shaun Robinson
Chief Executive
Mental Health Foundation of New Zealand

EXECUTIVE SUMMARY

The current research study was an exploratory investigation into social inclusion and exclusion – particularly as they relate to discrimination – from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand.

Methodology

Eight focus groups were conducted, two for each of the *Like Minds, Like Mine* target groups (Māori, Pacific peoples, and young people), with two additional general groups. The main inclusion criterion for participation was self-identification of personal experience of mental distress. These groups explored participants' perspectives of what led to exclusion/inclusion, what *resulted from* exclusion/inclusion, and what the experience of exclusion/inclusion is like for people with experience of mental distress.

Results

In total, eighteen themes were identified. Infographics provide a diagrammatic representation of these themes.

The following themes were identified variously as **both antecedents (possible causes), phenomena, and/or impacts of social exclusion *and* social inclusion**: 'Family and/or whānau as key determinant'; 'Caught between Pākehā/Palagi and Māori or Pasifika worlds: colonisation, racial discrimination, cultural disconnection and the medical model (exclusionary); reconnection with *tikanga Māori* (inclusionary)'; 'Employment as inclusionary or exclusionary'; 'Medication and medicalisation'; 'Self or others: is it me or is it you?'; 'Spirituality and religion'; 'The need for social masks'; and 'Sport, teams, healthy and active lifestyle: a lack of (exclusionary); involvement in (inclusionary)'.

The following themes were identified variously but specifically as **antecedents, phenomena, and/or impacts of social exclusion:** 'The causal role of mental distress in creating social exclusion'; 'Health care services and professionals as agents of exclusion'; 'Negative socialisation'; 'Government agencies as agents of exclusion'; 'The unrelatability of mental illness: an intractable divide?'; 'Self-exclusion'; 'Pervasion'; and 'Social representations of mental illness'.

The following themes were identified variously but specifically as **antecedents, phenomena, and/or impacts of social inclusion:** 'To look past mental distress, but not *right* past it'; and 'True face, right place'.

A number of sub-themes were also identified.

Conclusion

Overall, participants reported having experienced extensive social exclusion that had often commenced at a young age. In contrast, social inclusion was experienced as limited in scope, and often dependent on families and/or whānau, strategies to hide mental distress from others and/or havens within the wider exclusionary community. Most of the themes suggest *cyclical*, reinforcing processes: exclusion breeds exclusion (in vicious cycles) and inclusion breeds inclusion (in virtuous cycles). As phenomena, social exclusion and inclusion are distinct *subjective* experiences. Exclusion is typically a feeling of acute alienation, and for youth in particular, social exclusion (along with discrimination) is experienced as pervasive. The experience of inclusion is described as feeling as if you are where you should be, with the people you should be with, and as the person you really are.

Based on the results of the project, recommendations for the *Like Minds, Like Mine* programme are offered.

INTRODUCTION

Recent decades have shown an increase in the number of anti-stigma and anti-discrimination initiatives internationally (Stuart, 2009; Sartorius & Stuart, 2009). In Aotearoa/New Zealand, the *Like Minds, Like Mine* programme to counter stigma and discrimination associated with mental illness was established 20 years ago by the Ministry of Health in response to the 1996 Mason Report *(Inquiry under Section 47 of the Health and Disability Services Act 1993 in Respect of Certain Mental Health Services: Report of the Ministerial Inquiry to the Minister of Health Hon Jenny Shipley*).

The terminology and concepts of social exclusion and inclusion are being increasingly used throughout anti-stigma and anti-discrimination initiatives generally.

Enhancing social inclusion opportunities for those people whose lives have been most disrupted by mental distress was identified as a priority action for the five years from 2012-2017 through Aotearoa/New Zealand's Mental Health and Addiction Service Development Plan (Ministry of Health, 2012). Part of the work recognised as necessary in support of that action was continuing national efforts to reduce stigma, including by way of refreshing the *Like Minds, Like Mine* programme.

The refresh saw the terms 'social exclusion' and 'social inclusion' first appear explicitly as key features of the *Like Minds, Like Mine National Plan 2014–2019: Programme to Increase Social Inclusion and Reduce Stigma and Discrimination for People with Experience of Mental Illness* (Ministry of Health and Health Promotion Agency, 2014), with the overall aim of the programme being extended to specifically include increasing social inclusion as well as reducing stigma and discrimination. This is most appropriate given that such programmes need to promote affirming positive ideas, attitudes and behaviours towards people with experience of mental distress, as well as countering negative ideas and myths, attitudes and behaviours, in order to be most effective (Corrigan *et al.*, 2014).

The definition and conceptualisation of social inclusion through the current *Like Minds, Like Mine National Plan* comes from earlier work by the Mental Health Commission that was informed by an unpublished review of literature and conversations with key people (Cuthbert, 2009). More specifically, in terms of the meaning of, and relationship between, the concepts of social inclusion, exclusion and discrimination, that work reported:

> Social inclusion is 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 reside...From this perspective, discrimination can be seen as one of the barriers to inclusion. However, there may also be other barriers to inclusion such as the effect of a mental impairment, lack of support or self-stigma. Exclusion may also be caused by cumulative actions, behaviours, prejudices and oversights which are often too complex to be identified as discrimination but are more likely to be picked up under a social inclusion analysis (Cuthbert, 2009, p. 9).

Cuthbert (*ibid.*) identified ten areas of life that directly or indirectly impact on the level of social inclusion experienced: family activity; social networks; employment, income and financial services; community participation/leisure; housing; transport; mental health; physical health; education and training; and civil/justice.

A distinction was made between how social inclusion and discrimination are measured:

> Discrimination is typically measured from a person's subjective perspective of whether an individual's or agency's behaviour was fair or whether he/she felt discriminated against. Discrimination surveys may rely on respondents' self-definition of discrimination, rather than whether a legally enforceable right had been breached. Social inclusion, on the other hand, can be measured from either a subjective or objective perspective i.e. through finding out whether a person has experienced feeling excluded (subjective) or through measuring actual rates of participation or access to services (objective) (Cuthbert, 2009, p. 10).

Since its inception, there have been a number of research projects (Barnett & Barnes, 2010; Lennan & Wyllie, 2005; Peterson, 2007; Peterson *et al.*, 2008; Peterson *et al.,* 2004) conducted as part of the *Like Minds, Like Mine* programme, that have investigated discrimination from the subjective perspective of people who experience mental distress. A quantitative investigation (Mental Health Commission, 2011) into social inclusion, using data from the 2008 New Zealand General Social Survey, found that people with experience of mental distress were significantly more likely than the general population to:

- feel isolated
- feel that they had been treated unfairly or had something nasty done to them
- find it difficult to express their identity in Aotearoa/New Zealand
- report having had a crime committed against them
- report difficulty in doing free-time activities;

and significantly less likely to:

- be partnered
- be employed and be satisfied with their job
- have a 'fairly comfortable' or better standard of living
- be satisfied with the housing they are currently living in.

With respect to these indicators, the level of severity of symptoms was often identified as something that significantly exacerbated disparities.

Despite considerable inroads having been made, it has been identified that there remains a lack of clarity, breadth of knowledge, and means of measurement in terms of both social exclusion and social inclusion, and the relationship between the two (Baumgartner & Burns, 2014; Coombs *et al.*, 2013; Wright & Stickley, 2013). Exploration of the concepts from cross-cultural and subjective perspectives has been identified as particularly lacking (Baumgartner & Burns, *ibid.*; Pfundmair *et al.*, 2015).

Stories of Success (Hamer *et al.*, 2014) is one of the more recent research-based publications to be produced through the *Like Minds, Like Mine* programme. It involved a qualitative investigation of positive experiences of social inclusion from the cross-cultural and subjective perspectives of people with a diagnosis of mental illness living in Aotearoa/New Zealand, with a particular focus on participants' perceptions of the internal factors and external factors that support inclusion within society. Based on the findings of the research, social inclusion was defined and described as:

- a fluid (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), subjective concept that is not merely the absence of social exclusion;
- 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;
- a two-stage process: the before stage representing the person moving beyond their self-stigma to a feeling that social inclusion was a possibility; the after stage representing an increased sense of personal power, a deepening of social relationships and a belief in the right to contribute to society;
- centering on the actions and words of others (such as family and friends, peers, employers, colleagues and professionals), and particularly the idea of reciprocity, and the 'give-and-take' of social connection, which generates mutual positive regard;
- a concept for which personal power is an integral part, providing people with the self-confidence to make decisions and choices in their daily lives, and to challenge existing institutional structures that perpetuate stigma and discrimination;
- often being linked to a champion, a particular person or event (e.g., health professionals, peers, family members and cultural leaders).

For Māori specifically, their positive experiences of inclusion were found to be based on the principles of whānaungatanga[1] and manaakitanga[2], and led to a restoration of their mana[3] and wairua[4]. For Pasifika, 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 of these groups, kaumātua, kuia, their elders, pastors and whānau were important people who fostered their deeper sense of inclusion.

One of the recommendations stemming from this work was that the *Like Minds, Like Mine* programme further develop and measure the Aotearoa/New Zealand concept of social inclusion, inclusive of Te Ao Māori and Pasifika realities. The present work sought to do this and to extend the body of research generally by undertaking a qualitative investigation to explore the concepts of social exclusion and social inclusion, as they particularly relate to discrimination, from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand.

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1   Whānaungatanga: 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 with whom one develops a close familial friendship or reciprocal relationship (http://www.maoridictionary.co.nz).

2   Manaakitanga: hospitality, kindness, generosity, support - the process of showing respect, generosity and care for others (http://www.maoridictionary.co.nz).

3   Mana: prestige, authority, control, power, influence, status, spiritual power, charisma (http://www.maoridictionary.co.nz).

4   Wairua: spirit, soul (http://www.maoridictionary.co.nz).

METHOD

Ethics

Ethical approval for the research study was sought and obtained from the University of Otago Human Ethics Committee.

Literature review

The first stage of the research study involved a selective review of recent (2005-2015) literature with the intention of gaining (i) greater clarity around the current state of meaning and measurement of each of the concepts – social exclusion and social inclusion; (ii) greater clarity around how the concepts relate to each other; (iii) greater clarity around how each of these concepts, and the relationships between them, relate to anti-discrimination programmes; and (iv) the current gaps in the literature.

A predefined set of search terms ("social exclusion" AND/OR "social inclusion") AND (disab* AND/OR ill* AND/OR distress* AND/OR disorder AND/OR health) was used to identify relevant literature via the following databases/search tools: PsycInfo, Medline, Cinahl, Google Scholar, Like Minds website (http://www.likeminds.org.nz/).

The review was limited to publications written in English where the full text was readily available online.

Qualitative investigation and analysis

Methodological approach

The results of the literature review informed the design of the research study: an exploratory investigation into social inclusion and exclusion (conceptualised in relation to multi-level and multi-dimensional participation) and the causal relationships involved – particularly in respect of discrimination – from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand, using semi-structured focus groups and a hybrid Interpretative Phenomenological Analysis (IPA)/ Thematic Analysis (TA).

'APP' development

A custom-made tablet application ("app") was developed to prompt and support each participant to identify and then depict/describe relevant personal experiences via an iPad. The app initiated this by presenting examples of groups of people and places where social inclusion or exclusion might occur (e.g., whānau, iwi, hapū, tribe, family, friends, workmates, sports teams, clubs, congregations, marae, whenua, country, city/town, community, workplace, school, university/polytechnic, church, clubrooms, gym, Facebook, bank, health service, government department, police force, armed forces, court, shops, movies), and then prompting and functionally supporting each participant to express their own story/stories through a drawing/s, appended with voice recordings, explaining the features of the drawing/s. Participants were then asked to share and discuss their drawings and descriptions as part of the semi-structured focus group discussion. The app recorded each participant's matched drawings and descriptions and these were then downloaded, transcribed, catalogued, and used in support of the TA undertaken with the focus group data (within an IPA framework).

Development of question schedule

A question schedule was developed to guide the semi-structured focus group discussion (Appendix 1). This included main questions aimed at supporting group discussion and exploration of the concepts in response to the sharing of experiences, with associated prompts that could be used to further clarify and probe as necessary in response to the group discussion and dynamic.

Focus groups

Three community-based mental health services were engaged to support the recruitment and hosting of the focus groups. This involved their disseminating the advertisement/invitation (Appendix 2) and Participant Information Sheet (Appendix 3) through their service and networks, and taking the names of those interested. For some, it also involved transporting participants to and from the venue.

A total of eight focus groups were convened, two for each of the *Like Minds, Like Mine* target groups (Māori, Pacific peoples, and young people), in addition to two general groups. The main inclusion criterion was self-identification of personal experience of mental distress[5], with those who identified as Māori, Pasifika, or youth being able to choose to attend either a general group or the relevant ethnic/age-specific group. There were no exclusion criteria (other than via adherence to the main inclusion criterion).

For Māori and young people (aged 18-25 years), one focus group was held in Hamilton and one in Lower Hutt. For Pasifika, one focus group was held in Lower Hutt and one in Wairarapa. The groups were held between the 10th and 19th March 2016 with between 4 and 12 participants involved in each. The duration of each focus group was approximately two hours.

Dr Sarah Gordon, Ramona Tiatia and Toa Waaka co-facilitated the focus groups with Sarah leading the general and youth focus groups, Toa the Māori focus groups, and Ramona the Pasifika focus groups. Each group began with a culturally appropriate welcome.

The lead facilitator then went through the information sheet verbally with participants and invited and responded to any questions that participants had. Those who wished to proceed to participate were then asked to complete the Consent Form (Appendix 4).

An overview of the schedule for the focus groups was provided by the lead facilitator; each group then commenced with introductions and a series of ice-breakers. Starting with social exclusion, in order to stimulate thinking but without explicit use of the concept words themselves and to demonstrate use of the app, the initial stimuli for each focus group involved the facilitators working through the drawing and verbal recording tools of the app to depict their own personal experiences of exclusion. Participants were then each provided with an iPad and instructed to use the app to draw and describe an experience/s where they have felt like they were not part of a group of people or

a place for people. Twenty minutes was allowed for completion of this exercise and all co-facilitators were on hand to provide support with use of the app. At the end of the 20 minutes, the group was brought back together and participants were asked to share their drawings and descriptions. A semi-structured group discussion was then facilitated, as per the question schedule.

The group then broke for food and fellowship.

The process was repeated for the concept of social inclusion.

On completion of each focus group, participants were thanked and provided with a $50 voucher in recognition of the time and knowledge they contributed to the work. The groups were concluded and participants farewelled in the respective culturally appropriate manner.

The focus group discussions were audio-taped and fully transcribed. Each participant was assigned a code for the purposes of anonymised analysis and reporting.

Analysis

The analytical approach taken was a hybrid of TA and IPA. Taking a TA approach, a frequently used method to develop interpretations of qualitative data, is consistent with the analysis of group-level data (Braun & Clarke, 2006). The highly structured approach of IPA, however, can additionally be used to develop models (including related to health and well-being) (Fade, 2004). Hence, by taking an IPA framework (as a tool rather than as a philosophical approach) and combining it with the standard meaning-making approach of TA, this allowed for a more structured consideration of meaning and possible causal relationships. To combine IPA and TA in this way is a novel approach agreed upon within the research team (discussions with the team also involved informal guidance from international academics using IPA, who have published on its use in focus group research).

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5   Note: The second of the Pasifika focus groups was attended only by Samoan community leaders, who did not themselves identify as having personal experience of mental distress.

Having chosen the structured approach of IPA, which utilises a four-column table to generate a coding framework (for full details, see Pietkiewicz & Smith, 2012), consecutive coding took place for each interview. The themes that emerged from the first interview provided the coding framework for subsequent interviews (i.e., throughout all Māori, Pasifika, youth, and the general focus groups), with new themes emerging along the way as the analysis proceeded. This was an iterative process, with repeated reconsideration of the emerging list of themes and of transcripts to ensure appropriate connections between themes/raw data.

The themes were organised according to whether they were possible causes of social exclusion or inclusion (or, at least, likely *antecedents* to these), effects of social exclusion or inclusion (or, at least events/ situations *subsequent* to these), indications of characteristics of the phenomena themselves (inclusion or exclusion), and/or strategies for promoting inclusion or avoiding exclusion. Indications of the concepts as phenomena (i.e., subjective experiences) were allowed to emerge without formal questions focused on this in the interview schedule. All of these categories retained links to the focus group types from which they were drawn. Themes emerged across all group types, some group types, or, in rare cases, only one group type. These themes are detailed in this report with a focus on implications for the target groups of interest.

Methodological limitations

A potential limitation identified was use of the app, particularly for those participants who lacked experience with the use of this type of technology. However, given that the purpose of the app was only to prompt and support each participant to identify and then depict/describe relevant personal experiences, this potential limitation did not present a risk to the primary data being sought (that of the focus group discussion). Irrespective of this, the potential limitation was mitigated by the use of comprehensive demonstrations, instruction and on-hand support. Generally, the feedback from participants was that they welcomed and enjoyed the opportunity to use the iPads, and mostly found them to be intuitive.

It was originally planned that one focus group for each of the target groups would be rurally based. This was not possible due to numbers.

The greatest challenge in terms of recruitment was with the youth focus groups. We have experienced similar challenges with other work and it raises questions about whether focus groups are an appropriate method of data collection with this population group.

The second of the Pasifika focus groups was attended only by Samoan community leaders, who did not themselves identify as having personal experience of mental distress. This meant that, in light of this, the data from this group had to be interpreted differently, and was used more as a way to illuminate findings from other groups.

FINDINGS

The research findings are outlined in the following sections. The first contains the literature review, followed by the emerging themes from the focus groups.

Literature review

Introduction

A total of 4,365 publications were identified through the initial search. A sift by title reduced these to 2,018 publications and a sift of those by abstract resulted in 388 publications passing through to the full text reading stage. At this stage, 234 publications were de-selected for either being too specific or too general for the aims of the review. Ultimately, then, 154 publications provided the basis for the final review.

Social exclusion

MEANING

There are ongoing attempts to define social exclusion, but it is clear from the current evidence base that it has varying meanings (Morgan *et al.*, 2007; Peace, 2001, cited by Wright & Stickley, 2013); and there is widespread recognition that there is no standardised concept or measurement of social exclusion. This creates difficulties for conducting research and evaluation (Heitzmann & Kaplan, 1988; O'Reilly, 1988; Morgan *et al.*, *ibid.*; all cited by Nicholson & Cooper, 2013).

Despite the vagueness and assumed meaning, social exclusion has dominated research on social variables such as unemployment, or at least in terms of the terminology used (Morgan *et al.*, *ibid*.).

More than poverty

The vagueness of social exclusion may be attributable to its political origins as a more (politically) acceptable term than 'poverty' within the domain of social justice (Burchardt, 2000; cited by Morgan *et al.*, *ibid*). Poverty has been defined, in part, as 'social discrimination and exclusion' (United Nations, 1995, p. 57; cited by Morgan *et al.*, *ibid*) or even as being synonymous with social exclusion:

> *Poverty and social exclusion are concerned with a lack of possessions, or an inability to do things that are considered normal by society* (Howarth *et al.*, 1998, p. 18, cited by Morgan *et al.*, *ibid.*).

The UK's Social Exclusion Unit (2004) played a significant role in moving the concept beyond that of poverty:

> *Social exclusion includes poverty and low income, but is a broader concept and encompasses some of the wider causes and consequences of deprivation* (p. 4).

More specifically, unlike poverty, social exclusion encompasses non-material aspects of disadvantage faced by people experiencing mental distress, such as the role of personal and institutional discrimination (Sayce, 2001, cited by Morgan *et al.*, *op. cit.*). Social attitudes towards mental distress play a part in rejection and isolation (Link & Phelan, 2004, cited by Morgan *et al.*, *ibid.*), which cannot be understood fully by taking a purely economic perspective. Social exclusion may also be associated with a range of other negative experiences, such as chronic illness, social isolation and cultural disconnection (Burchardt *et al.*, 2002b, cited by Boardman, 2011), all of which go beyond the issue of poverty.

Emphasising rights and participation

Recent emphases in the literature on social exclusion (and inclusion) are on rights and participation (Curran *et al.*, 2007). These can be considered complementary perspectives on social exclusion.

Social exclusion in relation to rights can be conceptualised as a lack of, or diminished access to, the rights that are generally available to citizens of a society, or to members of a group, community or institution (see Curran *et al.*, *ibid.* for discussions of the relationship between rights and social exclusion). For example, there are the rights to employment, education, and the right to 'free speech'.

In terms of participation, the emphasis is placed on the engagement of the individual in their sets of relationships with others, from the individual

level, up to the level of society and its institutions. We could give the same examples used for rights in, perhaps, a more tangible form: participation in the workplace, participation in school or a university course, participation in 'free speech' activities (e.g., speaking at a political rally, writing a newspaper article, or voting in a referendum). A concern about this emphasis is the possibility that individuals will be blamed for their social exclusion as a 'lack of participation' (the suggested remedy for which may be 'more participation', with the onus being on the individuals themselves to achieve this) (Berry *et al.*, 2010).

Writers often express the definition of social exclusion as a combination of the lack of both rights and participation. For instance, it "involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas" (Appleton-Dyer & Field, 2014, p. 5).

Multi-level, multi-dimensional, dynamic, relative, subjective and objective

Social exclusion is generally agreed to be a **multi-level** concept: it is applicable at the individual, household, community and institutional levels. It is also widely agreed to be **multi-dimensional**, incorporating political, economic, historical, cultural, and social dimensions (Bhalla & Lapeyre, 1997; GSDRC, 2014; Stewart & Langer, 2007; all cited by Appleton-Dyer & Field, *ibid.*; Silver & Miller, 2006).

The vagueness of the concept partly consists in a lack of consensus on which dimensions are necessary for defining the concept, or which dimensions need to be emphasised over others. It is also unclear whether it is necessary to have *multiple* deprivations in order to be socially excluded, or whether deprivation on a single dimension would be sufficient for social exclusion.

Other features that seem to be essential for a full conceptualisation of social exclusion include:

> The **dynamic** nature of exclusion. Participation levels change over time, having many accumulating and interlocking causes, coming together in the present and possibly continuing into the future, even into future generations (Todman *et al.*, 2013).

> **Relativity** (Burchardt *et al.*, 2002b, cited by Boardman, *op. cit.*). As exclusion occurs at a time and place, it can only be judged to exist relative to other situations.

> **Subjective and objective** perspectives (e.g., Payne, 2006). For someone to participate in 'key activities' (however these are to be defined) there is both a personal experience as well as an objectively measurable activity (see e.g., Morgan *et al.*, *op. cit.*).

Agency

Agency is also key (Burchardt *et al.*, 2002b, cited by Boardman, *op. cit.*) because social exclusion is an active process: someone or something is doing the excluding. For example, the agent may be an individual (e.g., a neighbour or employer) or group (e.g., a sports team), government, or an institution (e.g., a bank, a government department or educational establishment).

This has practical implications because, if social exclusion is to be challenged, the agent of exclusion first needs to be identified. If, for instance, social exclusion of people with experience of mental distress is socially driven rather than institutionally driven, then efforts to overcome exclusion had better not focus only on institutions. The experience of integrated employment can sometimes be an example of this, where employees with impairments are still isolated by co-workers despite rights, laws, rules and policies requiring workplace inclusivity (Novak *et al.*, 2011).

A related question has emerged from parts of the literature regarding the extent to which people's own agency is relevant to social exclusion. If someone had no desire to participate in society, could they still be socially excluded?

A response to this question is:

> *…individuals or groups are socially excluded if they are denied the opportunity of participation, whether they actually desire to participate or not* (Barry, 2002, p. 16, cited by Morgan *et al.*, *op. cit.*).

In other words, the issue of social exclusion does not come into play when someone decides to either participate or not participate, but rather when the factual (i.e., objective) *opportunity* to participate arises. This means that not wanting to participate has no bearing on whether social

exclusion exists, including in cases where there is no (objective) opportunity to participate. It may be that an individual expressing no desire to participate in society is being influenced by the pressures that already exist in society. This suggests the need for a nuanced definition of social exclusion as the **'enforced lack of participation'** (Burchardt, 2000, cited by Morgan *et al.*, *ibid.*).

This definition also shifts judgments regarding agency (and, therefore, blame) from individuals and groups to the wider structural dimensions. This is recognised in the *UN Convention on the Rights of Persons with Disabilities* (World Health Organization, 2007b) and the *New Zealand Disability Strategy* (Minister for Disability Issues, 2001), where a social model of disability prevails, emphasising the barriers created by the social and physical environment that inhibit the ability of persons with disabilities to exercise their human rights. The focus is then on those who exclude rather than those who are being excluded.

THE IMPACT OF SOCIAL EXCLUSION

Studies on social exclusion have shown it (however *it* is to be conceptualised) to be destructive. This is shown in its "unique ability" (Krill *et al.*, 2008) to simultaneously jeopardise four fundamental features of human well-being: belonging (Baumeister & Leary, 1995); self-esteem (Baumeister, 1994); control (Seligman, 1975); and meaningful existence (Williams, 2001, 2007) (all cited by Krill *et al.*, *op. cit.*).

People with experience of mental distress, immigrants and refugees, women, homeless people and the elderly are particularly vulnerable to social exclusion (Mathieson *et al.*, 2008; World Bank, 2007; Abbott & Sapsford, 2005; Crombie *et al.*, 2005). The carers of people experiencing mental distress are also at greater risk of social exclusion (Gray *et al.*, 2010). Much of the research to date has then, focused on one or more of these groups.

Social exclusion appears to sit within a complex, mutually reinforcing set of factors in relation to people with mental distress. These people are likely to experience multiple forms of deprivation, including crime, poverty, unemployment and poor physical health (Boardman, *op. cit.*). According to Iwasaki and Mactavish (2005):

> ...*social exclusion appears to create a vicious cycle whereby the various sources of stress experienced by people with disabilities–individual and societal– converge to reinforce and potentially intensify a cycle of stress and social exclusion* (p. 206).

Further, it has also been suggested that mental health professionals themselves contribute to the social exclusion of people with experience of mental distress (Social Exclusion Unit, *op. cit.*).

Finally, there has been some research on cross-cultural impacts of social exclusion (but notably, very little other cross-cultural research on social exclusion or social inclusion) (Pfundmair *et al., op. cit.*). More specifically, research has identified and compared individualist cultures (e.g., North American and Western European) with collectivist cultures (e.g., Asian and African) (Hofstede, 1980; Hofstede *et al.*, 2010, cited by Pfundmair *et al.*, *ibid.*). Findings from two separate studies suggest that people with an interdependent sense of self – as typically found in collectivist cultures – were less impacted upon by social exclusion (Gardner *et al.*, in press, cited by Pfundmair *et al.*, *ibid.*; Ren *et al.*, 2013). The idea then, is that social representations (collectivist as opposed to individualist) may function as a social exclusion buffer. One explanation for this is that exclusion of the interdependent self is not experienced as threatening, because its existence is by definition relational, hence exclusion is less likely to be experienced as personal (Markus & Kitayama, 1991, cited by Pfundmair *et al.*, *ibid.*). This would not be the case in more individualist cultures.

Consistent with this, Pfundmair *et al.* (*ibid.*) found in their cross-cultural research (involving participants from Mainland China, Hong Kong, India and Germany) that individualist participants from an individualistic culture (Germany) showed greater reactions to social exclusion than was shown by participants from collectivist cultures. This was found even when recording physiological responses (i.e., *biological* rather than social

reactions to social exclusion), suggesting that this occurs independently of any cultural 'down-regulation' of responses in collectivist cultures, which might otherwise explain the differences. Similar findings emerged in previous research comparing participants from North America and Japan (Fiske & Yamamoto, 2005).

THE MEASUREMENT OF SOCIAL EXCLUSION

General issues
As the concept of social exclusion is not well-defined, so there is currently no well-defined measurement. Rather, as the term is so often used unreflectively, attempts to measure social exclusion can be similarly unreflective, with pragmatism prevailing over clarity.

The measures that are available tend to be from the UK and mainland Europe where the concept of social exclusion was first popularised.

Indicator approach
Overall, researchers most often aggregate a series of quantitative indicators to measure social exclusion (Social Exclusion Unit,*op. cit.*), or else opt for a narrow focus (e.g., on homelessness) (Burchardt *et al.*, 2002a, cited by Clifton *et al.*, 2013).

Criticisms have been made of the indicator approach to measurement, namely that the sets of indicators that are actually used tend to overlook the social aspects that make social exclusion distinguishable from poverty (Levitas, 2006). The sets of indicators are often based on pre-existing datasets (e.g., government surveys) that had not been specifically developed to measure social exclusion – and so the indicators are somewhat artificial constructs. It is also often the case that indicators are hard to differentiate from risk factors, hence 'big picture' measures miss out on the details of causal relationships (Mental Health Commission, 2011).

In relation to the surveys that collect the data upon which indicators are based, a problem of representativeness has also been raised. The surveys may not include the people who are most likely to be subject to social exclusion – and to experience mental distress – as participants, because such people either live outside households or are not accessible in some other

way due to their situation (e.g., people living in institutions, asylum seekers, disabled people, or older adults) (Boardman,*op. cit.*).

An important point is that the majority of these surveys are *cross-sectional* rather than *longitudinal* and so are generally unable to capture the dynamic nature of social exclusion or make headway with identifying the causal relationships involved. In other words, their data are limited to a snapshot in time, not over time where influences between variables may be identifiable.

Examples

The European Commission (2006) has produced the 'Laeken Indicators', which provide an illustrative example of how sets of separate indicators are formed for the attempted measurement of social exclusion (at the population level). The 'Laeken Indicators' are based on the *EU Statistics on Income and Living Conditions* (a pre-existing dataset), and notably, use items collected longitudinally. This set of indicators comprises four dimensions: income inequality; unemployment; education; and health. It is divided into primary and secondary indicators, with a third level being left open for individual countries to determine relevant indicators for their own context.

This measure has attracted the common criticisms of indicator approaches: It lacks a clear conceptualisation, even to the extent that it may not be applicable for all EU member states (Mabbett, 2004), and it has a sustained focus on poverty/material issues, which does not – as discussed earlier – cover all aspects of social exclusion of people experiencing mental distress. Overall, this is not an obvious unification of indicators that would amount to a measurement of social exclusion (for those experiencing mental distress).

Other approaches have been suggested as more useful because the measures are the result of attempts to *theorise* social exclusion. Rather than pull together separate indicators to create an overall measure, they look to weave together theoretically key domains of social exclusion.

One prominent example of such is the dimensional approach of the Centre for the Analysis of Social Exclusion (CASE). A lack of participation in *any one* of the following four

dimensions is sufficient to indicate social exclusion, according to CASE:

- consumption (capacity to purchase goods and services);
- production (relating to economic or socially valuable activities);
- political activities; and
- social interaction. (Burchardt *et al.*, 2002a, cited by Morgan *et al.*, *op. cit.*).

CASE uses data from the *British Household Panel Survey*, which allows the indicators to be followed over time (i.e., longitudinally) using the same households, with the possibility then of identifying causal relationships.

Another prominent example of a theory-based measure, developed in 1999, is the Poverty and Social Exclusion survey (PSE). The PSE, measuring what is necessary for a minimum standard of living and social inclusion, was constructed via consultation with the UK public; if at least 50% of respondents included an item, then this was included in the measure. Data is collected at the household level, with the indicators involved being measured along dimensions: service exclusion, exclusion from social relations, impoverishment, and exclusion from labour markets (Gordon *et al.*, 2000, cited by Boardman, *op. cit.*). The survey is, however, cross-sectional so it offers limited possibilities for identifying causal relationships.

EVIDENCE GAPS

In addition to the obvious need for clear definition and conceptualisation of the concept, the literature has explicitly called for the need to **clarify the causal relationships involved in social exclusion**. Direct and indirect indicators of exclusion must then, be distinguished, along with the risk factors for exclusion (Morgan *et al.*, *op. cit.*). This, in turn, suggests the need for more *longitudinal measures* to be developed and implemented.

There is a clear need for **cross-cultural research** in this area. As stated in Whitson *et al.* (2015), "to date, little is known about how individuals from different cultural contexts choose to socially include and exclude others" (p. 24).

It was also clear from the current review that there has been little research focusing on the **subjective** experience of social exclusion.

Social inclusion

MEANING

The evidence base accessed by this review was often unclear regarding whether the term 'social inclusion' is to be seen as: (a) having a distinct meaning from 'social exclusion'; (b) simply the opposite of 'social exclusion', that is, if someone is not socially excluded, then they must be socially included and vice versa; or (c) a term being used to mean something else entirely (e.g., 'social cohesion'). The absence of a clear definition, or sometimes the absence of *any* definition, has been pointed out in other reviews (Wright & Stickley, *op. cit.*). It is "a protean concept; there is no standard single application of a term that is used in many different countries, by a multitude of professional disciplines and in many different contexts and settings" (Clifton *et al.*, *op. cit.*, p. 6).

One "widely cited definition" regarding people with experience of mental distress is:

> *A virtuous circle of improved rights of access to the social and economic world, new opportunities, recovery of status and meaning, and reduced impact of disability* (Sayce, 2001, p. 122, cited by Mathias *et al.*, 2015).

In Aotearoa/New Zealand, the Mental Health Commission (2009) 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" (p. 6).

Social inclusion and exclusion are often used interchangeably in the literature; hence, it is not surprising that what follows shows significant overlap with the evidence base on social exclusion.

Emphasising rights and participation

As was seen to be the case with social exclusion, rights and participation both play a part in defining social inclusion. In addition to the widely cited definition from Sayce (*op. cit.*) of "rights" and "new opportunities", there are comparable definitions, such as:

> *Social inclusion includes the opportunity and ability to participate as one wishes, to exercise the rights and responsibilities of full citizenship* (Mathias *et al.*, *op. cit.*, p. 2).

Rights are typically codified in law, in constitutions, as part of citizenry. In terms of participation, social inclusion may be definable as the positively expressed *opportunity to participate*, as opposed to the *enforced lack of participation*. To participate is to exercise the *opportunity* to participate just as to participate is to exercise the *right* to participate. The *opportunity to participate* then, could be interpreted to be synonymous with a rights-based approach to social inclusion.

For people experiencing mental distress, in particular, a common feature of the range of available definitions of social inclusion points to the importance of participation, and of being able to access those participatory opportunities (rights) available to everyone else in society (Mental Health Commission, 2009; Slade, 2009).

Multi-level, multi-dimensional, dynamic, relative, objective and subjective

As with social exclusion, social inclusion is generally considered to be a **multi-dimensional**, **multi-level**, **relative**, and **dynamic** concept (e.g., Hall, 2009; Cobigo & Stuart, 2010; Curran *et al.*, *op. cit.*). The need for both **subjective and objective** perspectives has also been emphasised in relation to social inclusion (Huxley *et al.*, 2006; Le Boutillier & Croucher, 2010; Morgan *et al.*, *op. cit.*). For instance, according to one definition, the subjective perspective may refer to a person's desire to increase participation in some respect (Stewart *et al.*, 2010), whereas the objective perspective may refer to the number of activities participated in (Lloyd *et al.*, 2008). Despite this recognition of the need for both perspectives, first-person reports from those with experience of mental distress are not common in the literature (Cobigo & Stuart, *op. cit.*).

Based on a meta-analysis of fifteen qualitative studies involving participants with disabilities, Hall (2009) (cited by Cobigo & Stuart, *ibid.*) identified six dimensions of inclusion, which include multiple levels, and subjective and objective perspectives. It is one of the few examples of a first-person focus:

1. *being accepted and recognised as an individual beyond the disability;*
2. *having personal relationships with family, friends, and acquaintances;*
3. *being involved in recreation, leisure, and other social activities;*

4. *having appropriate living accommodation;*
5. *having employment;*
6. *having an appropriate formal (service system) and informal (family and caregiver) supports.*

Social inclusion as recovery

It is perhaps unsurprising that the notion of recovery has been linked to the social inclusion of people with experience of mental distress. It is already present in, again, the definition from Sayce as "recovery of status and meaning, and reduced impact of disability" (Sayce, 2001, p. 122).

Recovery may positively impact on social inclusion or, vice versa, social inclusion may impact positively on one's mental health (Harrison & Sellers, 2008). These are all likely to be connected (Social Exclusion Unit, *op. cit.*).

Social inclusion "has parallels with the recovery-oriented approach to mental health care" (Newman & Dickens, 2012, p. 28). This connection between recovery and social inclusion emphasises, in turn, the link between the importance of having the opportunity to participate and personal agency:

> *…recovery and social inclusion* [for those experiencing mental distress] *may be linked by agency and opportunity: the opportunity to participate in one's community and gaining a sense of control* (Boardman, *op. cit.*, p. 114).

It, again, emphasises the notion of regaining control/agency:

> *…the recovery of the self, which includes gaining control, taking care of vulnerability and developing a more integrated identity, and the recovery of social inclusion, taking steps towards participation in social life* (Ammeraal *et al.*, 2013, p. 69).

Mental health service users have highlighted the importance of hope, control/agency and opportunity in recovery (Repper & Perkins, 2003, cited by Boardman, *op. cit.*).

From these sources then, mental distress, social exclusion, lack of control, and lack of opportunity to participate are all to be replaced by – respectively – recovery, social inclusion, regaining control/agency/the self, and opportunities for participation. It is important to be clear regarding the role of recovery, especially in light of the

shift in emphasis referred to earlier towards the promotion of social inclusion (Ministry of Health and Health Promotion Agency, *op. cit.*). It is not enough to remove (recover from) the negatives relating to social exclusion. The *positive* replacement is social inclusion, which extends beyond the removal of negatives.

Some writers have openly questioned the view, from a recovery perspective, that social inclusion should always be considered an unqualified good:

> *There may be a need for a positive withdrawal from society where roles and identity are maintained but without the social demands for full involvement, providing the space and time needed for recovery* (Ammeraal *et al.*, *op. cit.*, p. 69; referring to Sells et al., 2004).

A positive withdrawal may sometimes be what is needed, but whilst retaining the 'opportunity to participate'.

THE IMPACT OF SOCIAL INCLUSION

This review found that the impact of social inclusion as a separate concept has been less researched than the impact of social exclusion, with notably fewer relevant findings. This has also been identified elsewhere; for example, in relation to the concepts themselves:

> *Whilst the concept of social exclusion has attracted much interest and debate…there has been less critical attention paid to social inclusion* (Spandler, 2007, p. 3).

And, in relation to both concepts and mental health research:

> *Despite extensive policy development the dearth of papers within this review indicate that the concepts of social inclusion and exclusion have not established themselves within the field of mental health research* (Wright & Stickley, *op. cit.*, p.74).

Those research studies that do refer to social inclusion give reason to believe that inclusion increases happiness, self-esteem and confidence (Forrester-Jones *et al.*, 2006), and decision-making ability (Johnson *et al.*, 2009).

However, not all studies addressing social inclusion report wholly positive outcomes. A body of literature focused on supported housing

for people with experience of mental distress, that stretches back to the 1990s (e.g., Carling, 1993; Ridgway & Zipple, 1990, cited by Wong *et al.*, 2014), reports less positive outcomes. Whilst the presumption of a positive connection between supported accommodation and integration within the community led to a focus on housing in the context of social inclusion of those with mental distress, social disconnections are yet seen to remain despite integration programmes (Tsai *et al.*, 2012; Yanos *et al.*, 2012). This is not, of course, to say that social inclusion (as the opportunity to participate) is in any way negative but may simply emphasise the pervasiveness of the problem and the inability to address it through a singular focused strategy.

THE MEASUREMENT OF SOCIAL INCLUSION

The current situation with the measurement of social inclusion is similar to that of social exclusion. Huxley *et al.* (2012) note that in a review of the literature on the measurement of social inclusion and related concepts (e.g., social capital), whilst there were numerous attempts to measure social capital, only two studies were found to have attempted the measurement of social inclusion.

Another publication states:

> *Strikingly, our review has shown that in fact there is very little work in this field and, in our view, no single instrument currently available measures the core components of social inclusion and integration in a manner that is globally accessible and relevant* (Baumgartner & Burns, 2014, p. 361).

This same review also concluded that all identified measures of social inclusion were developed in high-income countries with limited attention paid to how a scale could be adapted for cross-cultural use (*ibid.*).

Examples

In a review responding to Australia's *National Mental Health Plan 2009-2014* (Australian Health Ministers, 2009), two measures were highlighted as meeting the criteria for an individual measure of social inclusion for public mental health services. These criteria included emphases on qualitative data, subjective and objective aspects, and multiple domains of inclusion. The measures that were ultimately suggested were the Activity and Participation Questionnaire (APQ-6) (Stewart *et al.*, 2010) and the Social and Community Opportunities Profile (SCOPE) (Huxley *et al.*, 2012).

The APQ-6 is based on pre-existing data taken from the Australian Census (from 2006), the Survey of Disability Ageing and Carers (from 2003), the General Social Survey (from 2006), and the ongoing Labour Force Survey. The questionnaire is intended for self-report in community mental health settings. It covers several domains of activity, which are work-related (paid or voluntary), related to education/training, social/community participation, and 'readiness for change' (i.e., an individual's desire for changing their levels of participation).

The SCOPE is a bespoke measurement tool (i.e., not created by pulling together pre-existing data), and is in a minority of tools that aim to measure social inclusion directly (Baumgartner & Burns, *op. cit.*). It incorporates subjective and objective items on choice, opportunity and participation. It is then, multidimensional, and has been established as valid and reliable for use with a range of mental health groups.

Using 48 items (in the short version), it consists of various formats, including closed (i.e., quantitative) or open (i.e., qualitative) responses. There are also two sub-scales relating to: (i) level of satisfaction with opportunities for inclusion; and (ii) the perception of there being opportunities for inclusion. These are measured via 7-point and 5-point 'Likert Scales', respectively. The SCOPE is completed by self-report or interview (Huxley *et al.,* 2012).

A relatively prominent multi-indicator measure is the Social Inclusion Questionnaire User Experience (SInQUE), which is based on the Poverty and Social Exclusion Survey (Gordon *et al.*, 2000, cited by Mezey *et al.*, 2013). The SInQUE was designed for people with experience of severe mental distress. It is a structured interview rather than self-report, and again covers the dimensions of productivity (e.g., education, employment), consumption (e.g., owning a home), access to services (e.g., attending a general practitioner's surgery), social integration (e.g., attending clubs), and political engagement (e.g., voting) (Mezey *et al.*, *ibid.*).

The aforementioned review by Baumgartner and Burns (*op. cit.*) proposed requirements for a social inclusion measure, drawing on much of the foregoing research. A measure must encompass subjective and objective elements, participation, structure and agency issues, relativity, dynamism,

and usability across time and place. The following features need to be integrated within any instrument to measure social inclusion:

- **Sense of belonging** in one's community and social acceptance
- Level of **participation** in community and civic life
- Sense of **agency** and **capacity to choose whether to participate**
- **Opportunities for** and **barriers to participation**.

In addition, the instrument should be:

- based on **theory** or a **framework**
- validated in individuals with a range of mental disorders
- sensitive to **changes** over the course of the illness, its treatment and the ongoing process of recovery
- composed of both **subjective** and **objective** measures
- reflective of the **values** of affected persons
- relevant to the **person** and the **context/ environment**
- of a global standard or be adaptable for **cross-cultural use**.

Currently, the tool that most closely matches these requirements is SCOPE, with its emphasis on choice, opportunity and participation (*ibid*).

EVIDENCE GAPS

Firstly, and very much related to the fundamental research required at the conceptual level, is the need for **psychometric assessment of the various available indicator-based measures** of social inclusion (Coombs *et al.*, *op. cit.*).

There is a clear need for **cross-cultural research** on both the conceptualisation and the measurement of social inclusion (Pfundmair *et al.*, *op. cit.*).

If social inclusion is to participate in, and have the opportunity to participate in, social life, then the activities that constitute this need to be defined according to time and place (i.e., **what are the 'key activities'?**) (Morgan *et al.*, *op. cit.*).

In addition to indicator-based approaches, there have been calls for a greater **qualitative focus** in research to provide insight into the subjective experiences of inclusion (Morgan *et al.*, *ibid.*).

The interconnections between concepts

Overall, there is limited explicit consideration of the concepts in relation to each other. They are often used interchangeably in the literature without explicit consideration (Baumgartner & Burns, *op. cit.*) or, occasionally are referred to explicitly as being interchangeable, such as by Mathias *et al.*, (*op. cit.*, p. 2) in their statement, "inclusion and exclusion can be conceptualised as an interwoven continuum".

A few studies have specifically compared and contrasted the two concepts, concluding that they were being increasingly used "as if they were polar opposites, as if one was the unproblematic negation of the other" (Spandler, *op. cit.*, p. 4 referring to Levitas, 2004) and "unproblematically as diametrically opposed poles within policy making" (Spandler, *ibid.*, p. 5).

In relation to the idea that social inclusion is more than simply the absence of social exclusion, there is a useful comparison with the concept of mental health:

> ...whilst 'mental health' cannot be seen merely as the absence of 'illness', social inclusion cannot be seen as necessarily the absence of exclusion as they have complex interrelated, contested, but independent meanings (*ibid.*, p. 4).

One attempt to compare and contrast the concepts, suggests a richer categorical distinction:

> 'Inclusion' denotes relations and practices that people with mental health problems perceive to signify their positive involvement in and 'mattering' to a local setting...By contrast, 'exclusion' denotes more negative eventualities that involve rejection, avoidance and distancing from other community members, such that individuals are 'made different' through more or less deliberate social actions reinforcing their problematic mental health status (Parr *et al.*, 2004, p. 405, cited by Morgan *et al.*, *op. cit.*).

The definition of social exclusion as "a risk factor for the development of mental health problems" (Coombs *et al.*, *op. cit.*, p. 906, referring to Bertram & Stickley, 2005) has been compared with the statement "social inclusion

can have protective benefits, ameliorating the negative effects of stress, and contributing to mental illness recovery" (Coombs *et al.*, *ibid.*, p. 906, referring to Harrison & Sellers, 2008). These statements may again suggest a categorical distinction, with social exclusion as risk and social inclusion as protective. To continue with analogy, eating a high fat diet is a risk factor for heart disease, but it is eating *well* that is protective against heart disease, rather than simply not eating high quantities of fat. Similarly, the mere absence of social exclusion is not necessarily protective against mental distress. (For explicit distinctions between inclusion and exclusion see Labonte (2004), and Kieselbach (2003, cited by Iwasaki & Mactavish, *op. cit.*).

Some publications offer reasons why there is no simple dichotomous relationship between the two concepts. One view is that to be socially included or excluded is a subjective state somewhere along a spectrum of social inclusion and exclusion (Parr *et al.*, 2004, cited by Morgan *et al.*, *op. cit.*). With such a view, someone is more or less included/excluded in a changeable state that cannot be objectively measured. To be *included* is not thereby to be, in any absolute sense, *not excluded*.

A related view is the 'Intersectionality-Informed Model' of social exclusion and social inclusion (Hunting *et al.*, 2015). This sees the categorical view of the two concepts as a false separation that ignores their dynamic relationship:

> ...specifically, that the processes and systems of power that shape social exclusion across populations (e.g., stigma, discrimination, racism) simultaneously shape experiences of social inclusion (p. 109).

The writers give the example of Caxaj and Berman (2010) who advanced the view that newly arrived youth in Canada can experience inclusion and exclusion concurrently, with a sense of inclusion experienced *within* their wider experience of exclusion.

The 'Intersectionality-Informed Model' takes into account a range of relevant factors that ultimately manifest in a location on the inclusion-exclusion spectrum; for example, a location based on factors of age, race and ethnicity, and socio-economic status, which are

themselves, shaped by a wider socio-political context. In practice then, the two concepts are inseparable (Hunting *et al.*, *op. cit.*).

Another view (Secker *et al.*, 2009) sees social inclusion and exclusion as wholly separate dimensions, with exclusion as an objective, structural barrier within society, and inclusion as a subjective barrier – a societal attitude. This applies again to the case of 'inclusive' workplaces for those with experience of mental distress or disability: if, after addressing institutional barriers, colleagues still exclude, then removing this barrier does not amount to social inclusion. The societal attitude remains, barring the way to inclusion.

A consequence of assuming a simple dichotomy – that the opposite of exclusion is inclusion – along with the assumption that exclusion is wholly negative, is that people *should* be socially included and, further, we should find ways to negate exclusion, to gain inclusion. This can, practically speaking, lead to perverse outcomes, such as:

> *Paradoxically, such policy measures may actually reproduce exclusion by enforcing a moral conformism. For example, the more social inclusion is seen to relate to paid work, the more those not in paid work will feel excluded and marginalised (Lister, 2000). In this way, the inclusion imperative could actually increase the gap between the supposed 'included majority' and the 'excluded minority'* (Spandler, *op. cit.*, p. 9).

An innovative response to this is the suggestion of neither promoting inclusion nor ignoring exclusion, but to develop opportunities for 'healthy segregation' in relation to the workplace by developing 'survivor businesses' (Church, 1997; Church *et al.*, 2000, cited by Spandler, *ibid.*). These then create a form of inclusion without the assumption of there being only one way to achieve this. In Church's view, the strengths developed within a survivor movement have greater value to those who are socially excluded, than the offerings from wider society.

Besides these considerations, the identified evidence base did not show any further conceptual developments.

Social exclusion, social inclusion, stigma and discrimination

SOCIAL EXCLUSION AND STIGMA AND DISCRIMINATION

The relationship between social exclusion and stigma and discrimination has been variously described in the research or policy literature on mental health as:

- discrimination *driving* exclusion, including within the domains of employment, access to services and social networks (Boardman, *op. cit.*)
- social exclusion being *linked* to stigma and discrimination within a number of domains (Stickley *et al.*, *op. cit.*)
- stigma and discrimination being a 'core domain' of exclusion (Social Exclusion Unit, *op. cit.*)
- social exclusion *entailing* stigma and discrimination (Krill *et al.*, *op. cit.*)
- stigma and discrimination being a *risk factor* for social exclusion because it is a barrier to participation (Morgan *et al.*, *op. cit.*)
- social exclusion being a *symptom* of discrimination and stigmatisation (Nietlisbach & Maercker, 2009)
- social exclusion being seen as a *compounding set of problems*, which includes discrimination (Sayce, 2001, cited by Mathias, *et al.*, *op. cit.*)
- social exclusion being a term used subjectively to describe *the sense of inequality that has arisen from discrimination* (Nicholson & Cooper, *op. cit.*)

Putting aside the multifarious attempts to provide a definitive account of what causes what, there are a number of other useful considerations regarding their associations.

For example, the social exclusion of people with impairments, in education, work and in the community, is at least reinforced by stigma and discrimination (e.g., Shier *et al.*, 2009; Abbot & McConkey, 2006; Anaby *et al.*, 2013). The stigma associated with mental distress makes finding (and retaining) work and accommodation difficult, and inhibits integration into the community (Bordieri & Drehmer, 1986; DePaulo & Morris, 2006; Morris, *et al.*, 2007, cited by Nietlisbach

& Maercker, *op. cit.*; Thornicroft *et al.*, 2009). In addition to barriers to work and education, stigma and discrimination is linked to political and judicial exclusion (Stickley *et al.*, *op. cit.*).

In terms of specific areas of research, a systematic map of the literature on social exclusion and mental health stigma in Europe identified that:

> *Advances in the field of mental health stigma and social exclusion will require a move from descriptive approaches of the phenomenon to analyses of underlying social mechanisms, which could form the basis for future interventions to reduce stigma and promote inclusion* (Evans-Lacko *et al.*, 2014, p. 387).

There is also a wealth of literature on the general subject of stigma and discrimination associated with mental health/illness/distress (i.e., not explicitly related to social exclusion), which is far wider than the current review.

SOCIAL INCLUSION AND STIGMA AND DISCRIMINATION

As stated previously, the Like Minds, Like Mine programme has shifted emphasis from *reducing* discrimination to also *promoting* inclusion of people with experience of mental distress. Similarly, Evans-Lacko *et al.* (2014) indicate the need to conjoin stigma reduction with the active promotion of inclusion, especially given the perspective that social inclusion is more than simply the removal of a negative state, whether this be social exclusion or stigma and discrimination. The idea, then, of overcoming discrimination for social inclusion is one of moving from a negative state (discrimination, social exclusion), to a neutral state (no discrimination, no social exclusion), to a positive state (social inclusion, however defined).

The evidence base for the connections between social inclusion and other concepts – in this case stigma and discrimination – is yet sparser than that for just social inclusion. This may be due to the tendency to identify social exclusion and stigma and discrimination as problems requiring a solution; rather like the 'problem' of mental distress requiring the 'solution' of treatment, but not necessarily involving *positive* outcomes (e.g., well-being and happiness).

However, where inclusion is explicitly connected with stigma and discrimination, the use of the positive term 'inclusion' – as opposed to 'exclusion' – does seem to result in a shift in focus in the literature: from mostly descriptive accounts of how social exclusion relates to stigma and discrimination, to more practical endeavours of how to overcome the latter to thereby gain social inclusion.

A frequent point made in publications is that **greater contact** with people with experience of mental distress results in reduced stigma and discrimination, thereby increasing opportunities for social inclusion. For example:

> *…familiarity (direct contact) with mental illness decreases the levels of stigma, social avoidance, and perceived dangerousness/ unpredictability, possibly opening new opportunities and creating favorable conditions for social inclusion, conditions that improve social functioning and quality of life in this population* (Sousa *et al.*, 2012, p. 192, referring to Angermeyer *et al.*, 2004).

SOCIAL EXCLUSION AND SOCIAL INCLUSION, AND STIGMA AND DISCRIMINATION

A rare example of an article that addresses the combination of social exclusion, social inclusion and stigma and discrimination is that written by Hunting *et al.* (*op. cit.*). This article seeks to address the problem of stigma and discrimination by a spectral conceptualisation of inclusion-exclusion as socially and politically contextualised.

This conceptualisation places each individual or group at some point along a spectrum. There is, then, no 'one-size-fits-all' approach to deal with an essential problem of social exclusion via some essential solution of inclusion. Each case is different for an individual or group within a society, depending on the interaction of factors that contribute to the social exclusion or inclusion (and hence where someone is on the spectrum). All of these factors are also the outcome of a complex collection of societal influences.

To overcome discrimination, it would be necessary to clarify the dynamics between the two concepts of social inclusion and social exclusion, and how discrimination has arisen. Whilst this may be acceptable at the conceptual level, it presents difficulties in practice, as indicated by Hunting *et al.* (*ibid.*):

Of course, bringing such thinking into the realm of policy is difficult because it is generally perceived that manageable interventions are those that focus more on individual behaviours and even institutional arrangements rather than on structures of oppression and the large-scale societal changes that need to be realised in order to effectively mitigate inequities (p. 116).

In other words, anti-discrimination programmes tend to take a relatively simple, static (non-dynamic) view of social inclusion and exclusion, which makes it easier to focus on more manageable details of behaviour and institutional practices. To attempt to develop programmes of anti-discrimination that address the dynamic interplay of social processes presents a very different, far less manageable, prospect.

EVIDENCE GAPS

It has been identified that there is an "urgent need for **qualitative** and contextually located accounts of stigma, inclusion and exclusion in global mental health research" (Mathias *et al.*, *op. cit.*, p. 2). Without this, there cannot be a full picture of the intersection of the concepts of social inclusion, social exclusion, and stigma and discrimination, and neither can there be a full research base upon which to develop anti-stigma and discrimination programmes.
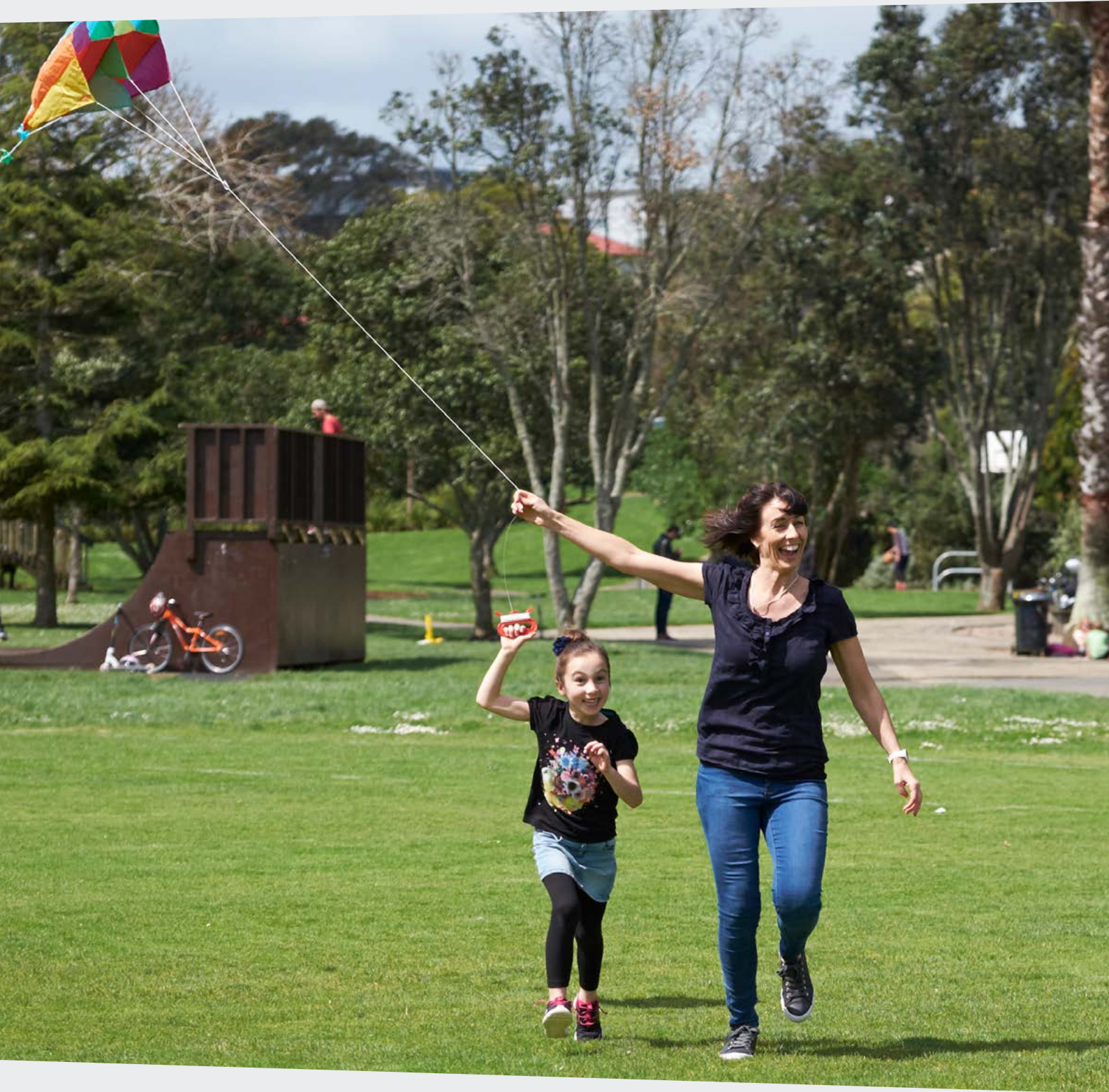
Focus groups

Collections of distinct antecedents, impacts, and characteristics for each phenomenon (exclusion/inclusion)

Social exclusion

THEME: 'Social representations of mental illness' [antecedent, phenomenon, and impact *for exclusion*]

DESCRIPTION: This theme focuses on the ways in which mental distress (identified in this case as an illness) is construed by other people, from the perspectives of the focus group participants. This is a pervasive theme for the phenomenon of social exclusion, which ran all the way through participants' views, from potential cause, to the subjective experience itself, to impacts.

The data from across the focus groups, including across group types, show that participants perceived people experiencing mental illness/distress to be understood or socially represented in wider society as:

- **Emotionally unstable:** (*"…because hello, you've got mental health issues and you be might [be] stressed…"* [F, General 15th]);
- **Dangerous:** (*"There's the stigmatisation of it too you know like, I guess for an example, the other day I was talking to a guy I went to school [with] and I said that I'd had a drug induced psychosis, he said did you kill anyone…"* [B, General 15th]);
- **Contagious:** (*"They need to stop thinking that just because someone's got depression or anxiety or schizophrenia or whatever that they're going to completely pull everyone down with them and end up in the deep dark hole. 'Cause that's what a lot of people feel who don't understand mental [distress]."* [C, Youth 15th]*; "…when you get a couple of knocks that really get you inside, you do tend to retreat, it's a protective thing and you do get the feeling like you're a leper or you should be isolated or you're an untouchable…"* [F, General 15th]);
- **Incompetent/non-credible:** (*"…when they find out that you've got a mental illness, they suddenly think oh is she capable of doing what you've asked of her."* [C, General 15th]*; "…because I've got a history of mental illness, no…you lose credibility, you lose validation…"* [L, Pasifika Group 1]); and

- **[Latently] criminal:** ([Interviewer] *"Did you disclose it [mental distress] when you did your job application?"* [Participant] *"No they didn't do a criminal record check or anything."* [E, Youth 15th]).

For the Māori and Pasifika focus groups, the dominant Pākehā/Palagi culture was considered as having a key role in the social representations of mental distress (i.e., creating, and maintaining, the notion of mental distress/illness). Given its importance, particularly in the Aotearoa/New Zealand context, this has been identified and discussed later (see pp. 40-41) as part of the stand-alone themes of 'medication and medicalisation' and being 'caught between Pākehā/Palagi and Māori or Pasifika worlds: colonisation, racial discrimination, cultural disconnection and the medical model (exclusionary); reconnection with tikanga Māori (inclusionary)'.

Participants identified television and film as having a key role in the promulgation and pervasion of these social representations of mental distress. The mass media as a whole was referred to as being misrepresentative; for example:

> *"Churchill was Prime Minister who had actually had a mental illness, you know instead they put on the news oh you know, somebody with um schizophrenia had a gun and shot up the place, you know it's the attachments, that's attached to media, nobody wants to know that, as soon as they hear all the media stuff…"* [L, Pasifika Group 1]

Finally, in addition to being part of the cyclical process of cause-effect, the 'social representations…' theme manifests as a phenomenon because it displays a sense that to be socially excluded in relation to mental distress is akin to being an alien, to be 'Other' than others. For example, participants said, *"I just felt like have I just landed on another planet…when you're in the normal everyday life world and everybody else around you doesn't have mental issues, you do feel like you're a bit, like the odd one out, like you're not quite the same."* [C, General 15th]*; "You don't even feel human."* [D, Youth 15th]*; "…you're some weird alien creature who is just dropped onto earth…"* [C, Youth 15th]; and *"You're labelled like um, not normal."* [H, Māori 11th].

A clash of social representations was found in the data, between the representation of mental illness as 'Other' and the social representations related to being Christian: despite being in a church, one participant reported feeling ridiculed by Christians. The power of the need to exile mental illness is hereby illustrated, given that in this instance it was more powerful than the Christian motivation to 'love thy neighbour as thyself'.

Another instance in the focus groups of the 'Other-ness' of mental illness is the sense that if one has a diagnosis, then this somehow precludes the possibility of also being a sexual being:

> "Oh exactly, that's a big issue that's never, it's always skirted around and people, they were completely asexual because you know, we have issues…" [B, General 15th]

THEME: 'The unrelatability of mental illness: an intractable divide?' [antecedent and impact *for exclusion*]

DESCRIPTION: This theme relates strongly to the previous theme, and especially the notion of the 'Other…'. It arose from the perspectives of some focus group participants that the unrelatability of mental illness (i.e., the fact that it may be difficult, or impossible, for people who have not experienced mental distress to understand and relate to it), together with efforts perceived as attempting to make it more relatable, are experienced as both a cause and an impact of social exclusion.

This theme came primarily from the second general focus group, and was not represented across all groups (e.g., it was not evident within the Pasifika or the first of the general focus groups).

In relation to being and feeling socially excluded, participants reported that the inability of others to relate to the experience of mental distress was a key factor:

> "I think also too with the general public that aren't mental health consumers, don't know how to relate to mental health consumers…" [D, General 15th]

> "…it was hard to go to my family because they just, they didn't understand. And um, I grew up, yeah basically going through life on my own." [D, Māori 14th]

However, it was similarly reported that the participants themselves did not relate to the experiences of people with experience of mental illness as portrayed through, for example, the Like Minds, Like Min*e* anti-discrimination campaign. Again, the media was implicated. The following exchange reflects this theme well:

> "…the messages that are coming across are not the messages that we are feeling, living in society, like a reverse psychology kind of advertising on TV and it's all wrong… ok it's nice for some people that you can hand pick a small group of people and they've succeeded so well and they've gone to university and they've got this career, the bigger handful is the group of us that can't work and when we do get a medical certificate and work part time in an average retail job…TV is photography, you can pick a small select group of people that have succeeded, you can't use that example to make the bigger group of people feel un-succeeded…" [H, General 15th]

> "Yeah, if Joe Bloggs reads the Nutters Club, ohh…" [F, General 15th]

> "No-one can relate to that, that's the problem." [H, General 15th]

Participants also expressed that they did not relate to the 'reclaiming' of the language and power-base related to mental illness (e.g., through 'mad'-pride and the 'nutters'-club) and instead experienced this as being reinforcing of negative stereotypes.

THEME: 'The causal role of mental distress in creating social exclusion' [antecedent *for exclusion*]

DESCRIPTION: One key issue is whether mental distress causes social exclusion. This is a difficult issue to resolve as mental distress may be implicit in people's experiences of exclusion; this theme is based only on explicit reports of its causal role. In the examples focus group participants gave, however, whilst it is clear that mental distress was seen as having a causal role in the creation of instances of social exclusion, it is not always clear whether there had also been a background of pre-existing social exclusion that had previously caused the mental distress itself (i.e., as part of a negative cycle).

The data for this theme came from the second Māori focus group and the first of the general focus groups.

Some participants, then, explicitly reported the experience of mental distress as being the cause of social exclusion:

> "I had a nervous breakdown and I lost everything. I lost my house, my kids, my possessions, all my worldly possessions. I lost everything. And I went living on the streets for a little while." [F, Māori 14th]

> "Before I had mental illness, my family was my life but when I was diagnosed, I hardly seen my family, just my friends." [M, General 10th]

> "Um yeah I've got a mental illness. Um I've had it for about twenty years.... Um but once I was diagnosed um, people were funny with me. Um even my own family. Um no they just wanted to shut it, you know behind doors." [D, Māori 14th]

> "Oh mine's um at school when I first had my episode and other friends found out, I lost a lot of friends from that illness and, and I felt outcast and depressed, yeah, it was really a tough time in my life at that time." [M, General 10th]

In connection with 'negative socialisation' (see below), other respondents reported drug and alcohol use as being likely contributors to exclusion, but with the experience of mental distress arising before substance use became an issue:

> "Yeah I suffered from depression way before I started on drugs and alcohol, when I started having kids I got post-natal depression as well, that's when I turned to the drugs and alcohol so...I think it's more of a hormonal imbalance." [J, General 10th]

> "I think that letting the days go by and not doing, saying or doing anything means you get worse and you sort of take to drugs and alcohol...didn't think you belong anywhere." [I, General 10th]

One other example of 'the causal role of mental distress in creating social exclusion' relates to the theme of 'Government agencies as agents of exclusion'. In referencing the picture they drew on the iPad, a Māori focus group participant spoke of their multiple experiences of arrest *"because of mental illness"* and consequent abuse *"by the police"* (see p. 33).

THEME: 'Negative socialisation' [antecedent and impact *for exclusion*]

DESCRIPTION: This theme refers to negative social contexts with a predominance of drug and alcohol use/abuse, and how these relate to social exclusion. In terms of variations/consistency across the focus group types, this theme was mainly supported by the first general focus group, but also from a number of other groups: youth, Pasifika and the second general focus group.

The role of drugs, smoking and alcohol was mostly antecedent to social exclusion and to mental distress, with some respondents considering this to be the primary cause of one or both. Often, drugs and alcohol were reported to be a normal and pervasive feature of early family and social life:

> "Drugs and alcohol was just a normal part of our life and I've been doing it since very young, I didn't think too much about it until my boys just started." [J, General 10th]

> "I'm basically the same, drugs and alcohol, ... other things ... people do, people drugging around me, you know people too young, ... bury your kid sort of thing, you know, yeah." [P, General 10th]

However, although infrequently, negative socialisation was also reported as being a result of social exclusion:

> "...and I turned to drugs and alcohol and experienced hard-out social exclusion from the Army 'cause that was like a family of brothers to me and yeah that drove me to drugs and alcohol." [I, General 15th]

Others explicitly considered negative socialisation to be part of a causal mixture, which included mental distress and family pressures:

> "Yeah no I thought that it was the family squabbling and the death of my two cousins that I was close to sort of pushed me to taking pills that I wasn't supposed to and drinking and smoking so it got me in trouble and it started from there." [I, General 10th]

"A combination of things, alcohol and drug-induced mental illness and probably from trauma from family fighting and that when I was young, like … and later on in life being hospitalised and needing medication." [?, General 10th]

In addition to the negativity of drugs and alcohol, the negativity of relationships in this social context is reflected in the following quotation:

"People that are down here and they want me to be down here with them. They don't want me to prosper and they're my friends as well." [E, Youth 15th]

This statement points to a social context where there is a form of social inclusion (*"they're my friends…"*), but which was experienced as a negative form of inclusion (*"they don't want me to prosper"*). The participant in question subsequently cut these people out of their life in recognition of this negativity.

THEME: 'Health care services and professionals as agents of exclusion' [antecedent and impact *for exclusion*]

DESCRIPTION: Whilst 'medication and medicalisation' is a distinct theme identified as being antecedent to both social inclusion and exclusion (see p. 40), the only experiences relayed in terms of health care services and professionals were related to social exclusion. The Pasifika group was the most vocal about this, but other groups voiced similar sentiments.

Participants variously reported health care services and professionals as agents of exclusion in the following ways.

Not listening to service users (see p. 42), which is likely an impact of social exclusion: (*"…and I think that's what's taken out of the equation is they don't ask us what we need, they tell us what we need."* [L, Pasifika Group 1]; *"…and I think they don't take time to get to know who you are or know your story or your background…"* [?, Pasifika Group 1]; *"But I feel like a lot of like, not psych doctors, every other type of doctor is very much like do your mental health or if you've got an issue going on that's physical they try and blame it on your mental health stuff and they say that actually there's*

nothing wrong with you because we can't find anything wrong so nothing is wrong. You're just making it all up, it's all in your head. But I feel like if, if you didn't have a mental health issue they wouldn't say that to you and they wouldn't use the words that they use towards patients with mental health issues if you didn't have mental health issues."* [C, Youth 15th]);

Making service users conform, which, in this case, was antecedent to physical exclusion: (*"…next thing you know, you say something out of line, you're in lock-up so you have to like conform…"* [L, Pasifika Group 1]);

Isolating and blaming, which seems to be an impact, or perhaps an instance, of exclusion: (*"I was scared that I was never gonna be able to get out of it…but then I started opening up and telling them all about the problems and that's the last thing I should've done you know…'cause I felt isolated, I felt like it was my fault…"* [C, Youth 10th]); and

Being abusive, which could be either/both, an antecedent or impact: (*"When I was in [an inpatient service], the nurses like walk around verbally abusing everyone 'cause they know they're not gonna say anything 'cause they're so unwell…"* [?, Pasifika Group 1]).

Being admitted into a health service also led to experiences of exclusion:

"…nobody came to see us when we were locked up in hospital, nobody, there were no, no advocates, no nothing…" [L, Pasifika Group 1]

"Um I felt isolated with my family when I was first um, when I left the hospital, no-one visited me there, my family didn't visit me there and also I felt isolated with my first experience in the hospital with the staff and other patients." [D, General 15th]

In contrast, places of non-clinical support were experienced far more positively:

"…I've found it [Mix] much more beneficial than mental health…" [I, General 15th]

THEME: 'Government agencies as agents of exclusion' [antecedent and impact *for exclusion*]

DESCRIPTION: The frequency with which participants referred to public institutions as being exclusionary resulted in it being regarded as both a standalone theme as well as a contributor to several other themes. The majority of supporting statements came from Māori and Pasifika participants, which may relate to their experiences of compounded exclusion (see p. 41-42). Examples were reported in relation to the following organisations and variously related to either potential cause (antecedent) or effect (impact):

- **WINZ (Work and Income New Zealand):** (*"Yeah I, I felt like I didn't belong there. I felt so discriminated. I felt embarrassed. I felt shameful. Um but because I had no support worker with me I felt so ashamed. I felt humiliated...Yeah I just find that in myself to stop me from feeling those sorts of negative feelings, I just don't go to WINZ at all and source other places where they might be able to help me."* [G, Māori 14th]); *"...when I go into Work and Income, I feel like that they're lying to me and they're playing 'guess who' and they should be offering grants that are available..."* [H, General 15th]);
- **The Police:** (*"Um it's [i.e. the picture they drew on the iPad] to do with um, the Police. Um I have been um, taken to the cells quite a few times. Um but it was because of mental illness. Um they arrested me a few times because I tried to self-harm and then they, they would put me in the cells and half the time I would get abused by the Police. Um and yeah just abuse because I had a mental illness."* [D, Māori 14th]);
- **CYF (Child, Youth and Family):** (*"...it all crashed on me when I had post-natal depression. And that's where it started. And like you said there are people coming in trying to tell how to do things, look after my family and my kids and um, they just put me under the system. You know and all CYF have to say about it all was, "Oh she was damaged goods.""* [F, Māori 14th];
- **Housing New Zealand (HNZC):** (*"[HNZC] kicked me out and got me another, got me a transfer. And sent me all the way down*

there where there's nothing. All there is is buses and trams. They sent me so far away from reality, this is just not worth it down there. I feel like I've come to the end of the line down there."* [E, Māori 14th])

For some, their experience in this regard was pervasive:

> *"...you know whatever government service you wanna go into, as soon as you mention the word mental illness or mental services, you'll get treated differently."* [L, Pasifika Group 1]

THEME: 'Self-exclusion' [antecedent, phenomenon, and impact *for exclusion*]

DESCRIPTION: The manifestations of 'self-exclusion' are clear and multifarious in the data as an antecedent, phenomenon and impact of social exclusion that emerged across the groups/group types, although this theme was particularly pronounced within the youth focus groups.

Participants reported self-excluding for the following reasons:

- **Being afraid of rejection:** (*"I think people, you know the fear of rejection is quite a common one, you sort of, be very careful of who you tell about what's going on in your life..."* [C, General 15th]);
- **Not trusting others:** (*"They didn't care, they never did. So from like that point as I was growing up I just couldn't trust anyone and I guess I isolated myself really in a way but they still made me feel isolated."* [D, Youth 15th]);
- **Self-excluding to avoid conflict:** (*"It was like I tried to get away from the family 'cause they were fighting but it was like everything turned wrong so the pressure was on, on me, like it was, and probably thinking it was my fault too and not knowing oh is it my fault or is it not."* [?, General 10th]);
- **Going into a defensive shell/cocoon**: (*"[Social exclusion] just makes you shut down, yeah and you go into your cocoon."* [D, General 10th]; *"I stayed inside, I wouldn't go out. If, if I felt like I was going out the gate, that everyone would be still staring at me. Watching me, you know."* [G, Māori 14th]);

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- **Self-judgement and discrimination:**
  (*"...you're different, 'cause you're different compared to people out there."* [C, Youth 10th]; *"And because they make you feel different aye...Yeah like...the way they look at you, the way they talk to you."* [E, Youth 10th]; *"People are judging you, discriminating..."* [C, Youth 10th]; *"...when I go into groups and that, I don't feel like I belong there or I shouldn't be there."* [E, Māori 14th]).

A sub-theme of 'self-exclusion' refers to a lack of communication (of those with mental distress with people around them). Not talking to others is, for some of the participants, a way to self-exclude, and was expressed mainly by those in the youth focus groups:

> *"And most of the time I don't bother speaking because it's like actually they don't give a fuck what I say."* [D, Youth 15th]

> *"What's the point of trying when people don't actually care?"* [C, Youth 15th]

> *"No I don't open up with people at all."* [E, Youth 15th]

> *"[As a child] half the time I wouldn't talk. I just couldn't talk to anyone."* [F, Māori 14th]

THEME: 'Pervasion' [phenomenon for exclusion]

DESCRIPTION: The sense that social exclusion, stigma and discrimination have pervasive impacts was found almost exclusively within the Youth focus groups, with one respondent from the Māori focus group expressing similar sentiments.

An example of the sentiment for youth participants was the following exchange:

> Interviewer: *"Where do you find you encounter* [discrimination] *the most?"*
>
> *"Everywhere."* [H, Youth 10th]

Again, in the second Youth focus group, the sense that social exclusion is in some sense absolute was also apparent:

> *"Well I guess for me it affects everything because if you feel like you don't belong then where do you sit in the world?"* [C, Youth 15th]

Of note too, is that people in the first of the general groups supported the idea that this pervasion was something that they had previously, but no longer, experienced:

> Interviewer: *"Can I ask you guys as a group do you, do you often feel like you don't belong, is it a common experience for you?"*
>
> M: *"Not any more for me, not anymore."*
>
> E: *"Same with me too..."*

Possibly, there are different reasons for the sense of pervasion in the case of Māori, with racism and colonisation as key factors in combination with mental distress, which may then relate to the inclusion of 'country' in the statement *"...and where I fit in this country is really, I don't feel like I fit anywhere"* [E, Māori 14th]. This expression of not fitting in anywhere in Aotearoa/New Zealand is discussed further in relation to colonisation and the theme of being 'caught between Pākehā/Palagi and Māori or Pasifika worlds...' .

Social inclusion

THEME: 'True face, right place' [antecedent, phenomenon, and impact for inclusion]

DESCRIPTION: In one sense, this is the most important of the themes relating to social inclusion, particularly as a depiction of the phenomenon of *what it is like* to be socially included (e.g., *"I just let it flow over me, it was so, so nice and that was a sense of belonging."* [F, General 15th]). The 'true face' reference is the personal state of self-knowledge and being authentic, being able to just *"be yourself"* [D, General 15th] without 'the need for social masks' (see p. 51). The 'right place' reference is simply where having a mental illness is not relevant because it is accepted (*"...they accept you for who you are..."* [C, Youth 10th]) – there is a *"feeling of family"* [I, General 15th], of *"belonging"* [J, Māori 11th], feelings of connection, of feeling wanted and of receiving support (*"...'cause they [whānau] always cared and helped me and that"* [B, Māori 11th]). The theme covers most of the groups, but is perhaps dominated by the second of the two general groups (although there is no compelling evidence to identify anything like a pattern here).

This includes instances of apparent 'negative socialisation', which were nevertheless experienced as social inclusion:

> *"I went to jail I felt like I belonged...I felt jeez this could be a good place to stay for the rest of my life. I met, all the guys that I met were in jail were all good, good, good they all had good hearts and I thought man this is better than out on the street."* [E, Māori 11th]

> Discussing a gang: *"It's like...it's like me feeling at home with those guys..."* [?, Youth 10th]

A sub-theme of 'true face, right place' that is very much part of this refers to the power of inclusion as a form of support, which is mostly found as an antecedent or enabling factor of social inclusion. Participants from the Lower Hutt groups highlighted these aspects when speaking of Mix (a not-for-profit organisation that supports those who live with the experience of mental illness, through a variety of creative and life skill opportunities) and of drug and alcohol support groups as being one of the few, or only, places where they had experienced inclusion, in the midst of wider societal exclusion, and the importance of that to their recovery in general:

> *"...it's there for all those different cultures in Naenae that they can come together and come to Mix, to feel a part of society..."* [H, General 15th]

> *"I think you get your self-esteem back a little bit because you can be involved with people that know what you're going through so you don't actually have to put on a mask, you can just be there."* [C, General 15th]

> *"For me, like one of mine was obviously Mix was the feeling of acceptance, like there's no, nobody's judging you and that also because you have common backstory I suppose that you can relate when they're not well and so you don't judge them because they're not well that day or if you're struggling that day..."* [C, General 15th]

For some, this experience acted as a springboard into social inclusion, beyond Mix:

> *"And I think with...oh I think with Mix, it's really good as a springboard as well in that you know, you go to Mix and you heal...you know recharge or become stronger, energise and it gives you the confidence and energy to maybe look around at different places that you can, you've got your safe base but you can kind of go around, just put your feet in water and test things to just broaden in your..."* [F, General 15th]

Finally, being part of the Like Minds, Like Mine programme was also identified as providing a sense of belonging and an opportunity to socialise as part of a like-minded group that included people not ordinarily engaged with:

> *"And then with the 'Like Minds, Like Mine', I tell ya we used to have fun. When we used to have our functions, they have karaoke. [Laughs]. And they get on there and sing and you know and you're, you know you're standing next to the CEO and you're like, "This is the CEO guys." [Laughs]. The CEO. And you're standing there. You know and you're all being the part of a group."* [F, Māori 14th]

THEME: 'To look past mental distress, but not right past it: the need to balance support and equality' [antecedent for inclusion]

DESCRIPTION: For participants 'to look past mental illness, but not *right* past it' would be to recognise that someone with mental distress may require some support, but without any stigma, assumptions of incompetence, or making them feel that they are any different from others. It is to provide support without erosion of respect and agency. As an enabling, or possibly predisposing factor, this may lead to social inclusion. The theme emerged largely from the youth focus groups, with some representation also from the Pasifika and Māori groups.

Employment is one situation where this theme manifested:

> *"Just like maybe if I'm having a crap day but I'm still at work she [manager] sort of expected me to be cheery and helpful to everyone and not have an attitude or blah, blah, blah. Like I get it but sometimes it's not possible for me to act like everyone else."* [D, Youth 15th]

> *"I felt uncomfortable with being there and ... um 'cause the boss treated me differently than the others. And I got stressed out easily... [They treated me differently] because if I had to take time off 'cause of my mental illness, she would be all angry and stuff."* [D, Māori 11th]

One respondent clearly expressed the essence of balancing support and equality as being a matter of personal empowerment, by indicating that what is needed are *"people to support you to change to a better person"* [C, Youth 10th]. Similarly:

> A: *"So um...what type of things does your dad and your new partner do to..."*

> C: *"Oh she um helps us achieve goals and stuff, helps us making right decisions, make, help us lead in the right direction..."*
> [?, Youth 10th]

This integrates well with a strong sense throughout the data that participants want to retain their personal agency, and to work things out for themselves (see p. 45).

A sub-theme of looking '...past mental distress, but not *right* past it...' refers to being listened to, the desire for which was repeatedly expressed (e.g., *"And at the end of the day all I wanted was someone just to listen."* [F, Māori 14th]), mostly with regard to possible strategies to gain social inclusion. The importance of being listened to was mostly mentioned by Māori and Pasifika. Again, there was the example from involvement in the Like Minds, Like Mine programme:

> *"And at the end of the day, we weren't just speaking for ourselves but there were a whole lot of other people that didn't have voices."* [F, Māori 14th]

It is notable that *not* being listened to was associated with social exclusion within health care services (see p. 36): *"I think that's what's taken out of the equation is they don't ask us what we need, they tell us what we need."* [L, Pasifika Group 1].

Where someone's voice is heard, the personal benefits are clear:

> *"...it was a confidential forum and I saw it advertised in the paper where you could go and speak to this forum about your mental health experience and I actually did that and I talked for three hours solid and it was all recorded and that was the best thing I ever did, it that was my first experience of having been listened to and felt heard."* [D, General 15th]

Antecedents and impacts showing *overlap* between the two phenomena

THEME: 'Family and/or whānau as key determinant' [antecedent for both exclusion and inclusion]

DESCRIPTION: This theme encapsulates experiences that were reported as antecedents to social inclusion and social exclusion.

Participants often attributed social exclusion, in part, to early life experiences within the family and/or whānau; for example, abuse. Expressions of this theme were found in the majority of groups, including across all three group types. These were often linked to a complex array of negative social circumstances, and included:

- **Negative dynamics:** (*"I'm kind of like the middle child. So growing up being the middle child…was always difficult 'cause you were always that middle child. [Laughs]. And because I was the middle child I spent most of my young years quite rebellious…I just felt different."* [F, Māori 14th];

- **Conflict and tensions within the family:** (*"For me I think it was jealousy, my aunties were jealous that my Koro and Nanny, they used to spoil me and not their kids…"* [C, Youth 10th]);

- **Explicit abuse and trauma:** (*"…the [figurative emotional] wall got built from being sexually abused, ah beaten up in my family, from my father. But he's passed away now and I forgave him for what he'd done to me."* [E, Māori 14th]); and

- **The perception that the whānau and/or family fell short of a normative standard for family life** – that is, family and/or whānau was not sufficiently caring or supportive: (*"OK so when I was younger lots of shit went down and as I was growing up still more shit keeps going down but regardless of the shit it, it's how people that are supposed to care about you and love and should act compared to how they did and do."* [D, Youth 15th]).

Again, there is the overlap with 'negative socialisation' and 'the causal role of mental distress…', where early experiences explicitly involved mental distress, and drugs/alcohol:

"I first experienced mental distress at the age of nine when my parents divorced and my mother attempted suicide and I saved her." [I, General 15th]

"…combination of things, alcohol and drug induced mental illness and probably from trauma from family fighting and that when I was young…and later on in life being hospitalised and needing medication." [?, General 10th]

Conversely, whānau and/or family were also identified as being a locus of inclusion. This positive orientation mainly originated in the discussion of the first general group and the Māori groups. This is not, perhaps, surprising, given the emphasis in Te Ao Māori on connection with whānau, and health being in large part defined by whānau relationships (by contrast with the more individualistic Pākehā culture):

"Knowing that you're not alone in the world and the only one's that's not sick you know, and there's support from family and whānau and friends." [?, General 10th]

"I feel happy when, when I met my son and found out where he lived and went up and met all my grandchildren. 'Cause I've got no family now, nobody that loves me. And I just feel happy that I've found them and I feel great in that group. No one puts me down or anything there." [D, Māori 14th]

For some participants, including those who experienced negative family relationships and events, family and/or whānau was identified as being the people with whom feelings of normalcy and connection were associated: *"Family reminding you that you are normal, just going through a phase, yep."* [?, General 10th] This often included extended and 'adopted' families and/or whānau that also provided a pathway into wider social inclusion:

"Yeah mainly family, mainly family make me feel more accepted and confident that I could connect more with people and um…set my priorities straight for myself and just acknowledging them is probably the biggest thing in my life that I possibly could do…" [D, Youth 10th];

Discussing their iPad picture choice: *"…the Māori one with whānau 'cause I was*

actually the first intake in the army to join the army tribe, Tūmatauenga and I'm always welcome to go back to the marae in Waiouru, which is pretty cool that there's pretty hard out social inclusion for me…and a feeling of family, yeah"…" [I, General 15th]

"I chose my son's whānau um with this unconditional love from them and so did all my children and they really helped me and helped my kids and just took us in under their wing really and just, we're like the whānau I never had." [I, Pasifika Group 1]

"I felt belonged when my Dad found a new Mrs and they've got two boys now, I felt belonged when I was in their family, felt belonged to their family and my two little brothers…" [C, Youth 10th].

This notion of the 'feeling of family or whānau', then, which helps to define the theme 'true face, right place' (see p. 40), conveys the idea that family and/or whānau need not mean only one's immediate relations. For some people, pets are part of this extended family. They act as buffers of social exclusion or even promote a sense of social inclusion:

"I went into a pretty bad state where I would stay at home with my dog all day and just think it's me and my dog against the world and that was pretty bad social exclusion." [I, General 15th]

"…having those babies [cats] to come home to every day, greet you at the door and they're all like purr, purr, purr, purr and like jumping on you and all sorts of stuff. It makes you feel like you're more wanted and like you're needed and stuff." [C, Youth 15th]

Regardless of who participants identified as family and/or whānau or who they identified as providing them with a sense of family and/ or whānau, it was often considered central to people's lives; and potentially the most significant in terms of the experiences of social exclusion and social inclusion:

"…like family was always there but it was always the what if, you know like if you get rejected from your family, it's a pretty big thing." [D, General 10th]

THEME: 'Self or others: is it me or is it you?' [antecedent for both exclusion and inclusion]

DESCRIPTION: The data contains threads of dialogue which, when pieced together, appear to show a dichotomy in terms of who participants feel is responsible for the problem and who is responsible for the solution. Whilst some responsibility is directed at other people and at society, there also appears to be considerable self-blame and an emphasis placed on the primacy of one's own agency in providing the solution (and so this theme is an antecedent relating to inclusion and exclusion).

The theme is based firstly on the frequent finding that in addition to some surprisingly infrequent criticism of others in relation to antecedents to exclusion, participants would mostly criticise *both* themselves and others in the same utterance:

"Yeah, I don't know. I guess I'll just have to get over my trust issues but then people in my life keep on letting me down so it's like OK maybe I'm right. Everyone's just arseholes." [D, Youth 15th]

"I think 'cause you feel different, you don't feel part of the crowd, part of it is within you but I guess part of it is also how people react towards you…" [F, General 15th]

The tendency was so strong that a sub-theme of 'self or others…' referring to advocacy of public innocence was identifiable, indicating an unwillingness to blame others or society. Participants preferred instead to interpret and attribute actions to a lack of awareness. Examples include:

"I don't believe, I think the general public that don't have mental health are not mental health consumers, it's not a deliberate thing, they don't deliberately go out of their way to not relate to them, I don't think they do that, even with yeah, staff as well, the staff, I don't think they do, it's not that." [C, General 15th]

"It's definitely an ignorance thing out there." [H, General 15th].

Further, experiences of overcoming social exclusion often involved asserting individuality, independence and personal agency, which then resulted in a strong sense of self-empowerment. This was found most strongly in the youth focus groups:

> *"I mean people will be dicks or they'll be really good people regardless of you but only you can change situations I guess as they affect you, your perspective on things."* [D, Youth, 15th]

> Interviewer: *"Who or what made it different?"*

> Respondent: *"Me."*

> Interviewer: *"You made it different?"*

> Respondent: *"Yeah by getting a job. Is that right? Yeah, yeah I did it all myself. WINZ are fucken idiots. They don't help you. I did it all myself and I'm proud of myself for that."* [E, Youth, 15th]

Finally, being part of the Like Minds, Like Mine programme was also experienced as empowering:

> *"But the satisfaction was we were out there telling them how it was. You know 'cause when you're in that first setting and you're scared and you don't know what to say and you think they're going to lock you up and not let you out. You know we got past that. So we were telling them look this is what works. This is what doesn't work…"* [F, Māori 14th]

THEME: 'Medication and medicalisation' [antecedent for exclusion and inclusion]

DESCRIPTION: This is another strong theme, running through every group, with multiple statements that cut across a number of issues. It relates to social exclusion and inclusion in the following ways.

Firstly, the theme shows assumptions of accepting one's diagnosis, the medical model (e.g., medical explanations for mental distress), and pharmaceutical treatments as a prerequisite to getting better, staying well, addressing the problem of social exclusion and to thereby gain social inclusion. In this theme, no subtle distinction seems to be made between the two concepts; the absence of one is deemed the presence of the other:

> *"Like recognising you've got a mental illness is one step, know you need help is another step, committing yourself to the treatment's another step, you know and people go well you've got a mental illness, you know he's on medication, he's doing the right thing."* [D, General 10th]

> *"…[mental illness is] on both sides of the family. Like I guess it's in part what I was trying to say. I guess there's a little bit in there as well but maybe it takes some shit to maybe bring it out properly. I don't know."* [D, Youth 15th]

However, several participants conveyed their experiences of the negative effects of medication. These effects can contribute to social exclusion and contribute to being treated differently from others because of the stigmatising implications of taking these types of medication. Coupled with their side-effects on behaviour and appearance, medications have clear potential for exclusionary impact:

> *"Oh like I was with this recruitment agency for like two years, odd jobs here and there and then I had to do a drug test and he asked what sort of medications I had so I just told him straight up, then after that, no, no more work."* [G, Pasifika Group 1]

> *"…people on medication, people look at you differently…"* [C, Youth 10th]

> *"Half of us are sedated and we're still waking up off medication during the day."* [E, General 15th]

One interesting exchange reflected how a diagnosis can be experienced as both inclusionary and exclusionary:

> *"It's like a secret organisation, once you're in the club, you can't leave."*

> Interviewer: *"Is that, is it a good club to be in?"*

> *"Um I've, yeah, yes and no like you know, I've met a lot of people."* [D, General 10th]

Receiving a diagnosis, which constitutes formal admission into *"the club"*, is something that can never be verified as no longer being relevant (*"… you can't leave"*). However, this *"club"* seems to offer some level of inclusion, too, despite being an example of exclusion:

"...well sometimes um I feel, I feel like um, out of the mental health system I don't feel included but in the mental health system sometimes it's alright but out of the mental health system, I don't feel like that at all, even around my family, I don't feel like, they're not in the mental health system." [E, Pasifika Group 1]

THEME: 'Caught between Pākehā/Palagi and Māori or Pasifika worlds': colonisation, racial discrimination, cultural disconnection and the medical model [antecedent for exclusion]; reconnection with tikanga Māori [antecedent for inclusion]

DESCRIPTION: It is unsurprising that issues of colonisation, racial discrimination, and cultural disconnection were most prominently discussed in the Māori and Pasifika groups; and these issues compounded social exclusion for those participants. Conversely, addressing those issues and supporting reconnection was identified as a way towards social inclusion – that is, reconnection with tikanga, whānau, iwi and hapū to thereby gain a sense of belonging.

For Māori the issues of colonisation, racial discrimination, and cultural disconnection were experienced as antecedents to social exclusion in terms of:

- **Acting differently and having different values from everyday Pākehā society**: (*"When, when the Māori does something ... his own family they say "Oh don't, don't worry about it. You know not to do it that way next time." Pākehā punish you and punish you and they don't let you forget it. That's what I reckon anyway."* [G, Māori 11ᵗʰ];

- **Perspectives not being represented, understood or valued at the institutional/ governmental level**: (*"Like ah for parliament...because we didn't belong on our own land such as land occupation... fighting for the rights, sovereignty...We didn't belong on our own whenua. We didn't belong in our own tikanga..."* [J, Māori 11ᵗʰ]);

- **Being caught between two worlds**: (Discussing causes of mental distress: *"Could be clash of the two different cultures; Pākehā and Māori cultures. But we do things at home that Pākehā don't*

approve of...Like, and like putting a hangi down." [G, Māori 11th]; *"I'm just trying to fit in with, in a Pākehā world 'cause I was bought up in the Pākehā world because ah, I had no Māori upbringing. My father and mother used to speak Māori but they, you know were caned at school so they had to stop."* [E, Māori 14th]; *"I felt like I didn't belong there, partly because there was only four other Māori...we'd always get left out of playing together, we'd always get left out of some sports things and yet, most of us were quite fast, good at sports but we wouldn't get that opportunity."* [K, Youth 10ᵗʰ]); and

- **Being completely disconnected from *tikanga Māori***: (*"I know so little about the Māori, my Māori life or my land or anything about you know, don't know much."* [E, Māori 14th])

Similar experiences were reported by Pasifika participants, particularly in relation to issues of having migrated to Aotearoa/New Zealand and having to adjust to a clash of cultural values:

"...us kids having to go to European school so here we were living in Tonga in the house and every time we opened the door it was a Palagi world so for us um, there was a lot of confusion and being left out 'cause all the Palagi kids were doing very different things from my family..." [J, Pasifika Group 1]

In terms of the experience of mental distress in particular, cultural tensions exacerbated perspectives that medication and the medical model were antecedent to social exclusion.

One sustained discussion related to whether taking medication takes away *mana*. This appeared to show a split between perspectives even within a Māori group. One member of this group expressed a Māori value in opposition to what may be considered to be a value originating in Pākehā society (i.e., that medication has supreme value in recovery from mental distress). What follows is an extract from this exchange (from Māori 11ᵗʰ):

H: *"It's like um, they're taking the mana away from our Māori people. That they got no mana. Medication has got it. They got ... It's the medication. I'm sorry, I'm sorry..."*

Interviewer: *"No that's, it's a point of view. It's your point of view..."*

H: *"Sorry for that but hey you know? They're taking the mana away. You've got to get it back. Get your mana back. Fuck the medication. Sorry my, sorry for swearing."*

Interviewer: *"Would you like to hear a response from anyone? Anyone like to respond...?"*

?: *"We have to take medication to keep well..."*

C: *"So we won't end up back in the hospital. And if we, like for us here who is taking medication, we stop taking our meds we'll get sick bro."*

H: *"Got to have your mana too."*

C: *"...taking medication and that it's keeping you on a level that you, that you are where sort of where you are. I'm not a hundred percent but way better before, before when we were sick."*

Members of the Pasifika group were particularly critical of medication and the medical model itself:

"We [the medical establishment] *don't wanna hear your, about your stories of your abuse, we just wanna give you medication so you can be quiet and live in society quietly...because you know, doctors prescribe medication, that's all they're good for, it's like they're glorified pill pushers..."* [L, Pasifika Group 1]

"It's because it's a psychiatric model and it's a Palagi way of being...what's missing is if we're talking about all paths being connected...so how come they focus on one thing?" [L, Pasifika Group 1]

Whānau, iwi and hapū were experienced and seen by some participants as ways to reconnect with *tikanga Māori* and to gain a sense of belonging and social inclusion:

"I went to parliament 'cause I was living on the streets, I went to parliament and I seen [Māori Member of Parliament]. And I went to have a lengthy talk with [them] because I didn't know who I was by then. By the time I ended up talking to [them] all I knew was I was a Māori living in Wellington, that's it. Um [they] helped me find my Dad's iwi after conversation about whakapapa and connections. [They] helped me identify my linkage to Ngāti Kahungunu. It wasn't 'til I moved back into Wellington that Ngāti Kahungunu come in and then they gave me a difference perspective to Pākehā life. 'Cause that's all I knew was Pākehā life. I didn't realise there was this other side to life." [F, Māori 14th]

L: *"Is it important um for your wellbeing to feel like you're, that sense of belonging?"*

J: *"Yeah it is. Mmm. In Māori way too eh? A sense of belonging is whakapapa. Eh am I right?"* [J, Māori 11th]

"...back in those old days. You know going out hunting. Going and get your own kai not diving into Pak'n'Save. Yeah sort of like in those kinds of ways you know? Now I'm sort of like in the city, being a city slicker. You know being flash, you know flash jeans, flash shoes you know? Not going up there picking puha or, you know I've never done that. I've done eeling but I've never, never really done hunting in my life. You know?" [H, Māori 11th]

THEME: 'Employment as inclusionary or exclusionary' [antecedent, and impact for exclusion and inclusion]

DESCRIPTION: 'Employment...' was not discussed as much as would perhaps be expected, with the theme being viewed as either an antecedent and/or impact of inclusion or exclusion relating to all group types. The negative aspect seemed to relate more to Māori and Pasifika participants, although it may be difficult to identify a pattern from this with any confidence.

Being employed and/or having a positive employment experience was identified as being significant to social inclusion in terms of providing a sense of purpose, belonging, relatability and opportunities to socialise, which may involve cyclical processes. To have opportunities to work may be an impact of social inclusion, in addition to then becoming an antecedent to continued inclusion through continued employment and the consequences of employment (*"money, friends, choices"* [C, Youth 10th]):

"Possibly not 'cause as this one said you sort of feel a little bit of purpose when you're working and it makes you, I don't know, it helps with your mental health. That's all I can say, I know that. It does." [D, Youth 15th]

"I felt in the workplace I belonged eh because um, I had one thing in common with, with the other workers and to get the job done and I felt ah that I belonged there because um, I love working." [E, Māori 11th]

Employment can have direct positive implications for socialising (and inclusion):

"...but when you grow up, you sort of go to work and they're the people that you associate or whatever so you get like social socials from work as well..." [?, General 10th]

Also reported as a cause of social exclusion, and as an effect, were:

- **The diminished options for employment for those with a mental illness diagnosis:** (*"Even like trying to find a job. If you put down you've got a mental illness, um they seem to shut it, shut you out. I've been trying to look for a job for ages."* [D, Māori 14th]);
- **A sense from colleagues that you might not be competent:** (*"...whereas sometimes people find out that you've got mental health issues and they suddenly, you're on a different level even though you might be doing something just as professional as them."* [C, General 15th]); and/or
- *Being treated differently due to mental distress:* (*"I had to take time off 'cause of my mental illness, she [manager] would be all angry and stuff."* [D, Māori 11th]).

Some participants felt that they had missed out on work and career opportunities generally as a result of their experiences:

"I could've had a career by now if my situation was done differently, I would've had a career by now"..." [I, General 5th]

"I've wasted years of my life just doing drugs and alcohol, ...put a cap on seven years, it's like, I mean that's like an apprenticeship, you know maybe a mortgage or a house, you know, girlfriend maybe." [H, General 10th]

THEME: 'Spirituality and religion' [antecedent, and impact for exclusion and inclusion]

DESCRIPTION: The role of spirituality or religion in the lives of the participants was not widely expressed across the groups as a factor related to exclusion/inclusion. It was, however, especially prominent in the Pasifika group (it was also assertively expressed by a member of one of the Māori groups). The connection with friendship (fellowship with other 'believers') is present in this theme, as well as the relationship between God (or Jehovah or the Creator) and the 'believer'.

"...what that [picture] symbolises is my experience at church and the amount of relationships that I built in friendship and basically being just open and you know, honest and comfortable with my character and basically coming to a point where you know, everyone's close enough to just relax at church and get your business with your God and yeah, they made me feel really happy, really safe, really good..." [K, Pasifika Group 1]

"It's ah fellowship. Learning about God. Unity. Unite. Love, respect. And showing love for ah, for the Creator, the one that created, created all things. God Jehovah." [G, Māori 11th]

It is likely that, as an antecedent, this factor is predisposing for social inclusion, and probably reinforcing as an impact. In relation to social exclusion, however, one participant expressed the incompatibility between their religious practice and the views of mental health services, which categorise talking to God, Jehovah or the Creator (or similar deities) as symptomatic of psychosis:

L: *"It doesn't fit in the circle of the square of mental health services."*

D: *"Yes it is, it's a sign of hallucination and sort of, it's not realistic so I mean... but it's the physical appearance some people would see it in a different form you know, it just seems that you started, you know talking to God or hearing voices, they would consider that into your sickness, for example, like a psychosis or schizophrenic..."* [D, Pasifika Group 1]

"...but I mean you know we are all connected in our parts of being so if a GP denies the fact of the spiritual side, then how are we gonna heal, like our health..." [?, Pasifika Group 1]

This medicalisation of spiritual experiences is a potential antecedent to social exclusion (possibly compounding existing exclusion) and/or an impact of exclusion, which is likely reinforcing as an ongoing practice and worldview.

THEME: 'The need for social masks' [antecedent *for inclusion*, impact *for both exclusion and inclusion*]

DESCRIPTION: 'The need for social masks' is difficult to disentangle. Whilst it is a clear impact of social exclusion, 'social masks' were reported and discussed in reference to both social exclusion and social inclusion, across the majority of groups (and across all four group types).

Some people feel the need to wear this figurative mask to hide their experience of mental distress when in the "normal, everyday... world" [C, General 15th]:

> "I sort of [put up a] front that kind of camouflages or I don't really talk about the mental health side of things, yeah, maybe that's how I deal with it." [F?, General 15th]

The following quotations illustrate the type of problem to which mask-wearing is a response – that is, the types of situations where society appears to have expected certain behaviours necessitating the wearing of a mask in response:

> "They expect everyone to be a certain way." [C, Youth 15th]

> "And people can't accept for who, accept the way you are." [C, Youth 10th]

> "Basically she...just expected me to be this person that I'm not all the time." [D, Youth 15th]

> "I feel sometimes, I feel that society tries to, as individuals, try to put like, say, for example, a circle into a square..." [J, Pasifika Group 1]

Other statements illustrate how people have then responded:

> "Yeah like you're some weird alien creature who is just dropped onto earth and then somehow you're supposed to put on this mask and pretend to be a human and walk around but you know deep down that you don't belong and that you never will." [C, Youth 15th]

> "Mmm...just...trying to just not stress out about things...be like the others." [D, Māori 11th]

In addition, however, links to social inclusion cannot be entirely ignored. Wearing a social mask may be an antecedent to social inclusion, according to one participant who gave the example of going to an art group outside Mix:

> "...but the other acceptance one that I have is I go to another art group that has got nothing to do with mental health and they don't even know that I've got mental health issues but they, because we're on a professional level...they just treat me like another artist...And I feel complete acceptance because they have no idea [laughs], which is sort of weird...I'm an artist there, I'm not a mental health consumer so...But I've sort of found acceptance in both situations..."
> [C, General 15th]

This last part of the quotation "...I've sort of [author emphasis] found acceptance...." expresses the ambivalence of this theme. However, the same individual who made this statement, also stated categorically "And I feel complete acceptance [author emphasis] because they have no idea [laughs], which is sort of weird..." [C, General 15th].

THEME: 'Sport, teams, healthy and active lifestyle': a lack of [antecedent, and impact *for exclusion*]; involvement in [antecedent *for social inclusion*]'

DESCRIPTION: When reflecting on experiences of social inclusion, being involved in sport, teams and having a healthy and active lifestyle was often identified as being prominent in participants' past life ("*I wish I was still like fit looking, ... muscles and stuff (laughter), I wish I was running and maybe running New Zealand or something (laughs)*" [?, General 10th]).

There were a few indications that not being able to continue with playing sport, or be in sports teams and generally be physically healthy, were precursors to social exclusion for some participants. For instance, in the first general group, one participant stated of their experience of social exclusion, "*Oh with mine in the community it was starting up smoking, was smoking, picked up cannabis, and ciggies followed later and yeah, sort of gave up the sports, started on alcohol, being pushed away by family and friends*" [D, General 10th]. Incompatibility between the pursuit of sport and mental distress (and medication effects) was identified as being a possible cause but also a possible effect of social exclusion:

> "Mmm...that's pretty much the whole life, school, a lot of things, work and sports, I mean I'm having a hard time kind of understanding all the plays in league...yeah and everybody look at me and just, yeah and get pissed off at me 'cause I make mistakes, too much mistakes..." [E, Youth 10th]

> "...and John Kirwan goes keep active, it's probably not like the first thing, like [another participant] was saying, the first thing is mainly support but as you go along, you have to keep doing something, like I'm real bad right at the moment, I sleep until you know, 5 or 6, you know..." [D, General 10th]

Despite most participants identifying that they were not currently involved in sport, based on past experiences, it was mentioned frequently as a positive activity for inclusion. For example:

> "I chose sports [as an iPad example of social inclusion]...Because um, just the encouragement sort of make you felt welcome and belonging...So that's everyone like saying "Good work," and stuff like that... Can make anyone feel belonged I reckon." [Māori 11th]

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Pasifika group: Community leaders

Although participants from this group did not identify as having personal experience of mental distress (and hence the results are presented separately), the group of Samoan community leaders provided a wide range of views on social exclusion, inclusion and mental distress from a Pasifika perspective that shed light on some of the themes developed from the other groups.

Firstly, Samoan people experience a number of pressures that may contribute to social exclusion. There are particular pressures existing within the Samoan aiga, such as:

- **A strict upbringing:** (*"I felt my family didn't give me opportunity to grow as a person because of my upbringing was strict."* [E, Pasifika Group 2]; *"It's not a good relationship with my stepmother – they always got the growl from her or sasa or fasi [smack]."* [A, Pasifika Group 2]); and
- **A lack of communication:** (*"What's that one 'seen but not heard' and I think this is where our PI parents lack, you know we need to be open with the communication with our kids."* [E, Pasifika Group 2]; *"We have, we not have communication with her or my Dad too. So we end up, I end up running away from home."* [A, Pasifika Group 2]).

For Samoan people in Aotearoa/New Zealand there are also pressures created by a clash of cultural values. For example, there is particular emphasis in Samoan culture on:

- **Respect:** (*"...the one thing that Samoans have the highest in the world – and that's respect."* [M, Pasifika Group 2]);
- **Obedience:** (*"[Children]...asking permission, being obedient and all these important values, because we're here, that's where I really notice and see the differences."* [A, Pasifika Group 2]);
- **Spirituality:** (*"I always pray to God to show me the way."* [I, Pasifika Group 2]); and
- **Church values:** (The importance of being raised by the *"values of my church."* [L, Pasifika Group 2]).

These are sometimes at odds with a 'Western', secular society:

> *"At times it's hard, I try to keep to the fa'a Samoa, to teach it and the cultural practices. But, the children and youth have grown up here now and have changed ways from what they were first taught when they grew up in Samoa."* [O, Pasifika Group 2]

> *"Hardly ring up to say that they're with their friend so that Mum and Dad don't have to worry. That's what's difficult for me that we do try the Samoan approach, it's okay and other times it's not."* [A, Pasifika Group 2]

A practical issue is not being able to speak English upon arrival in the country, and possibly then losing touch with the Samoan language once this has been resolved:

> *"First time my child went to school, couldn't speak, just sat there because they couldn't understand the language here [group nodding, agreeing]. So, as time's gone on, it's now very hard for them to respond in speaking Samoan."* [O, Pasifika Group 2]

One frequent issue raised was the connection between alcohol, drugs, 'clubbing', gambling, and crime, and its deleterious effect on Samoan families:

> *"When I came to New Zealand, I understood the importance of not playing cards. Poker led to a person stealing from the bank here in New Zealand. I don't want to play cards because it can lead to stealing."* [L, Pasifika Group 2]

> *"It's here where lots of problems occur inside of families, and if it's not just this, it's the va between my husband and my children. There are times when some people who go to the night clubs in the weekends, go out and leave their children and family."* [G, Pasifika Group 2]

> *"My picture is about marijuana...it can lead to stealing, vandalism, and stealing money."* [I, Pasifika Group 2]

> *"I'd been to the night club about four or five times. I saw that this wasn't a good for young people, and realised I didn't belong

there. Lots of problems that I saw, so it wasn't good for kids. Lots of problems, like not enough money, not having enough money, drinking too much alcohol which caused a lot of fights. But on the other side, it was relaxing, maybe especially for Pākehās who go, but for us Islanders we don't belong there...am happy now going to church." [P, Pasifika Group 2]

Social media also came in for criticism:

M: *"I think Facebook is a cause of problems."*

A: *"Yes, I agree."*

E: *"We never had phones, we spent time with our families, and we're lost now, colonisation, when Palagi came in and took over mauli and we have to learn our language again, and we have to bring our fa'a Samoa in again to teach our kids, and these phones, technology is getting too much..."* [?, Pasifika Group 2]

In relation specifically to mental distress, there is fundamental tension between the traditional Samoan perspective and the psychiatric model of mental ill health (*"There's no mental in Samoa for me"* [E, Pasifika Group 2]). This again relates to spirituality and the role of prayer:

"Mental health mo au ia, e fasi ma tatalo ma fai mai sei ave'ese le aitu lea i totonu (to me, it's curse and prayer, its understood more as - take the spirit out that's inside (the person)). I mean that's how I was brought up, because we don't have mental health, whereas in New Zealand we have institution e ave iai tatou tagata (to take people to)." [E, Pasifika Group 2]

Medical treatment is perceived as not being receptive to, or inclusive of, traditional approaches to healing:

"...by stopping our prayers, or not allowing the patient to pray - we know that for us our faith in God and other strengths we gain through prayer actually helps with the treatment provided to the patient to heal them. But of course the doctor will say that their treatment is correct and it's not, and Samoans haven't had that training, but we have our own expertise and knowledge. Samoan families have their fofo, traditional healers and treatments, herbs that can

heal patients: healers not taught in this Western system. But, they have belief and connection with God through their work, to help the patient who is mentally unwell."* [M, Pasifika Group 2]

This results in concerns regarding medical efficacy:

"I think the doctor's getting worse, making him worse." [M, Pasifika Group 2]

In relation to mental distress, from a Samoan point of view, the sharing of feelings is considered especially important:

A: *"Mo au ia ma, you hear people say, they're mental, but I know ou ia iloa tatau ona iai sau (you should have) a trusted friend so you can share your problems, e share ai au problems ma au feelings, ae aua le tuu i totonu aua e tuputupu ona avea lea ma stress (share your inner feelings and problems rather than keep them inside because this generates stress) [group agreeing]."*

E: *"You know for me, like with my kids as an example, since they grew up they knew from the age of 10 upwards, that's when I started to talk to them, "Hey talk to me, if there's any problem"."*

R: *"How many of you agree, to the talking?"*

Several: *"Yes."*

A: *"Me, I talk to a person I trust."*

One perceived cause of mental distress that is very different from 'Western' understandings, with talking as the solution, is the need to forgive:

R: *"Do some people get sick because they don't forgive?"*

Group: *"Yes (agreeing)."*

U: *"You feel heavy, and to me I feel heavy when I don't forgive anybody, and besides, if I'm ready to preach and I was having problems with somebody, then I need to go and talk it out, just have to have a talk and conversation with that person, so that it leaves me to do what I'm going to do. It makes me lighter, light enough to move on, so that I feel forgiveness."*

This was discussed in the group as it relates to the process of *ifoga* (a traditional, formal apology in Samoan culture), but the perspectives in the discussion suggest that apology and forgiveness are less likely to happen for people with experience of mental distress:

> L: *"Because to me, because their thoughts and mental capacity is not well, so to me, because I have more understanding of what's happening, that if they do something wrong, like swearing or something, that they're not aware or know how to apologise when they've done something so do they have capacity, its important as we talk about this in relation to our people working in mental health and for people with mental illness."*

> A: *"Yes, I agree, patients can be rough with staff, they don't know sometimes how they can physically be rough, so often I say to myself, "Okay, just let it go", and other times it happens, "Oh let it go". And, they don't apologise and it's partly because of their mental illness, and they aren't aware so even if you try to explain, they sit there sometimes and acknowledge it and then other times they don't."*

Participants shared their perspectives on how and why people with experience of mental distress self-exclude:

> U: *"If you're mentally distressed or anything, you're withdrawn yourself from everyone and in that case, yeah, you're denied yourself from everyone and you're not included, from your own perspective and own behaviour, ignore the whole world."*

> E: *"So you become your own victim because you've already been labelled so why should I put myself forward, so I may as well seclude myself now."*

> U: *"And yes, and I'm not used to anything, I'm not useful, I'm denied, and I have to go back and just hide myself."*

The social exclusion experienced through interactions with Government agencies was also mentioned:

> E: *"To me in action, WINZ, for example, when I go into WINZ with my clients, like as soon as they know that they're coming, they don't wanna, you know they get someone else to deal with them and that's why I, a Social Worker goes in with that person, so I support them, so I don't really agree with it because I don't really agree with it because of that reason, they only tick the boxes to get funding."*

> R: *"So you can see that, what is it about the WINZ worker why do they do that?"*

> E: *"Well it's because they've got a mental illness, and mental illness for any Pacific Islander or any culture, they've got this fear of, they're gonna lash out or punch them, so there's already that barrier, that you'll be labeled, that you'll be labeled as a mental health worker or a PI it makes it worse, there's a Samoan or Mauli coming e ulu leaga, or ma'i mental health, so no, they'll try get someone, and yea."*

In terms of social inclusion, the importance of sport in Samoa was emphasised:

> L: *"I finished with rugby and other sports but to me it's really important, because I enjoy sports, lots of things you learn from playing sports. Meet new people, learn this thing and that thing, build connections."*

> F: *"Sports are important because we came from Samoa and true the language is vital to our culture and often we are not using it here much in the New Zealand society. However, being physically strong and healthy especially those of us overweight. It's useful for yourself, to train, play volley ball and all of that."*

Finally, the workplace and family were also identified as important to social inclusion:

> *"I get to work a colleague greet me with a "Good morning" I feel, I response back respectfully and nicely. I say to myself leave my anger at home and be happy here at work. In my work place I find peace and it's vice versa."* [O, Pasifika Group 2]

> *"...one is whānau – family, I see that as love God, your neighbour and yourself. And it's all about relationships. And so my other picture is then about church, my faith."* [E, Pasifika Group 2]

DISCUSSION

The overall aim of this work was to further investigate the concepts of social exclusion and inclusion as they relate to the experience of mental distress and stigma and discrimination. A selective literature review was undertaken initially, the results of which informed the design of the research study: an exploratory investigation into social inclusion and exclusion (conceptualised as multi-level and multi-dimensional participation) and the causal relationships involved, in respect of discrimination particularly, from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand. Semi-structured focus groups were the method of data collection, and a hybrid of IPA and TA was used for data analysis.

Literature review

Despite the terms 'social exclusion' and 'social inclusion' becoming much more of a focus within the literature and policy concerning social variables, there is widespread recognition that there is no accepted standardised definition or measurement of either, and that cross-cultural perspectives are particularly lacking. This creates difficulties for conducting research and evaluation. Recent literature on social exclusion (and inclusion) emphasises the importance of both rights and participation, with, for example, social exclusion being defined as a combination of the lack, or diminished access to, rights that are generally available to citizens of a society or to members of a group, community or institution, and the inability to participate in the normal relationships and activities available to the majority of people in a society. In contrast, social inclusion emphasises the extent to which people are able to exercise their rights and participate, by choice, in the ordinary activities of citizens. Both social exclusion and inclusion are considered to be **multi-level**, **multi-dimensional**, **relative,** and **dynamic** concepts with both **subjective and objective** perspectives, and **agency** considerations in terms of what or who is doing the excluding/including. The objective perspective has tended to be the focus of measurement through the use of convenient pre-existing datasets (e.g., government surveys)

and so the indicators are somewhat artificial constructs that tend to overlook the social aspects of the concepts. The majority of those pre-existing datasets involved *cross-sectional* rather than *longitudinal* surveying and so cannot capture the dynamic nature of social inclusion/ exclusion or make headway with identifying causal relationships and the interconnections between the concepts themselves and other factors, such as discrimination. From the current evidence base, social exclusion and social inclusion appear to sit within a complex, mutually reinforcing set of factors that have the abilities to jeopardise or engender fundamental features of wellbeing, respectively. Gaps in the literature pertain particularly to subjective, including cross-cultural, perspectives on the concepts and the causal relationships involved, including as they relate to each other and, in particular, discrimination.

Focus groups

A total of eight two-hour focus groups were conducted, two for each of the Like Minds, Like Mine target groups (Māori, Pacific Peoples, young people), and two general groups, with the main inclusion criteria being self-identified experience of mental distress. Between 4 and 12 participants were recruited for each group through community-based mental health services. One of the Pasifika groups was attended only by Samoan community leaders who did *not* identify as people with personal experience of mental distress. This group, in turn, became a way to gain contextual information regarding Samoan perspectives on social exclusion, social inclusion and mental distress.

In summary the hybrid IPA/TA of the focus group data identified the following themes:

Social exclusion

Family and/or whānau: Participants often attributed the beginnings of feelings of social exclusion to early life experiences within the family and/or whānau; for example, abuse.

Caught between Pākehā/Palagi and Māori or Pasifika worlds: For Māori and Pasifika, racial discrimination and cultural disconnection

compounds the exclusion related to mental distress. For Māori, in particular, colonisation and being disconnected from tikanga, whānau, iwi and hapū can lead to feelings of not belonging anywhere.

Employment: Having mental distress can result in barriers to gaining and retaining employment, and being treated as if you are less competent and/or different from other employees. This manifests as a cycle of exclusion; for example, exclusion can make it difficult to find employment, leading to more exclusion.

The causal role of mental distress: Whilst cause is often a complex issue to disentangle, some participants explicitly indicated that their experience of mental distress led to social exclusion.

Health care services and professionals: Some participants reported being physically and socially isolated by and within services, and not being listened to by health staff. They were told what to do, made to conform, blamed for their situation, and some reported abuse. The negative role of health staff may be part of a cycle of exclusion.

Negative socialisation: For many participants, drugs and alcohol pervaded early life and beyond, with some considering this to be the primary cause of either mental distress or social exclusion, or of both. Turning to drugs and alcohol may also be an impact of social exclusion, contributing to a cycle.

Government agencies: Organisations such as WINZ, HNZC, the Police and CYF can be experienced as exclusionary. Again, this process may be cyclical with organisations possibly being more likely to exclude those who are already excluded in society (such as those with experience of mental distress).

Unrelatability of mental illness: Some participants expressed the view that the public does not understand what mental illness is or what it is like, and so do not relate to people who experience it. However, some people also feel like they do not relate to portrayals attempting to make mental distress more relatable for the public. This likely manifests as a cycle of exclusion.

Self-exclusion: Many people with mental distress avoid others through fear of rejection/judgement/exclusion, a lack of trust, or to avoid conflict. This manifests as a cycle of exclusion.

Sport, teams, healthy and active lifestyle (a lack of): A healthy and active lifestyle is sometimes lost and difficult to regain when people experience mental distress and the side-effects of treatment. This can lead to social exclusion; for example, from sports teams – resulting in reduced access to sporting activities, in a cycle of exclusion.

Medication and medicalisation: A psychiatric diagnosis and the stigmatising and negative effects of medication on behaviour and appearance (e.g., sedation and weight gain) can lead to feeling different, being treated differently, and exclusion.

Self or others?: Many participants were ambivalent over whether they, other people, or society were the cause of their experiences of social exclusion.

Spirituality and religion: The incongruence of religion/spirituality and the medical model can lead to social exclusion via clinicians' medicalisation of spiritual practices (e.g., talking to God, Jehovah, the Creator or other deities). If such practices continue, this could result in an ongoing cycle of exclusion involving clinicians.

Social representations: Societal perspectives on mental distress, perpetuated by mass media, represent people with experience of mental distress as dangerous, unpredictable and unstable, and portray mental illness as somehow contagious. This creates and maintains cycles of discrimination and social exclusion. As a subjective phenomenon, it results in a sense of 'Otherness', as if one is an alien.

Pervasion: The feeling of being excluded and discriminated against everywhere was expressed mostly by young people. In contrast to the experiences of adult participants, younger people may have not yet found the places, supports and strategies to encounter social inclusion.

The need for social masks: Some participants saw the use of masks (i.e., not disclosing their experience of mental distress) as a way to avoid social exclusion.

Social inclusion

Employment: Having a job can provide a sense of purpose, belonging, relatability and opportunities to socialise, leading to a cycle of inclusion.

Sport, teams, healthy and active lifestyle (involvement in): Being involved in sport, teams and having a healthy and active lifestyle was often identified as being prominent in participants' past life and they considered it an important part of the pathway to inclusion, despite not currently being involved in such activities.

Medication and medicalisation: Accepting a diagnosis/illness and taking medication was seen by some participants as important for getting better, keeping well, and being socially accepted and included. Māori and Pasifika, however, did not always agree with this perspective.

Self or others?: Inclusion was thought to be achievable either by changing the attitudes of other people towards mental distress (through education) or by asserting individuality, independence and personal agency, which can result in a strong sense of self-empowerment.

Family and/or whānau: The notion of family and/or whānau is broad and includes extended and adopted family and/or whānau, and pets. Inclusive family and/or whānau relationships were typified by feelings of normalcy, acceptance, connection, and support for personal agency and empowerment.

Spirituality and religion: Fellowship with other 'believers' and the relationship between God, Jehovah, the Creator, or other deities and the 'believer' can be a cyclical process of social inclusion, particularly for Pasifika.

To look past mental distress, but not right past it: Whilst it is necessary for others to not discriminate, or assume incompetence, or make people feel different, it may still be necessary to provide some support. To do otherwise may result in social exclusion.

True face, right place: Being your 'true face' (able to be yourself) in the 'right place' (being with others who accept your 'true face') can lead to feelings of inclusion, define the subjective experience of being included, and also be an impact of social inclusion. It is the *"flow"* of social inclusion moving from the past, present and into the future as an ongoing self-perpetuating experience.

The need for social masks: Some participants saw the use of social masks as a pragmatic way to be included in the *"normal, everyday...world"*. Continual mask-wearing may lead to continued inclusion, in a cycle. It is not clear whether this can genuinely constitute social inclusion because it is conditional upon not being 'found out', and is still based on discrimination from others.

Caught between two worlds: reconnection with tikanga Māori: Some Māori participants saw re-connecting with tikanga, whānau, iwi, and hapū as a way to regain a sense of belonging.

Infographics provide a diagrammatic representation of these themes (pages 54 and 55).
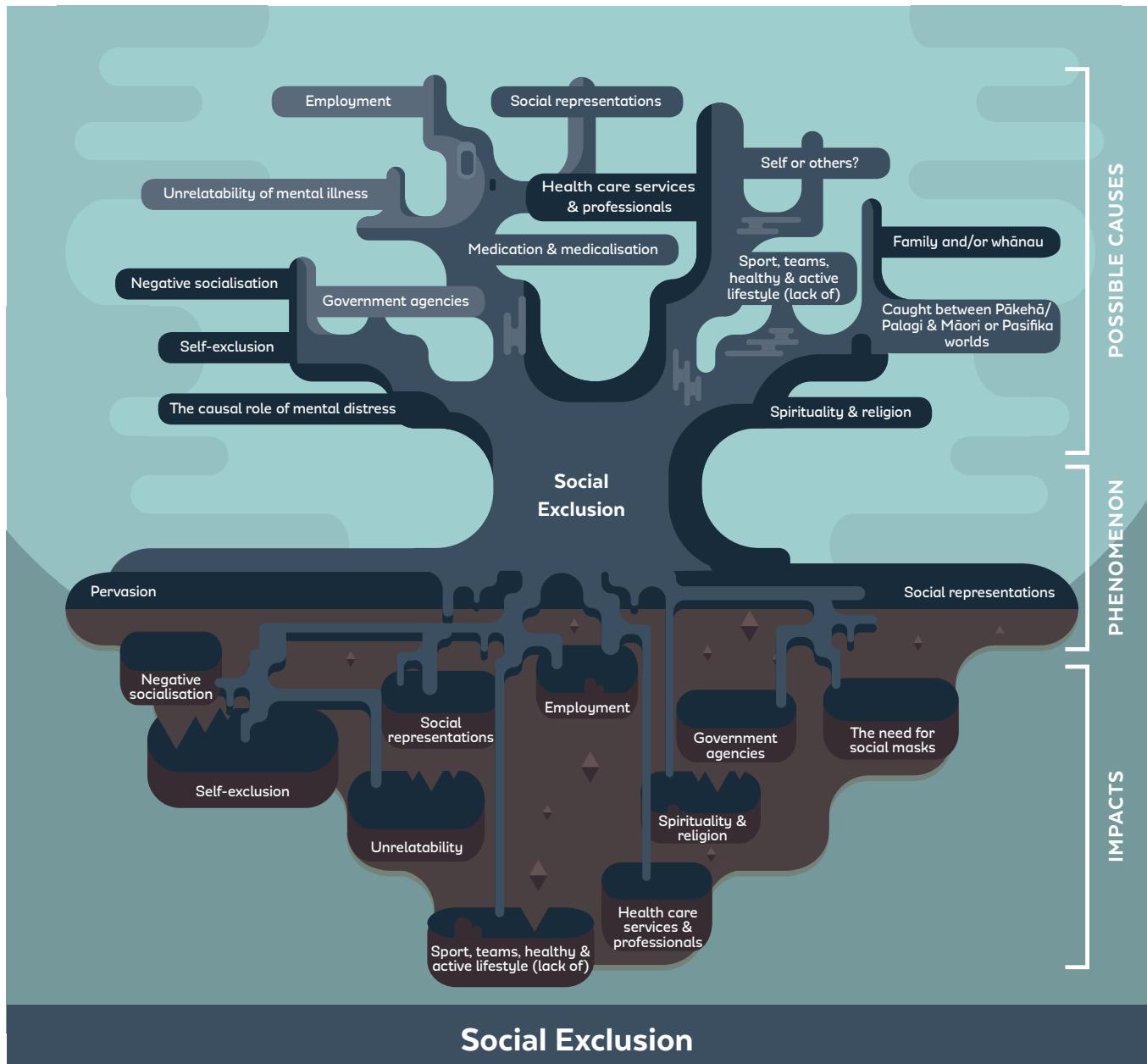
Social Exclusion

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Caught between Pākehā/Palagi & Māori or Pasifika worlds: For Māori and Pasifika, racial discrimination and cultural disconnection compounds the exclusion related to mental distress. For Māori, in particular, colonisation and being disconnected from tikanga, whānau, iwi and hapū can lead to feelings of not belonging anywhere.

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Health care services and professionals: Some participants reported being physically and socially isolated by and within services and not being listened to by health staff. They were told what to do, made to conform, blamed for their situation, and some reported abuse. The negative role of health staff may be part of a cycle of exclusion.

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Pervasion: The feeling of being excluded and discriminated against everywhere was expressed mostly by young people. In contrast to the experiences of adult participants, younger people may have not yet found the places, supports and strategies to encounter social inclusion.

The need for social masks: Some participants saw the use of 'masks' (i.e. not disclosing their experience) as a way to avoid social exclusion.

The causal role of mental distress: Whilst cause is often a complex issue to disentangle, some participants explicitly indicated that their experience of mental distress led to social exclusion.

POSSIBLE CAUSES

Caught between two worlds: reconnect with *tikanga Māori*

Employment

Self or others?

Sport, teams, healthy & active lifestyle

To look past mental distress but not right past it

Spirituality & religion

True face, right place

The need for social masks

Medication & medicalisation

Family and/ or whānau

IMPACTS

Employment

Spirituality & religion

The need for social masks

True face, right place

PHENOMENON

Social Inclusion

True face, right place
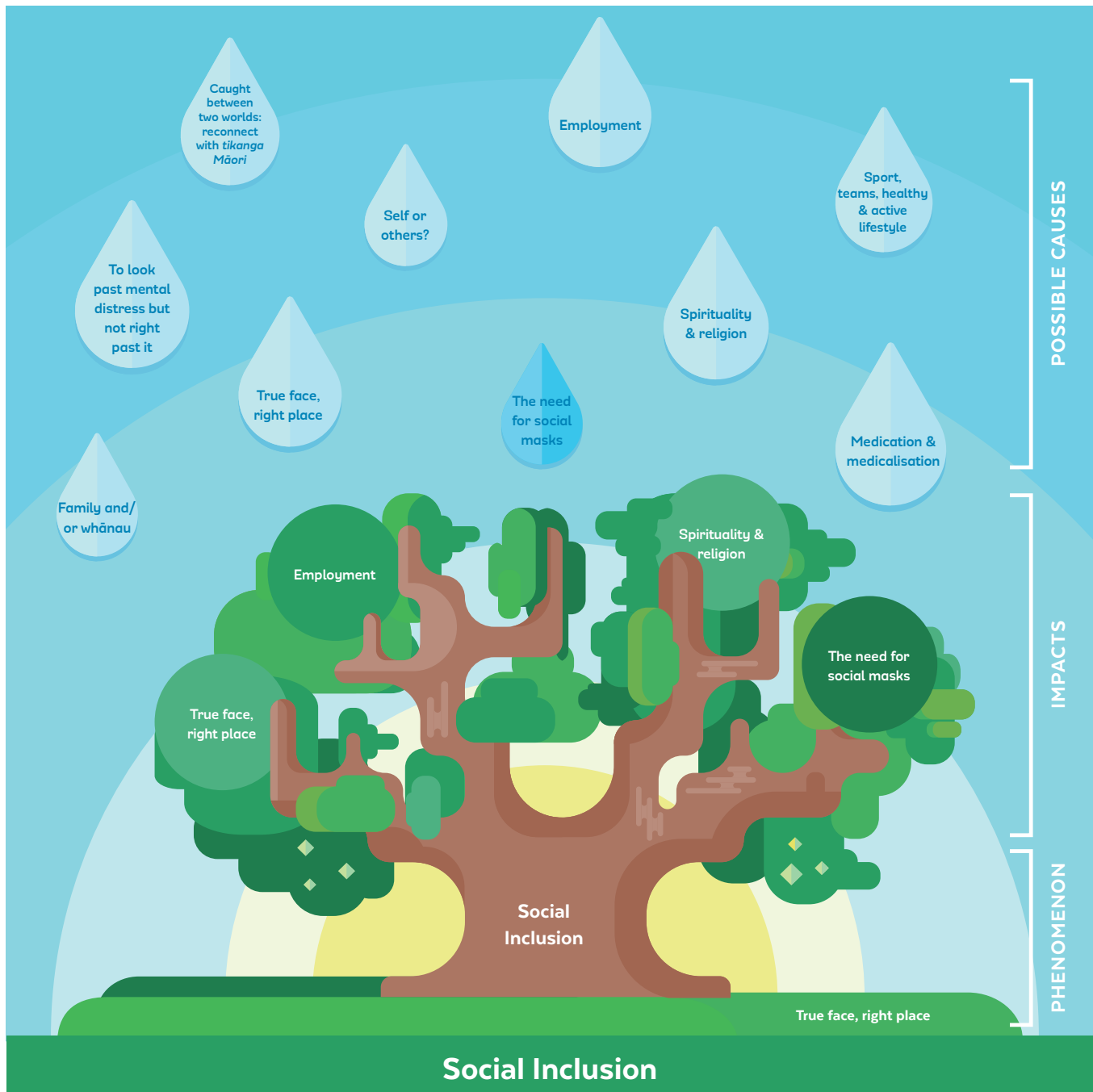
Social Inclusion

Sport, teams, healthy and active lifestyle (involvement in): Being involved in sport, teams and having a healthy and active lifestyle was often identified as being prominent in participants' past lives and they considered it an important part of the pathway to inclusion, despite not currently being involved in such activities.

Medication & medicalisation: A psychiatric diagnosis and the stigmatising and negative effects of medication on behaviour and appearance (e.g., sedation and weight gain) can lead to feeling different, being treated differently, and exclusion.

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The need for social masks: Some participants saw the use of social masks as a pragmatic way to be included in the "normal, everyday world". Continual mask-wearing may lead to continued inclusion, in a cycle. It is not clear whether this can genuinely constitute social inclusion because it is conditional upon not being 'found out', and is still based on discrimination from others.

Caught between two worlds (reconnect with *tikanga Māori*): Some Māori participants saw re-connecting with tikanga, whānau, iwi, and hapū as a way to regain a sense of belonging.

Making meaning of the findings

Participants reported having experienced extensive social exclusion that had often commenced at a young age, appearing to have been caused by 'cumulative actions, behaviours, prejudices, and oversights' (Mental Health Commission, 2009) or, alternatively, a complex, mutually reinforcing set of factors. This included, but was not limited to, discrimination that was explicitly and implicitly related to mental distress. In contrast, social inclusion was experienced generally as much more limited, and often seemingly contingent and conditional on families and/or whānau, strategies that hide mental distress from others, and/or havens within the wider exclusionary community that are accepting of mental distress.

The concepts were expressed as multi-level in terms of being experienced at the individual, family, community, institutional (e.g., dealing with WINZ and other government/public organisations) and wider societal levels (e.g., in relation to the pervasive negative sense conveyed by the 'social representations...' theme).

In terms of the various dimensions highlighted in the literature, the focus groups provided evidence of social exclusion occurring along the social (e.g., 'social representations...'), political (e.g., 'caught between...worlds...'), and historical/cultural dimensions (e.g., 'caught between...worlds...', 'spirituality and religion'). There was, however, little direct support for exclusion occurring along the economic dimension, apart from some occasional isolated or implied references to poverty/economic concerns, with discussions being focused on relational as opposed to material factors. This is perhaps surprising given the origins of 'social exclusion' as a more acceptable term than poverty. It may be, however, that this was due to the framing of the questions or that a lack of money was such an obvious factor in their overall situation that people chose to not discuss this in detail.

For social inclusion, there was support for this phenomenon occurring along the social (e.g., 'true face...'), and historical/cultural dimensions (e.g., 'caught between...worlds...'). There is also some support for inclusion along the economic dimension via the sentiment expressed by the *"money, friends, choices"* [C, Youth 10th] pathway provided by employment. However, there were no explicit references to the political dimension in respect of social inclusion.

The relative nature of exclusion and inclusion was also evident in the disparities faced by Māori and Pasifika, which were relative to the situations of Pākehā/Palagi, and the overall strong sense of (negative) relative difference participants felt in contrast to other people generally. Social inclusion and exclusion were also experienced relative to each other (see pp. 58-60).

The dynamic aspect – that is, social inclusion and exclusion are in flux – was also implied, despite this being cross-sectional research. The role of family and/or whānau in inclusion/exclusion may indicate the set of processes that move through families and/or whānau and across generations. Similarly, the dynamics of the workplace show how inclusion can become positively reinforcing, such as when inclusion in the workplace leads to other employment opportunities or opportunities to socialise.

The data, however, went further, and most importantly gave some sense of how social exclusion and inclusion are subjectively experienced. The phenomenal part of the concepts – the *'what it is like?'* – is the subjective experience reflected in the themes of 'pervasion', 'social representations of mental illness' (the 'Other'), for social exclusion – and in 'true face, right place', for social inclusion. On the one hand, the subjective experience of exclusion is one of acute alienation, which can feel inescapable (because, particularly for young people, it happens *"everywhere"*). Whereas, the subjective feeling of inclusion could not be more different from this – it is feeling you are exactly where you should be, with the people who you should be with, and as the person you really are. This enhances our knowledge in terms of the impact of the two concepts with social exclusion and social inclusion being experienced respectively as jeopardising or engendering those four fundamental *feelings* of human well-being: belonging (Baumeister & Leary, 1995), self-esteem (Baumeister, 1994), control (Seligman, 1975), and meaningful existence. This, however, should not be taken to indicate that they are categorically distinct in every respect (see pp. 58-60).

One of the most concerning results to have come from the present research is the pervasiveness of social exclusion experienced by youth. This reinforces the need for youth to remain as one of the priority audiences of the Like Minds, Like Mine programme, and for approaches tailored to them

to include attendance to the pervasiveness of their experience.

Colonisation, racial discrimination and cultural disconnection compound social exclusion

As a population group, Māori experience the greatest burden due to mental health issues of any ethnic group in Aotearoa/New Zealand (Ministry of Health, 2012) and this is a key driver of their higher-than-average disability rate generally (Statistics New Zealand, 2014). The present research identifies that such disparity is also faced in respect of the experience of social exclusion and barriers to social inclusion; or, in other words, the compounded social exclusion that is experienced by Māori. A key aspect of this is the social exclusion that has resulted from past and continued colonisation, racial discrimination, and disconnection from *tikanga Māori*, whānau, iwi and hapū, leading to feelings of being 'caught between two worlds'. However, it extends further than this, with Māori experiencing relatively (compared with other participants) more social exclusion across a number of themes, including 'Government agencies...', 'employment...', 'to look past mental distress...' (in terms of not being listened to) and 'the causal role of mental distress...'. This reflects that, for Māori, the complex, mutually reinforcing set of factors are thus especially complex and mutually reinforcing.

The compounded social exclusion and barriers to social inclusion experienced by Māori are particularly problematic in the Aotearoa/New Zealand context where acknowledging the status of Māori as tāngata whenua, and obligations under Te Tiriti o Waitangi, particularly in respect of the principle of participation, are imperatives.

In terms of social inclusion, many Māori participants considered that reconnecting with whānau, iwi and hapū, and tikanga, would be a pathway to inclusion, although most had not personally experienced this. This is consistent with Russell's (née Pere) work where it was found that cultural identity is an important factor in the mental health recovery process (Pere, 2006). The importance of this reconnection is also emphasised via the research comparing individualist and collectivist cultures where it has been found that people of collectivist cultures are less impacted by social exclusion (Pfundmair, *et al.*, *op. cit.*).

Pasifika also experienced compounded social

exclusion due to a disconnection from culture and to racial discrimination. This finding of the disconnection of Samoan people from both Samoan culture and from Palagi culture was also supported by statements made in the group of community leaders. Furthermore, Pasifika experienced relatively (compared with other participants) more exclusion in relation to the themes of 'Government agencies...', 'employment...', 'health care services...', 'to look past mental distress...' (in terms of not being listened to) and 'spirituality and religion'. In terms of social inclusion, however, Pasifika tended to refer to 'spirituality and religion' as a key source of belonging and fellowship, a finding which was again supported by the group of Samoan community leaders. *Stories of Success* also found that for Pasifika their sense of inclusion was equally related to the spiritual and religious realm, specifically the role that the church plays in their lives (Hamer *et al.*, *op. cit.*).

These results support the quantitative investigation into social inclusion where it was found that people with experience of mental distress were significantly more likely than the general population to find it difficult to express their identity in Aotearoa/New Zealand (Mental Health Commission, 2011). This reinforces the need for Māori and Pasifika to remain as priority audiences of the Like Minds, Like Mine programme, and for approaches to be tailored to their experiences. For Māori that means attendance to the disparities they face in the form of the compounded discrimination and social exclusion they experience due to colonisation, racial discrimination and cultural disconnection; it means recognition of their status as the first peoples of Aotearoa/New Zealand in the context of Te Tiriti o Waitangi; and it means understanding the importance to them of reconnection with whānau, iwi and hapū, and tikanga as a pathway to inclusion. For Pasifika it means attendance to the disparities they face in the form of the compounded discrimination and social exclusion they experience due to racial discrimination and cultural disconnection; and it also means understanding the importance to them of spirituality and religion as a pathway to inclusion.

Exclusion breeds exclusion, and inclusion breeds inclusion: vicious and virtuous cycles

This research sought to identify possible causes (reasons behind) and effects (impacts) of social exclusion and inclusion. Whilst it is difficult for people to 'unpack' their lives in order to identify causal relationships, an emerging causal picture nevertheless emerged. That is, when discussing the causality of exclusion and inclusion, respondents tended to uncover complex, mutually reinforcing sets of factors involving mostly *cyclical* processes. This is reflected in those themes identified as being both an antecedent or possible cause of, and impact on, either social exclusion (i.e., 'sport...: a lack of', 'self-exclusion', 'social representations...' and 'the unrelatability of mental illness...'), social inclusion (i.e., 'true face, right place' and '...social masks'), or both (i.e., 'employment...' and 'spirituality and religion'). Other themes that were suggestive, but not conclusive, of cyclical processes in terms of social exclusion included 'health care services and professionals...', 'Government agencies...', 'negative socialisation', 'caught between...worlds...', 'family and/or whānau...', and 'medication and medicalisation'. In terms of social inclusion, possible cycles included 'family and/or whānau...', and 'caught between...worlds: reconnection with tikanga'. Overall, it could be said from this that exclusion breeds exclusion, and inclusion breeds inclusion, which is consistent with the view in the literature that exclusion and inclusion involve vicious and virtuous cycles, respectively (Iwasaki & Mactavish, *op. cit.*; Sayce, 2001).

One key example of a cyclical process is evidenced in the theme of 'social representations of mental illness'. This is drawn from a wider theory (the Social Representations Theory) of Serge Moscovici (Moscovici, 1984), the idea being that people in society create the ways in which things and people are seen and, in turn, the people themselves are shaped by these understandings. This theme, then, depicts a cycle, and is one that links to several other cycles, including the theme on 'self-exclusion' and another important focus of the Like Minds, Like Mine programme: internalised stigma as another barrier to participation.

As social representations of mental illness involve seeing people as dangerous, contagious, and not competent, these representations are (cycles of) discrimination; people with mental distress are seen as negatively different, as 'Other'. Due to this 'Other-ness', the outcome is social exclusion. When social representations of mental illness become directed at the self by the self, self-discrimination, or 'self-stigma', occurs. As a consequence, just as people with mental distress are excluded by others, so people with mental distress exclude themselves due to their own internalised- or self-stigma, and, related to this, the fear of discrimination/exclusion from others. As cycles, then, social exclusion and self-exclusion run in tandem with social representations, because discrimination and self-stigma are the manifestations of the social representations.

Cycles of 'public stigma' and self-stigma have similarly been identified (Peterson *et al.*, 2008). Self-stigma occurs when public stigma – discrimination – becomes internalised by the person experiencing it, and possibly when the person perceives the discrimination as legitimate (Corrigan & Watson, 2002). It has also been found that this internalised discrimination can be even more damaging to the individual than the experience of discrimination alone (Ritsher & Phelan, 2004, cited by Peterson *et al.*, 2008), including by way of the impact it can have on social inclusion (Ritsher & Phelan *ibid.*). Racism can also exacerbate self-stigma (Peterson *et al.*, 2008), which is consistent with our findings regarding the compounded exclusion and discrimination experienced by Māori and Pasifika (see p. 57).

Other (vicious) cycles with social exclusion at their centre include sport and employment where, having been excluded, it then becomes difficult to get back into teams and work, and this is further exacerbated by the impact of the side-effects of medications. A sense of lost and limited opportunities and possibilities were associated with these cycles.

In contrast, virtuous cycles – of social inclusion – relate to the phenomenal theme of 'true face, right place': having found a place to be oneself, people find social inclusion. Having found social inclusion, individuals then continue to feel the sense of being themselves and with the right people, and choose to continue to be in these places, resulting in a reinforced sense of inclusion. Employment arises again here as a 'right place': in the positive manifestation of being employed, this situation yields more positivity in employment,

which is another reinforcing process. Religion, particularly for Pasifika, provided another example of a virtuous cycle.

Two of the most significant themes in terms of vicious cycles of social exclusion and virtuous cycles of social inclusion relate to employment and sport. Workplaces are a current focus of the Like Minds, Like Mine programme and the present work provides support for that focus to continue. The significance of sport is perhaps reflective of the emphasis that is placed on participation and engagement in sport as part of the 'Kiwi' lifestyle and culture. Interestingly, of the 37 groups identified by experts with lived experience from the United States of America as needing to be targeted by anti-stigma programmes, there was no specific reference to sports activities, teams or clubs (Corrigan *et al.*, 2014). Article 30(5) of the Convention of the Rights of Persons with Disabilities states, however, that with a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures, including to encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels. This is in contrast to the New Zealand Disability Strategy (Minister for Disability Issues, 2001), which, in relation to sport, presently only includes the actions of educating arts administrators/organisations and other recreational and sporting organisations about disability issues and inclusion; and supporting the development of arts, recreational and sports projects, including those run by and for disabled people.

Unfortunately, for participants in the present research, engagement in sport was primarily identified in relation to past experiences or as having the potential to support social inclusion, but not presently. The results of the current project suggests that in the Aotearoa/New Zealand context there needs to be a much greater emphasis on encouraging and promoting the participation of people with experience of mental distress in sporting activities. This should be considered specifically in terms of the Like Minds, Like Mine community focus.

Vicious cycles seem to present a greater challenge than linear cause-effect relationships due to their potential for ever-increasing intensity. However, they may also present an opportunity for effecting positive change because the cycle can be broken – or the impact reduced – by disrupting any part of that cycle (either by preventing initial causes or preventing the feedback from effects back into causes). Indeed, this is precisely the recommendation from Peterson *et al.* (2008), to interrupt cycles (of stigma) using the following suggested 'circuit breakers': 'Celebrating and accepting difference', 'Disclosure', 'Recovery-oriented practices', 'Leadership', 'Empowerment', 'Affirmation of human rights', Recognition of the contribution of people with experience of mental illness', 'Challenging attitudes and behaviour' and having 'Positive role models' (p. 66).

The relationship between social exclusion and social inclusion

The two concepts of social exclusion and social inclusion appear to be wholly distinct in terms of their characteristics as subjective *phenomena*, according to the emergent themes. Presumably, then, social exclusion is experienced as the opposite of social inclusion, rather as sadness and elation are experienced as diametrical opposites. But, does this mean they are polar opposites in every respect, objectively? If we get rid of exclusion do we thereby get inclusion and vice versa? Or are they in wholly distinct categories?

Whilst the concepts have been defined as distinct vicious or virtuous cycles, suggesting that the concepts relate to separate categories, in practice the current research study has found this to be only partly true. The negative, cyclical interactions of social representations, self-exclusion and unrelatability were indeed wholly exclusionary. Conversely, the 'true face, right place' theme and the nurturing inherent in the 'to look past mental distress, but not *right* past it' theme seem to be wholly inclusionary. This would, then, support a categorical distinction. However, as has been seen, the concepts also overlap significantly across other themes by antecedent, impact and the cycles these create. Within this overlap there is also ambiguity/vagueness between the exclusionary and inclusionary (e.g., whether inclusion is compatible with wearing social masks). It appears that the situation is likely to be one of grey areas, rather than clear, distinct categories.

In relation to this, our findings suggest that inclusion and exclusion are in fact not polar opposites, like north and south, with the

negation of one entailing the other. When asked, participants tended to say they were neither wholly included nor wholly excluded. Their experiences of inclusion or exclusion are then either indexed to different situations (i.e., we are included in one, excluded in another) or the experiences themselves are mixtures of inclusion and exclusion (as Hunting *et al.*, *op. cit.* propose). The concepts may then be polarised as pure descriptions – in the abstract - but yet never wholly separable in the real world. The themes of 'medication and medicalisation', 'self or others...', 'caught between...worlds...', 'employment...', 'family and/or whānau...', 'spirituality and religion', 'sport...' and '...social masks' are all points of intersection between the concepts; all support the idea of intersectionality, and thereby challenge the idea that the concepts are simple opposites such that to get rid of one is to gain the other. This intersection, using real world examples, also shows the precariousness of exclusion/inclusion: the same people and places can contribute to either/both exclusion and inclusion.

Given the degree of overlap, there is then no strong case here for any clear distinction to be made in terms of either possible causes, possible effects, or strategies. This finding is supported by Hamer *et al.* (*op. cit.*) where it was similarly found that social inclusion is:

> *...a fluid concept...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* (p. 71).

A spectral approach, along a continuum, seems a more reasonable interpretation for the objective sense of inclusion/exclusion (as suggested by Hunting *et al.*, *op. cit.*). We are all positioned somewhere along this continuum, neither wholly excluded nor wholly included, objectively speaking. The only categorical distinction to be made based on our data is at the subjective,

phenomenal level: it appears possible for the subjective experience at any point to feel like complete rejection or complete acceptance, as indicated by reports in 'social representations...' (i.e., alienation) and 'true face...' (i.e., the *"flow"* of just being yourself). In practice, of course, people may feel neither extreme at a certain point. But based on our data, it seems at least possible for someone to experience the acute alienation of exclusion, at one point, and the joyful flow of inclusion, at another. It may be that at the subjective level, the concepts can be completely separable, whilst at the objective level, intersectionality of inclusion-exclusion is the reality. This, then, extends the idea that there is a categorical distinction between the concepts at the level of pure description, in abstraction, but also in one's own personal experiences.

The apparent lack of a simple objective dichotomy, however, suggests that the Like Minds, Like Mine programme is right to focus on promoting social inclusion, affirming positive ideas, attitudes and behaviours towards people with experience of mental distress, as well as countering negative ideas and myths, attitudes and behaviours (Corrigan *et al.*, 2014). On a spectral view, as opposed to a 'polar' view, the situation would not clearly permit a removal of the negatives to thereby guarantee gaining the positives. To 'move up' the spectrum towards greater inclusion would seem to be a positive process rather than a negative process of removal.

Agents of social exclusion

The agents of social exclusion were identified as other people/institutions, such as medical professionals, family, employers, the media, Government agencies, and wider society. One of the most concerning aspects of this is the social exclusion that was experienced at the hands of those who have responsibilities and obligations to provide support; namely, health care services and professionals, and Government agencies. It is, therefore, recommended that these are an additional focus for the Like Minds, Like Mine programme.

In relation to health care services and professionals there was the theme on 'medication and medicalisation' of mental distress, which, in contrast to the former, was identified as relating to both inclusion and exclusion. In terms of

inclusion, many people felt the acceptance of illness, diagnosis and the need for treatment was a pathway to inclusion, despite barriers being faced as a result of the side-effects of medication. However, there was also a sense of this being conditional (i.e., social inclusion being conditional upon such acceptance of medication etc.) and feelings of disempowerment and resignation associated with this theme. For Māori and Pasifika, 'medication and medicalisation' was experienced more as exclusionary, particularly in terms of how their distress was framed and the consequent treatment, and the impact of such on personal agency (discussed further below), as reflected most powerfully through the discussion of the impact of medication on *mana*. The group of Samoan community leaders also reinforced the conclusion that medicalisation is an issue for Pasifika, particularly in relation to the discussion of *ifoga* and Samoan views on mental distress, which are highly divergent from the dominant Western paradigm in Aotearoa/New Zealand.

In terms of the general public, advocating the medical model as an explanation for mental illness is known to have little to no impact on stigma, and may actually increase it (Pescosolido *et al.*, 2010; Kvaale *et al.*, 2013), particularly in respect of the representations of people with mental distress as dangerous, unpredictable, unstable, and contagious. It would not be surprising if self-stigma and exclusion were to occur as a result of this focus and framing through mental health services. It also needs to be considered how the Like Minds, Like Mine programme perpetuates this with the continued use of the concept of 'illness' through their messaging.

In relation to the health professions and their role in discrimination, Knaak *et al.* (2014) recommend developing ways to see past the illness of people with mental distress (consistent with the theme 'to look past mental distress...'). That is, to move from a 'pathology-first' perspective to a 'person-first' perspective, using combined contact and education/training, for instance to demonstrate the reality (and, therefore, the possibility) of recovery, via contact with people who have recovery stories. Their final conclusion was the need for a culture change within healthcare, but recognising that healthcare workers are subject to wider social and cultural influences (e.g., from media). This is, indeed, consistent with the

existence of social representations (which are also strongly related to mass media). This has implications for both health services and the Like Minds, Like Mine programme.

Finally, to emphasise again the role of recovery here, Knaak *et al.* (*ibid.*) indicate that this emphasis – or its demonstration - and multiple forms of social contact, are the two most effective 'ingredients' in anti-stigma programmes for health care staff. This may indeed be effective in overcoming stigma as a likely barrier to social inclusion. However, as emphasised throughout this report, this may well not amount to social inclusion itself, given inclusion's positive status, as something to be actively promoted, rather than obtained by the removal of a negative.

Methods of countering social exclusion and enabling social inclusion

The agents of social exclusion were indeed identified as other people/institutions, such as medical professionals, family, whānau, employers, the media, Government agencies, and wider society. However, there is also the insistence from participants that other people are not to blame because their attitudes are based on ignorance. This, together with the fact that people considered a significant causal factor to be *unrelatability*, led participants to propose more public education on mental distress as the solution to countering social exclusion and promoting social inclusion.

This is inconsistent with the evidence that interventions utilising contact or combined education and contact approaches (in contrast to education alone) are the most effective in countering stigma and discrimination (Ashton & Gordon, in review).

Interestingly, Sampogna *et al.* (2016) found that whilst an educational approach was the most endorsed by service users, compared with a challenge approach, those who had taken part in the Time to Change programme (one of the largest anti-discrimination programmes in England) were more likely to endorse challenging. This was despite Time to Change not involving a challenge element. Whilst it is, then, unclear why there was this impact, it may be that service user involvement in an anti-discrimination programme is in itself a self-empowering experience, which then encourages a direct, challenging approach to stigma.

THE USE OF 'SOCIAL MASKS'

Some participants used social masks to avoid discrimination. This manifested as not disclosing their experience of mental distress when in the company of people who were not known to also have had such personal experience. The analysis also pointed to mask-wearing as a possible pathway to inclusion. However, this nevertheless remains a pathway based on discrimination, and can lead to cycles of mask-wearing to continually avoid exclusion. Given that discrimination provides the basis for this mask-wearing, it must in some sense, be part of the cycles, and whether discrimination can ever exist in a virtuous cycle of inclusion is questionable.

The tenuous nature of this situation is clear if the person with mental distress were to disclose their experience in places where they would usually wear a mask: it may be that the 'inclusion' would be exposed as conditional; or, given that contact is the most effective strategy to counter discrimination, it may be more likely that such disclosure would then lead to the inclusion becoming unconditional. Irrespectively, this remains a highly precarious form of inclusion.

In a similar vein, we could even question the virtuous circle of 'true face, right place'. This theme depicts people and places in a self-reinforcing absence of discrimination. Whilst this theme represents the zenith of inclusion, it too may be a conditional form of inclusion, based on discrimination. The 'right place' is, after all, a *haven* of non-discrimination, and this is so, precisely because it exists in a wider context of discrimination. The haven essentially provides respite from the wider societal exclusion and discrimination. The supposed 'virtuosity' of 'true face…' actually consists in its being conditional upon wider social exclusion and discrimination.

Interestingly, and possibly of use for furthering our understanding of the two concepts – at least at the level of 'pure description', temporarily putting aside the 'Intersectionality' approach of Hunting *et al.* (*op. cit.*) – wearing '…social masks' as an example of 'precarious inclusion' may challenge the definition of social exclusion as the 'enforced lack of participation' (Burchardt, 2000, cited by Morgan *et al.*, *op. cit.*) and challenge the definition of social inclusion as 'the opportunity to participate' (Boardman, *op. cit.*). This is because mask-wearing is not clearly inclusionary but masks still give the 'opportunity to participate'.

However, if mask-wearing is instead considered to be an example of exclusion, then the 'enforcing' (from '*enforced* lack of participation') would be *concurrent with someone participating* (but via the use of a mask). From this, it appears that the current definitions cannot categorise this example as either inclusion or exclusion, and are not then consistent with the intuition that mask-wearing is not inclusionary, and even seems exclusionary.

The definitions should perhaps involve an additional element, relating to conditions. Social exclusion then becomes the 'enforced conditions for non-participation' and social inclusion becomes the 'unconditional opportunity to participate'. Under this definition, mask-wearing would not be an instance of social inclusion because it is not unconditional. It is, however, classifiable as social exclusion because, unlike 'enforced lack of participation' (Burchardt, 2000, cited by Morgan et al., op. cit.), the definition 'enforced conditions for non-participation' can co-exist with actual participation whilst wearing a social mask.

Another perspective is simply to recognise the possibility of inherently "positive withdrawal" (Ammeraal et al., op. cit., p. 69; referring to Sells et al., op. cit.) and 'healthy segregation' (Church, 1997; Church et al., 2000; cited by Spandler, op. cit.). The experience of being in places such as Mix are positive experiences in their own right, an enjoyable 'voluntary exclusion'. This is perhaps the meaning of the statement "It's like a secret organisation, once you're in the club, you can't leave" [D, General 10th], which was not experienced by the participants as a wholly negative form of membership. Peer support is an example of how engagement with other members of the club can be a most positive and inclusive experience; however, if this is the only option available to you then, it probably means that the problem of wider social exclusion has not been addressed.

THE IMPORTANCE OF PERSONAL AGENCY IN OVERCOMING EXCLUSION AND GAINING INCLUSION

Several themes identified through the present research (i.e., 'social representations…', '…unrelatability…', 'medication…', 'caught between… worlds…', 'health care…' and 'Government agencies…') highlight that the lack of support for personal agency (manifesting, for example, as not

being listened to, taking away mana, representing people with mental distress as unstable and non-competent, or treating people with explicit disrespect) was associated with social exclusion. In contrast, a number of other themes (e.g., 'to look past mental distress…'; 'family and/or whānau…' and 'self or others…') highlight that support for the personal agency of people with experience of mental distress (e.g., listening, helping to achieve goals and make the right decisions, or opportunities to speak for oneself and others) is significant in overcoming social exclusion and enabling social inclusion. Indeed:

> …recovery and social inclusion [for those experiencing mental distress] may be linked by agency and opportunity: the opportunity to participate in one's community and gaining a sense of control (Boardman, *op. cit.*).

Given that self-stigma has been identified as having the potential to be even more damaging to the individual than the experience of discrimination alone (Ritsher & Phelan, *op. cit.*), some suggest that addressing self-stigma could be more effective than addressing discrimination/ public stigma (Bagley & King, 2005, cited by Peterson *et al.*, 2008).

Addressing the cycles that connect discrimination and self-stigma/exclusion as identified through the present work require programmes to focus on both:

- *Reducing* stigma/discrimination, exclusion *and promoting* social inclusion with others; *AND*
- Reducing self-stigma, self-exclusion, the impact of discrimination and exclusion *and promoting* social inclusion with people who experience mental distress.

Anti-discrimination programmes that concentrate on one or the other can be effective in reducing the viciousness of the cycle. However, programmes that focus on *both* forms, possibly at the same time, may have the best chance of success at completely disrupting the cycle before it can regenerate.

The current report suggests that there needs to be more of a focus on supporting the personal agency of people who experience mental distress. More specifically, any such support needs to address:

- self-stigma;
- self-exclusion faced as a result of that self-stigma and anticipated discrimination; and
- self-blame.

It needs to enable people to assert their own individuality, independence and personal agency to challenge social exclusion when it is experienced. The sense of empowerment that comes from asserting yourself in this way is in direct contrast to how social exclusion typically jeopardises one of those fundamental features of human well-being: control. In relation to the *Stories of Success* research, this concept of personal agency was identified as key in terms of social inclusion being "a concept for which personal power is an integral part, providing people with the self-confidence to make decisions and choices in their daily lives and challenge existing institutional structures that perpetuate stigma and discrimination" (Hamer et al., *op cit.*, p. 8). In terms of the process of getting there, that same research identifies two stages: the before stage, where the person moving beyond their self-stigma to a feeling that social inclusion was a possibility; and the after stage, where an increased sense of personal power, a deepening of social relationships, and a belief in the right to contribute to society is represented. The reference to the 'right to contribute to society' is most pertinent here in relation to social exclusion and social inclusion being conceptualised as both 'rights' and 'participation'. As identified above, it might be the self-empowering experiences, as well as becoming aware of rights, that moves people to endorse challenging approaches over educational approaches.

Some participants identified having been supported to develop their personal agency through involvement with the Like Minds, Like Mine programme in the past; however, there was also a sense that service-users were no longer engaged as much in that capacity through the programme.

This may be because at one level this approach does not appear consistent with the social model of disability, which places the responsibility for social exclusion and discrimination firmly and solely on society and its institutions rather than the individual. This is one of the guiding principles of Like Minds, Like Mine. However, in emphasising the agency of people with mental distress in the process of social exclusion, there then

remains the possibility of self-empowerment to overcome it, rather than this being in the control of governments, institutions or the nebulous collective called 'society' (all of which seem beyond one's personal influence). Supporting the personal agency and self-empowerment of people with mental distress should play a key part in the process, rather than them being passive recipients of changes to social attitudes. However, this should be part of a complementary approach that also remains focused on the responsibilities of others.

'To look past mental distress, but not *right* past it…'

The theme of 'to look past mental distress, but not *right* past it' could essentially be seen as a synonym for reasonable accommodations. For example, the obligation to not discriminate, which includes the obligation to provide necessary and appropriate modification and adjustments that do not impose a disproportionate or undue burden (where adjustments are needed), to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

With regard to employment, there is little to suggest that people with mental distress require a great deal in terms of work-based support. Provided that there are good standards of employee entitlements (e.g., relating to sick leave, flexible working etc.) then this is often sufficient (Gordon & Peterson, 2015).

Unrelatability makes discrimination intractable?

'The unrelatability of mental illness: an intractable divide?' raises a problem for attempts to reduce discrimination, highlighting the inadvertent harm that such attempts may cause.

The reports from some participants indicated that whilst they acknowledge that anti-discrimination programmes are there to help them by changing negative social attitudes, they can in themselves be experienced as exclusionary.

If you make mental distress more relatable for the general public by depicting people with mental distress who in many other respects are shown as having a life that is going well (educationally etc.), and in so doing successfully reduce levels of discrimination, this comes at the cost of misrepresenting the experience of many people with mental distress whose lives do not fit this positive image. This then risks socially excluding the very people who the anti-discrimination programme sought to benefit.

If, however, you represent mental distress as it is experienced by many (i.e., as part of multiple forms of deprivation), then the general public cannot relate to it, which does nothing to reduce discrimination and may even exacerbate it. So, this suggests a (seemingly) intractable divide if the aim is to provide unquestionable benefit to people who experience mental distress.

The key focus for a developer would then be *how* to bridge this (seemingly) intractable divide.

It is strongly recommended, therefore, that personnel involved with the Like Minds, Like Mine programme keep this focus in mind when developing the methods and messages of campaigns.

Limitations

There are a number of limitations associated with the present work that need to be taken into account when interpreting the findings. This includes those limitations identified in respect of the methodology (see p. 13). One of those limitations related to the challenges encountered in recruiting youth for the focus groups. Furthermore, it was evident that the young people who participated did not find the focus groups easy to engage with; overall, the youth focus groups provided relatively less content than the other groups. This raises further questions about the appropriateness of the focus group method for gathering data from young people.

The relatively small amount of content on social inclusion may have been partly due to the social inclusion questions being asked in the second half of the schedule (after eating), as was the standard format across the focus groups. In retrospect, it may have been better to have had one focus group from each group type covering exclusion first, with the other covering inclusion first. Some participants also explicitly identified that it is easier to remember negative events (e.g., *"...it's probably easier to remember bad things than it is good things..."* [D, General 10th]).

It was also sometimes unclear whether participants in the focus groups were talking about social exclusion in particular, or mental distress (i.e., what led to *this*, what was *its* impact). This may either be a finding in itself or just confusion in the way the groups were facilitated. In order to gain a clear understanding of how discrimination relates to exclusion/inclusion, it may have been better to have had a specific question asking about this in addition to the general question on potential causes.

Finally, a potential source of bias is that some examples of experiences of social inclusion were linked to those organisations that had supported the recruitment and hosting of the focus groups.

CONCLUSION AND RECOMMENDATIONS

The current research study was an exploratory investigation into social inclusion and exclusion – particularly as they relate to discrimination – from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand. The conclusions from the work and resultant recommendations for the Like Minds, Like Mine programme include:

- Youth experience social exclusion as being pervasive.
- *Recommendations:*
  - *Retain youth as one of the priority audiences of the Like Minds, Like Mine programme; and*
  - *Tailor approaches to addressing the pervasiveness of their experience.*

- Māori experience disparities in the form of compounded social exclusion and barriers to social inclusion due to colonisation, racial discrimination and cultural disconnection.
- *Recommendations:*
  - *Retain Māori as one of the priority audiences of the 'Like Minds, Like Mine' programme;*
  - *Recognise the status of Māori as the first peoples of Aotearoa/New Zealand; and*
  - *Tailor approaches to address the disparities Māori face in the context of Te Tiriti o Waitangi, which recognise importance to them of reconnection with whānau, iwi and hapū, and tikanga as a pathway to inclusion.*

- Pasifika experience disparities in the form of compounded social exclusion and barriers to social inclusion due to racial discrimination and cultural disconnection.
- *Recommendations:*
  - *Retain Pasifika as one of the priority audiences of the 'Like Minds, Like Mine' programme; and*
  - *Tailor approaches to address the disparities Pasifika face, which recognise the importance to them of spirituality and religion as a pathway to inclusion.*

- A removal of the negatives of social exclusion does not guarantee the gaining of the positives of social inclusion.
- *Recommendation:*
  - *Retain the focus of the programme on increasing social inclusion as well as reducing stigma and discrimination.*

- Social exclusion and social inclusion are experienced as vicious and virtuous cycles respectively, as is consistent with previous work on self-stigma.
- *Recommendation:*
  - *Use the "circuit breakers" identified in Peterson et al. (2008) to inform future strategies.*

- Anti-discrimination programmes need to concentrate on *both* reducing stigma and discrimination, reducing exclusion and promoting social inclusion with others, *AND* reducing self-stigma, self-exclusion, the impact of discrimination and exclusion, and promoting social inclusion with people who experience mental distress.
- *Recommendation:*
    - *Establish a programme to support people who experience mental distress to 1) address self-stigma, self-exclusion that results from self-stigma and anticipated discrimination, and self-blame; 2) assert their own individuality, independence and personal agency to challenge discrimination and social exclusion when it is experienced; and 3) pursue social inclusion.*

- Two of the most significant themes in terms of vicious cycles of social exclusion and virtuous cycles of social inclusion relate to employment and sport.
- *Recommendations:*
    - *Retain workplaces as a current focus of the Like Minds, Like Mine programme; and*
    - *Consider making sporting teams, clubs and activities a focus of the programme.*

- Agents of social exclusion include government agencies and health care services and professionals.
- *Recommendation:*
    - *Consider government agencies and health care services and professionals as additional foci for the Like Minds, Like Mine programme.*

- The medicalisation of their distress was experienced as exclusionary by Māori and Pasifika particularly, which is consistent with the literature in terms of this framing being known to either have little to no impact on stigma, or to make it worse.
- *Recommendations:*
    - *Consider the appropriateness of the continued use of 'illness' through the Like Minds, Like Mine programme; and*
    - *Consider developing a programme for health care services and professionals based on the 'key ingredients' of anti-stigma programmes for health care providers identified by Knaak et al. (2014).*

- Some people experience attempts to make mental distress more relatable for the public as exclusionary, due to their perception that the people being portrayed in those attempts are not relatable to *them* and *their experience*.
- *Recommendation:*
    - *Be cognisant of this potential unintended harm when developing campaigns.*

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APPENDICES

Appendix 1:
Question schedule to guide semi-structured focus group discussion

The questions for the semi-structured interview on **social exclusion**:

(i)   What led to this happening?

The following prompts are intended to be linked to the questions (i) – (iv), but not to each other. That is, they are not a 'series of questions', but can be asked as appropriate, in response to the group dynamic.

Prompts: Who or what made the experience happen?
           What role was played by your then current experience of mental distress?
           How had people been treating you in the lead up to the experience?

(ii)   What happened because of it?

Prompts: How did you feel about it? [Tentatively trying to find out whether it was all negative]
           Did it affect your well-being?
           Which things could you not do (or do) as a result?

(iii)   How common is this type of experience for you?

(iv)   How could it be different?

(v)   What needs to happen for it to be different?

The questions for the semi-structured interview on **social inclusion**:

(i)   How did this experience differ from your experience where you felt like you were not part of a group of people or a place for people?

Prompts: Who or what made it different?
           What happened differently because of it?
           How common is this type of experience for you? Should we be trying to promote more of this type of thing and if so, how?

Finally:

"Can you just say, briefly, whether overall you feel included or excluded in New Zealand".

Appendix 2:
Advertisement

Aotearoa/New Zealand: Social Inclusion, Social Exclusion and the experience of mental distress

We are conducting a research study to find out about how people who experience mental distress feel like they can or can't participate in the ordinary activities of people and places in society.

We would like to find participants from Aotearoa/New Zealand society who have experienced mental distress and are willing to discuss this. There will also be a focus on the experiences of Māori, Pacific, and young people (aged 18-25).

If you are 18+ years of age, identify as being a person who experiences mental distress, and are interested in taking part in a focus group discussion and a short drawing exercise (using an iPad), then please contact [name] (email: [address]; telephone: 04 [number]).

Your involvement would be for 3 hours. A meal will be provided during this time.

The groups will be held **Monday 14th March** (**10am-1pm** for a self-identified Māori group; **2-5pm** for a self-identified Pacific Islander group) and **Tuesday 15th March (10am-1pm** for a 'general' focus group; i.e. for people who do not self-identify with the other groups; **2-5pm** for a self-identified youth group, aged 18-25).

Research Team Contact Details: Dr. Sarah Gordon, Dept. of Psychological Medicine, University of Otago Wellington, 23A Mein Street Newtown, Wellington 6021, New Zealand. Tel: [number] Email address: sarah.e.gordon@otago.ac.nz

[This project has been reviewed and approved by the University of Otago Human Ethics Committee, (Health). Reference: H16/010]

Appendix 3:
Participant information sheet

Study title:	*Aotearoa/New Zealand: Social Inclusion, Social Exclusion and the experience of mental distress*	
Principal investigator:	**Name** Dr. Sarah Gordon **Department** Psychological Medicine **Position** Service User Academic	**Contact phone number:** XXXXXXXXXX

Introduction
Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?
Our aim is to find out about how people who experience mental distress feel like they can or can't participate in the ordinary activities of people and places in society. We would like, in particular, to find out about these experiences for Māori, Pacific, and young people (aged 18-25), as well as from other people experiencing mental distress. Māori, Pacific, and young people are among the most affected in society in experiencing mental distress and not feeling able to participate.

Who is funding this project?
This project is funded by the Mental Health Foundation.

Who are we seeking to participate in the project?
We are talking to a diverse range of people in this project. In particular, however, we want to invite Māori, Pacific, and young people (aged 18-25), who are priority groups for the *Like Minds, Like Mine* programme to increase social inclusion and reduce stigma and discrimination for people with experience of mental illness. The project will include people outside of these groups, too, and who also experience mental distress.

If you participate, what will you be asked to do?
You would be asked to come to [venue] for approximately 3 hours. You would then be asked to do some simple drawings about your experiences and to say something about this picture. These drawings would be done using an iPad tablet. The picture and voice recordings would be saved onto a computer. After this, you would then join up with other people with similar backgrounds who have just done their drawing/recording to discuss these, as part of a focus group. The group would be led by a member of the research team, who will also say something about their personal experiences as part of the discussion.

Participation in this research is voluntary and at no point during the research will you be pressured to continue. Each research team member will be very sensitive to the needs of the group members, and would be happy for you to leave the group early, if you chose to do so.

A meal will be provided during the 3 hour visit.

Is there any risk of discomfort or harm from participation?

We do not expect you to experience any ill effects from taking part in this study.

If you do, you may wish to contact your local mental health support person or organisation. Alternatively you can contact one of the research team members (contact details below) who will be able to help you to access the support you need.

What data or information will be collected, and how will they be used?

The information to be collected is the drawing and voice recordings, followed by the voice recordings of the focus group discussion. The voice recordings will be transcribed by an approved company. We will then analyse the voice recordings to identify and report themes that have come through the focus groups. We will also identify and report drawings and quotes that reflect certain themes well.

You are most welcome to request a copy of a summary of the results of the project and any publications resulting from the study should you wish. There is a section on the consent form that allows you to make your request known.

The research will also inform the work of the Health Promotion Agency (HPA) and their programme to counter stigma and discrimination, and to promote participation.

What about anonymity and confidentiality?

All information taken from you will be treated anonymously: only the research team will be able to identify participants from the information they give during their involvement in the research.

Each participant will be linked to a code and only these codes will be used outside of the research team when referring to any participant. So, for instance, in any future publication, it will not be possible to identify a participant because only their code will be used. These codes will be allocated to each participant's voice recording before being sent to the transcription company.

Also, any personal information given during the focus group or drawing exercise, from which it may be possible to identify a participant, would not be reported in any piece of writing resulting from this research.

The recorded information and transcripts will be securely stored in such a way that only members of the research team can access them. Once the study is completed and the results published, the recordings and transcripts will be stored for 10 years in a locked filing cabinet in a locked storage room at the University of Otago, Wellington and then they will be destroyed.

Finally, it will be important for each member of the focus group to agree to confidentiality. The group will all agree to ensure that what is said in the group, stays within the group.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project at any time and without any disadvantage to yourself. Any information that can be linked to you can also be withdrawn at that time.

However, once the information you provide has been analysed and written into publications, it will obviously not be possible for you to withdraw your contributions by that time.

If you wish to participate, please contact [name] (email:[address]; telephone: [number]).

Any questions?

If you have any questions now or in the future, please feel free to contact either:

	Contact phone number:
Name Dr. Sarah Gordon **Position** Senior Research Fellow - Service User Academic **Department** Psychological Medicine	
Name Mr Anaru Waa (Advisor for the project) **Position** Research Fellow **Department** Public Health	Contact phone number:
Name Dr. Ramona Tiatia **Position** Research Fellow **Department** Public Health	Contact phone number:

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix 4:
Consent form

Aotearoa/New Zealand: Social Inclusion, Social Exclusion and the experience of mental distress

Principal Investigator: Dr Sarah Gordon (sarah.e.gordon@otago.ac.nz; Tel: XXXXXXXXXXX)

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:

1. My participation in the project is entirely voluntary.

2. I have read the Participant Information Sheet concerning this study and understand the aims of this research project.

3. I have had sufficient time to talk with other people of my choice about participating in the study.

4. I confirm that I meet the criteria for participation which are explained in the Participant Information Sheet.

5. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.

6. I understand that I am free to withdraw from the project at any time without disadvantage.

7. I understand that my drawing and voice recordings, followed by the voice recordings of the focus group discussion, will be recorded.

8. I understand that what is said in the group, stays within the group.

9. I know that all information remains confidential between myself and the researchers during the study and will be reported anonymously in any spoken or written report of the study.

10. I know the results of the project will be published and will be available in the University of Otago Library (Dunedin, New Zealand).

11. I know that the recorded information and transcripts will be securely stored in such a way that only members of the research team can access them; and that once the study is completed and the results published, the recordings and transcripts will be stored for 10 years in a locked filing cabinet in a locked storage room at the University of Otago, Wellington and then they will be destroyed.

12. I wish to receive a summary of the results of the study   YES/NO

13. If YES, would you like to receive the summary by?

14. E-mail _____   (please print your e-mail address)

15. Postal mail _____ (please print your address)

Signature of participant: _____ Date: _____

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