



MONASH University

The Social Inclusion of Young Adults aged 18 to 25 with Serious Mental Illness

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Abstract

Social inclusion is a complex phenomenon that involves opportunities for social participation, as well as subjective perceptions of such opportunities. It is familiar as a general concept, but emergent as an empirical construct. There is increasing evidence that indicators of social inclusion are associated with positive health outcomes, suggesting that a greater emphasis on this construct is warranted. Developmental processes during young adulthood (e.g., cultivation of social roles) influence lifelong trajectories, suggesting that this may be a sensitive period for social inclusion. Young adults with serious mental illness (SMI) are vocationally disengaged and have relatively small social networks. However, there are gaps in the literature making it difficult to fully assess the extent that this group is socially excluded. The particular dimensions and indicators of social inclusion relevant to young adults with SMI have not been elucidated. The degree to which social inclusion is discrepant between young adults with SMI and those from the general community therefore remains unclear. Contributing to these gaps is the paucity of psychometrically sound measures of social inclusion that have embraced the developmental features of young adulthood. Thus, the overarching purposes of this research program were to clarify dimensions and indicators of social inclusion among young adults with SMI, and to better characterise the putative social exclusion of this cohort relative to same-aged peers in the community. Specific aims were to conduct a preliminary examination of psychometric properties of a social inclusion measure among young adults with SMI, and also among young adults in the general community, and to examine differences on this measure between these two populations. Three studies comprise the research program.

The first study involved an examination of psychometric properties of the Filia Social Inclusion Measure (F-SIM) among $N = 159$ young adults aged 18–25 years with SMI. Results suggested three dimensions underlying the F-SIM in this population (*Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*), each with excellent internal consistency (Cronbach's α range = .82–.94). Results also suggested that test-retest reliability was good (Intraclass Correlation Coefficients $\geq .70$). Each dimension demonstrated convergent validity with measures of social inclusion, social functioning, quality of life (QoL), loneliness, and psychological distress. Having established these findings among young adults with SMI, we conducted a comparable study among same-aged peers from the general community.

The second study involved an examination of psychometric properties of the F-SIM among $N = 152$ young adults aged 18–25 years from the general community. Results suggested two dimensions underlying the F-SIM in this population (*Interpersonal Connections*, and *Community Integration*), each with excellent internal consistency (Cronbach's α range = .87–.92). Results suggested that test-retest reliability was good (Intraclass Correlation Coefficients $\geq .60$). Both dimensions demonstrated convergent validity with measures of social inclusion, social functioning, QoL, loneliness, and psychological distress.

The third study involved an examination of group differences in social inclusion between $n = 159$ young adults aged 18–25 years with SMI and $n = 152$ same-aged peers from the general community. The three F-SIM dimensions identified in the first study accounted for large amounts of variation in group membership. Young adults

with SMI were socially excluded in each of these dimensions (*Interpersonal Connections, Vocational & Financial Security, and Healthy Independent Lifestyle*).

Relative to those from the general community, young adults with SMI were less likely to feel they had friends who would call on them in a crisis, and to be vocationally engaged. They were more likely to live with their parents, and to report unstable accommodation.

This research program produced psychometric data suggesting that, with further development, the F-SIM may have clinical applications for young adults with and without SMI. Findings of social exclusion among young adults with SMI relative to peers in the community combine replications of previous research with novel discrepancies that are apt for further exploration. They suggest the need for cross-sector interventions (e.g., mental health, vocational, housing) to improve social inclusion for young adults with SMI. In identifying similarities and differences among F-SIM dimensions across the two groups, these findings raise the question as to whether dimensions of social inclusion are fixed across populations. This has theoretical and methodological implications, which may contribute to a more nuanced understanding of social inclusion in the literature.

Publications during enrolment

Filia, K. M., Jackson, H. J., Cotton, S. M., **Gardner, A.**, & Killackey, E. J. (2018). What is social inclusion? A thematic analysis of professional opinion. *Psychiatric Rehabilitation Journal*, 41(3), 183–195.

Gardner, A., Filia, K., Killackey, E., & Cotton, S. (2019). The social inclusion of young people with serious mental illness: A narrative review of the literature and suggested future directions. *Australian & New Zealand Journal of Psychiatry*, 53(1), 15–26.

Gardner, A., Cotton, S. M., Allott, K., Filia, K. M., Hester, R., & Killackey, E. (2019). Social inclusion and its interrelationships with social cognition and social functioning in first-episode psychosis. *Early Intervention in Psychiatry*, 13(3), 477–487.

Gardner, A., Cotton, S., O'Donoghue, B., Killackey, E., Norton, P. & Filia, K. (2019). Preliminary psychometric properties of a measure of social inclusion for young adults aged 18 to 25 with serious mental illness. *Psychiatric Rehabilitation Journal*. Epub ahead of print, doi: 10.1037/prj0000382

Gardner, A., Cotton, S., O'Donoghue, B., Killackey, E., Norton, P. & Filia, K. (2019). Group differences in social inclusion between young adults aged 18 to 25 with serious mental illness and same-aged peers from the general community. *International Journal of Social Psychiatry*, 65(7-8), 631–642.

Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes two original papers and one narrative review paper published in peer-reviewed journals and one submitted publication. The core theme of the thesis is social inclusion among young adults aged 18 to 25 with serious mental illness. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within two organisations: (i) the Research and Translation unit at Orygen under the supervision of Dr Kate Filia, Professor Sue Cotton, and Professor Eóin Killackey; and (ii) the Monash University School of Psychological Sciences under the supervision of Professor Peter Norton.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapters two, five, six, and seven, my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status (published, in press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) and nature of co-author's contribution
2	The social inclusion of young people with serious mental illness: A narrative review of the literature and suggested future directions	Published	80%. Conceptualisation of the paper; literature search strategy; literature searches; preparation of manuscript; submission of manuscript including preparation of revisions and correction of proofs.	1) Dr Kate Filia, input into manuscript 2) Prof Sue Cotton, input into manuscript 3) Prof Eóin Killackey, input into manuscript
5	Preliminary psychometric properties of a measure of social inclusion for young adults aged 18 to 25 with Serious Mental Illness	Published	70%. Obtained ethics approval; Study design and protocol; Recruitment of participants; Data collection and analysis; Conceptualisation of the paper; literature review; preparation of manuscript; submission of manuscript; Preparation of revisions and correction of proofs	1) Prof Sue Cotton, input into manuscript and methodology 2) Dr Brian O'Donoghue, input into manuscript and methodology 3) Prof Eóin Killackey, input into manuscript 4) Prof Peter Norton, input into manuscript 5) Dr Kate Filia, input into manuscript and methodology
6	Preliminary psychometric properties of a measure of social inclusion among young adults aged 18 to 25 in the General Community	Submitted	80%. Obtained ethics approval; Study design and protocol; Recruitment of participants; Data collection and analysis; Conceptualisation of the paper; literature review; preparation of manuscript; submission of manuscript.	1) Dr Kate Filia, input into manuscript and methodology 2) Prof Sue Cotton, input into manuscript and methodology 3) Prof Eóin Killackey, input into manuscript
7	Group differences in social inclusion between young adults aged 18 to 25 with serious mental illness and same-aged peers from the general community	Published	70%. Obtained ethics approval; Study design and protocol; Recruitment of participants; Data collection and analysis; Conceptualisation of the paper; literature review; preparation of manuscript; submission of manuscript.	1) Prof Sue Cotton, input into manuscript and methodology 2) Dr Brian O'Donoghue, input into manuscript and methodology 3) Prof Eóin Killackey, input into manuscript 4) Prof Peter Norton, input into manuscript and methodology 5) Dr Kate Filia, input into manuscript and methodology

I have renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

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Glossary of Abbreviations

ABS	Australian Bureau of Statistics
APQ-6	Activity and Participation Questionnaire, Six Item
AQoL-8D	Australian Quality of Life instrument, eight dimensions
AUD	Australian dollars
CATPCA	Categorical Principal Components Analysis
CTT	Classical Test Theory
DSM	Diagnostic and Statistical Manual of Mental Disorders
EM	Expectation-maximisation
FEP	First-episode psychosis
F-SIM	Filia Social Inclusion Measure
GC	General community
GP	General Practitioner
HREC	Human Research Ethics Committee
IBM	International Business Machines
ICC	Intraclass Correlation Coefficient
IPS	Individual Placement and Support
IRT	Item Response Theory
K10	Kessler-10 Psychological Distress Scale
MCAR	Missing completely at random
NEET	Not in employment, education, or training
OECD	Organisation for Economic Co-operation and Development
OR	Odds ratio
QoL	Quality of life

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SCOPE	Social and Community Opportunities Profile
SD	Standard deviation
SDoH	Social determinants of health
SIS	Social Inclusion Scale
SMI	Serious Mental Illness
SPSS	Statistical Package for the Social Sciences
SRT	Social Recovery Therapy
T1	Time point one
T2	Time point two
UCLA	University of California, Los Angeles
WHO	World Health Organisation
YRC	Youth Research Council

List of Appendices

Appendix 1

Preliminary version of the Filia Social Inclusion Measure (F-SIM).

Appendix 2

What is social inclusion? A thematic analysis of professional opinion: Filia et al. (2018).

Appendix 3

Understanding what it means to be socially included for people with a lived experience of mental illness: Filia et al. (2019a).

Appendix 4

Developing and testing the F-SIM, a measure of social inclusion for people with mental illness: Filia et al. (2019b).

Appendix 5

Scree plot identifying three dimensions of the F-SIM in a sample of young adults aged 18 to 25 with serious mental illness

Setting the Scene

This PhD candidature has progressed continuously across approximately four years, from February 2016 until February 2020. Confirmation of the candidature occurred in August 2017 and a progress review was completed in May 2018. A final pre-submission review occurred in June 2019. The narrative literature review, which laid the foundation for the subsequent data-based studies, was published in January 2019. It involved six-monthly literature searches spanning February 2016 until February 2018. Advances in knowledge since that time are accounted for in the write-up of individual studies and the discussion chapter at the end of the thesis.

The candidature has taken place under the stewardship of an exemplary supervisory team at Orygen, and with invaluable input from senior academic staff in the School of Psychological Sciences at Monash University. In many ways, the thesis may be considered an extension of prior social inclusion research completed by members of the supervisory team (especially Dr Kate Filia). Three prior studies in particular have been foundational for the research conducted in this thesis (one of which includes the candidate as a co-author). These publications are included as appendices, as they are discussed numerous times throughout the thesis and form an integral part of the research story presented here. It is worth noting that British English is the default grammar style used throughout the thesis, whereas American English is used in some of the published articles (depending on the style guides of the particular journals).

CHAPTER ONE: INTRODUCTION TO SOCIAL INCLUSION

In this chapter, the concept of social inclusion is introduced and placed within a historical and evolutionary context. Relevant aspects of the empirical literature are then summarised (e.g., dimensions of social inclusion, objective and subjective phenomenology, relationships to health). The emergence of people with serious mental illness (SMI) as a population of interest within the social inclusion literature, and efforts to measure the construct in this cohort, are briefly discussed. The chapter ends with a summary that sets the scene for the subsequent published literature review, which elucidates the importance of considering social inclusion among young adults with SMI.

What is Social Inclusion?

The term ‘social’ originates from the Latin *socialis* (meaning ‘allied’) or *socius* (meaning, ‘friend’), and the term ‘inclusion’ originates from the Latin *includere*, meaning ‘to shut in’ (Oxford University Press, 1989). Literally, social inclusion denotes shutting in friends or allies. By extension, social exclusion denotes shutting out those who are not friends or allies. As lay terms, they refer to the extent to which individuals and/or groups, particularly those who are stigmatised, are accepted within or isolated from society (Peters & Besley, 2014). Most studies using these terms in the academic literature offer no formal or consensus definition, use them interchangeably, and mention them incidentally in the context of other research interests (Filia et al., 2018). Social inclusion and exclusion are often taken to be self-evident concepts, which has permitted them to become ‘all things to all people’ (Atkinson, 1998). Hence a vast range of studies, from the examination of labour market trends (Vinson, 2009) to the experimental induction of ostracism (Eisenberger, 2012), have been characterised as social inclusion/exclusion research. Nonetheless, a small but instructive social inclusion/exclusion literature concerned with explicit definition and operationalisation is emerging (e.g., Evans-Lacko et al., 2014). A detailed conceptual and methodological review of this literature is beyond the scope of this thesis, and has been undertaken

elsewhere (e.g., Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007; Wright & Stickley, 2013). A brief summary of the literature regarding definitions of social inclusion/exclusion is offered below.

Definitions.

There is no unanimously agreed definition of social inclusion or exclusion (O'Donnell, O'Donovan, & Elmusharaf, 2018). This perhaps reflects the complexity of the construct/s: while broad themes (e.g., social connectedness) may apply across populations, specific characteristics might vary in 'mainstream' populations relative to marginalised populations (Rawal, 2008). Definitions of social inclusion or exclusion are typically operationalised with reference to putatively excluded individuals and/or groups, e.g., adults diagnosed with mental illness (Cordier et al., 2017). Most commonly this refers to forms of serious mental illness, i.e., those that contribute to significant functional impairment, such as schizophrenia (e.g., Mezey et al., 2013; Perry et al., 2011). Some definitions of social inclusion focus on access to socio-political and legal citizenship rights, while others emphasise social participation (Huxley & Thornicroft, 2003). A subjective sense of belonging or acceptance is central to most definitions of social inclusion (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012). Social exclusion tends to be considered as the polar opposite of social inclusion (Baumgartner & Burns, 2014). Indeed, it is difficult to discuss one without reference to the other (Hayes, Gray, & Edwards, 2008). Accordingly, social exclusion is thought to involve lack of access to participation in valued social roles (Burchardt, Le Grand, & Piachaud, 2002), and a subjective sense of alienation or loneliness (Levitas, 2006). Alternatives to the common conceptualisation of social inclusion and exclusion as polar opposites have been offered. Secker (2009) suggests that these are best viewed as distinct yet intersecting phenomena, where exclusion operates on a broad structural level and inclusion operates at the individual and/or group level. Within this research program, it is a basic philosophical assumption that social inclusion and exclusion are opposite ends of the same continuum. Accordingly, the author follows the convention established by previous researchers (e.g., Baumgartner & Burns, 2014; Hayes et al.,

2008; Ryan & Sartbayeva, 2011) who switch between the two terms. Social inclusion, however, is the term that will primarily be used throughout the thesis.

Historical Context

As noted above, belongingness is considered central to definitions of social inclusion. It is also considered a core psychological need in empirically supported theories of human motivation (Ryan & Deci, 2017). This suggests that social inclusion may have an evolutionary basis.

Evolution and the Need to Belong.

The ability to cooperate with other members of the species is arguably the ‘crown jewel’ of human evolution (Wilson, 2018). In the environment of evolutionary adaptiveness, cooperative food acquisition, child-rearing, and defence against predators likely conferred significant advantage over non-cooperation (Coelho & McClure, 2016). This would have effects at group and individual levels: species survival as contingent upon group cooperation, and individual survival as contingent upon group membership (Stevens & Fiske, 1995). Importantly, groups who adopt such cooperative strategies are likely compelled to sanction group members who do not cooperate (Wilson, 2015). As our ability to cooperate evolved through increasingly complex social systems, so too did our approach to managing instances of non-cooperation. Public forms of sanction ranging from shunning and ostracism to execution have been applied to individuals who have been perceived to violate cooperative norms (Bowles & Gintis, 2011). It is plausible that such norms were internalised as social systems elaborated throughout human history (Bowles & Gintis, 2011). This implies that human beings have evolved an innate sensitivity to whether they are included within or excluded from the group. Empirical support for this argument comes from experimental evidence of overlap between the neurobiological processes involved in physical pain, and those involved in subjective experiences of social exclusion. There is evidence for increased dorsal anterior cingulate cortex and

anterior insula activity (the brain regions associated with the affective component of physical pain) in response to social exclusion (Eisenberger, 2012; Eisenberger, Lieberman, & Williams, 2003).

An evolutionary account relevant to social inclusion has been articulated by Baumeister and Leary (1995), who proposed belonging as a fundamental human need. They posited that this need cannot be satisfied by mere interpersonal contact, but rather requires sufficiently frequent and subjectively valued social interactions. This is consistent with the common conceptualisation of social inclusion as an interaction between objective participation and subjective satisfaction with opportunities to participate (Huxley et al., 2006). Baumeister and Leary reviewed empirical findings across a range of research areas relevant to the need to belong hypothesis. The desire to form social attachments exists under a wide variety of situations and settings. People who lack social attachments more commonly experience psychological and physical health problems. Even among people who report an indifference to, or dislike for, social connection (e.g., those with a dismissive-avoidant interpersonal style), there are subjective benefits of belonging. The authors reported evidence that social attachments generally predict positive emotions, whereas real and perceived threats to such attachments predict negative emotions, and that a disproportionate amount of cognitive resource is allocated to processing social information. They also found evidence that motivational patterns of satiation and substitution are apparent. That is, once a subjectively satisfactory level of social connection has been attained, additional bonds tend not to be sought. Conversely, when people lose social attachments they tend to actively seek connections to replace those that have been lost. Based on this accumulation of evidence, Baumeister and Leary concluded that the need to belong influences a range of human behaviour so broad that its reducibility to other motives is implausible. Subsequent reviews offering updates on the empirical case for the need to belong have also concluded that it is likely fundamental for human beings (Gere & Macdonald, 2010). While this may provide a compelling theoretical underpinning for social inclusion research, it does not explain how the term became established in the academic and general public lexicons.

The Emergence of the Term Social Inclusion.

The terms social inclusion and exclusion were introduced by French academics in the 1960's to describe the separation of disadvantaged groups from mainstream society (Beland, 2007). In 1965, Jean Klanfer published *L'Exclusion Sociale: Étude de la marginalité dans les sociétés occidentales* (Social Exclusion: The Study of Marginality in Western Societies). Klanfer acknowledged that some people were socially excluded (i.e., unable to benefit from the economic progress of the society around them). He invoked neoliberal notions of individual responsibility in explaining this phenomenon. In 1974, René Lenoir published *Les Exclus: Un Français sur dix* (The Excluded: One French person out of ten). Lenoir emphasised the impact of economic and social conditions on those who are excluded (e.g., people with SMI and other disabilities). Though initially coined in France, usage of the terms social inclusion and social exclusion rapidly spread throughout Europe and other Western societies – particularly within political contexts (Beland, 2007).

Political Context.

The proliferation of the term social inclusion was partly a response to the impact of the so-called 'crisis of the welfare state' (Rawal, 2008). In developed countries, increasing unemployment and rising inflation throughout the 1970's eroded the financial base from which social assistance payments could be drawn (Joppke, 1987). In the 1980's and 1990's, governments throughout Europe and beyond continued to grapple with issues of poverty and disadvantage, and increasingly embraced the terms 'social inclusion,' and 'social exclusion' in their policy rhetoric (Levitas, 2006). In the UK the Blair government created the Social Exclusion Unit in December 1997. Until it was abolished in 2010, the Social Exclusion Unit was tasked with discovering why social exclusion appeared to be increasing in the UK, and what could be done to reverse the trend (Batty, 2002). The initial demonstration of political will to address issues of social inclusion and/or exclusion

necessitated a clarification of what was meant by these terms (i.e., policies required the terms to be operationalised as empirical constructs). This likely contributed to an increased interest in the empirical examination of social inclusion.

Empirical Research

Two issues that have been important to address in terms of operationalising social inclusion are: (i) capturing underlying dimensions; and, (ii) adequately incorporating the objective and subjective phenomenology of the construct.

Dimensions.

Social inclusion is widely agreed to be multi-dimensional, but it is also thought to be dynamic (i.e., process-like) and relative to a given society, place, and time (Huxley, Evans, & Munroe, 2006). An implication of this is that dimensions may differ depending on the population being considered, but this has not been an assumption of the extant literature. A systematic review of social inclusion measures in any population posited three overarching dimensions: (i) participation; (ii) connectedness/sense of belonging; and (iii) citizenship rights (Cordier et al., 2017). Yet the majority of social inclusion studies are conceptual and not empirically driven (Good-Gingrich & Lightman, 2015). This makes it difficult to answer practical questions about what it means to be socially included across these dimensions (e.g., Participation in which activities? Connectedness to whom, or what? How do citizenship rights manifest?). There has been relatively little research taking an empirical approach to clarifying such matters (Morgan et al., 2007; Wright & Stickley, 2013), although there are two notable examples. Huxley and colleagues (2012) completed a concept mapping process wherein they: (i) recruited participants from various segments of the community; (ii) asked them to write down what comes to mind when they think of social inclusion; (iii) iteratively arranged these statements into clusters; (iv) generated tables based on the clusters; (v) used a contents analysis approach to determine whether the clusters could be

considered dimensions; and (vi) agreed on a core set of dimensions. More recently, Filia and colleagues (2018) conducted a thematic analysis of social inclusion to identify key contributors and underlying dimensions. The analysis surveyed 25 peer-reviewed papers from the non-population-specific social inclusion literature, 26 peer-reviewed papers from the social inclusion and mental illness literature, and 20 pieces of grey literature (e.g., reports from grass-roots community services). Ninety individual contributors to social inclusion were identified and grouped according to common themes. Interestingly, both Huxley et al. (2012) and Filia et al. (2018) identified the following common dimensions of social inclusion: employment/education, leisure activities, housing and accommodation, financial situation, family and social relationships, and health.

Across these dimensions, opportunities to participate in social roles (e.g., to work) and exercise citizenship rights (e.g., seek income support) are objective phenomena that are integral to social inclusion. Yet subjective appraisals of such phenomena are also integral to social inclusion (Huxley, 2015).

Objective and Subjective Phenomenology.

It is generally agreed that social inclusion is a phenomenon that comprises objective and subjective elements (Huxley & Thornicroft, 2003), although it is unclear whether these are best conceived as separable or combined. Objective phenomena are observable elements of the environments within which people live, and subjective phenomena entail peoples' evaluation and perception of their living conditions within such environments (Lee & Marans, 1980). With respect to social inclusion, it may be intuitive to assume a positive relationship between the two (i.e., that increased social participation is associated with greater sense of belonging). There is some evidence of this at the group level in the general population (Na & Hample, 2016), and among people with SMI (Lloyd, King, & Moore, 2010). However, at the individual level, the relationship may be more complicated. Someone who works full-time in a job they find unfulfilling and in a workplace they

find isolating can hardly be described as socially included (Secker, 2009). Alternatively, someone who is not dissatisfied with observably low levels of social participation may not be socially excluded (Groth-Marnat, 2009). This reveals the inability of a ‘one-size-fits-all’ approach to capture the idiographic aspect of social inclusion, and highlights the importance of considering subjective satisfaction with objective level of participation (Huxley et al., 2012).

Despite social inclusion’s status as a putatively benevolent phenomenon, it is important to note that some ideological criticisms have been made.

Ideological Critiques of Social Inclusion.

Spandler (2007) argues that implicit assumptions underlying the social inclusion imperative may have unintended consequences. Well-meaning attempts to help marginalised individuals and/or groups improve their social inclusion may be imbued with value judgements about normality: social inclusion might entail ‘fitting in’ rather than truly belonging (Brown, 2017). That is, an uncritical acceptance of the social inclusion imperative may perpetuate conformity to the norms of a society that is inherently exclusive (Spandler, 2007). This echoes Foucault (2003) who suggested that social inclusion and exclusion might be employed as processes of social control. Such critiques of social inclusion tend to view it as a superficially virtuous sociological construct, which may or may not be useful in terms of explaining inequality and alienation. In this research program, social inclusion is conceptualised through the evolutionary framework outlined earlier (i.e., reflective of a fundamental need for human beings). To demonstrate the empirical support for this conceptualisation, it is worth briefly summarising findings from the literature on the relationship between indicators of social inclusion and positive health outcomes.

Social Inclusion and Health.

There is evidence that indicators of social inclusion are associated with better physical health (e.g., Cacioppo, Cacioppo, Capitanio, & Cole, 2015; Heinrich & Gullone, 2006; Kiecolt-Glaser et al., 1984). In a sample of healthy adults, Floyd et al. (2016) found that greater self-reported social activity (e.g., time spent with friends) predicted lower blood-glucose levels and fewer low-density lipoproteins. Meta-analyses suggest that internationally and across sexes, having a higher quantity and perceived quality of social relationships reduces mortality risk, and that the moderate effect size is comparable to more commonly known protective factors such as exercise (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Holt-Lunstad, Smith, & Layton, 2010). Holt-Lunstad and colleagues found that the effect size was largest for those who had a variety of relationships across multiple domains (e.g., friends and family, colleagues in the workplace). There was no statistically significant difference in effect size between objective and subjective indicators, suggesting that both observable and perceived decreases in social inclusion are harmful (Holt-Lunstad et al., 2015). There is also evidence that social inclusion is associated with better psychological health (Davies, Davis, Cook, & Waters, 2008; van Bergen, Hoff, van Ameijden, & van Hemert, 2014; Vanhalst et al., 2015). A large longitudinal study in the general population found that perceived social acceptance was a stronger and more consistent predictor of decreased psychological distress over time than vice versa (Saeri, Cruwys, Barlow, Stronge, & Sibley, 2017).

The above findings have contributed to advocacy for the objective (i.e., structural, functional) and subjective (i.e., qualitative) aspects of social inclusion to become public health priorities (Holt-Lunstad, Robles, & Sbarra, 2017). Yet these findings come from a range of methodologies using diverse indicators of social inclusion. Policy initiatives require a consistent approach to the measurement of social inclusion, which may best be achieved via psychometric instruments that include objective and subjective indicators (Shepherd & Parsonage, 2011). For example, psychometric measures are required to screen for social exclusion among the general

population in primary health care settings (O'Donnell et al., 2018). This remains an unmet need: such evidence-based tools have not been sufficiently developed (Cordier et al., 2017). While it has become familiar as a general concept, and there is increasing awareness of its relationship with health, social inclusion is a relatively novel construct in the empirical literature. This is perhaps best understood by summarising the chronology of social inclusion's emergence within that literature.

A brief Chronology of the Empirical Social Inclusion Literature.

As noted earlier, social inclusion has historically been a political term (Morgan et al., 2007). Accordingly, the construct was typically examined via macro-level population data such as indices of neighbourhood crime, poverty levels, and labour market trends (Vinson, 2009). In the early 2000's, an increasing emphasis was placed on looking beyond macro-level indicators in order to better understand processes of inclusion/exclusion at the individual and group levels for those who were marginalised (Parr, Philo, & Burns, 2004). Curiously, this did not appear to generate a parallel interest in the establishment of normative data (i.e., what does social inclusion entail for the general population?). Arguably, this is a necessary preliminary step towards accurately assessing social inclusion among marginalised groups. Despite this potential limitation, people with SMI were identified as an important marginalised group to focus on (Evans & Repper, 2000; Sayce, 2001).

Social Inclusion and Mental Illness.

From the beginning of the 21st Century, a growing number of papers on social inclusion and mental illness began to appear in the academic literature (e.g., Huxley & Thornicroft, 2003; Stickley, 2003) and in government policy documents (e.g., Social Exclusion Unit, 2004). As noted previously, such publications were largely conceptual (Good-Gingrich & Lightman, 2015). For example, Sayce (2001) discussed the complex and likely bidirectional relationships between mental illness and social exclusion. Lloyd, Tse and Deane (2006) described a number of activities that may promote social inclusion for people with SMI, and argued that social inclusion provides a

framework for developing mental health policy. Morgan et al. (2007) published a conceptual and methodological review of social inclusion/exclusion and mental illness. The authors noted an ongoing lack of conceptual clarity and precision in this literature. Some suggested that this may be addressed by focussing on more precise sub-groups of interest, e.g., people with SMI who are at key transitional life stages (Hayes et al., 2008). Young adulthood is one such stage that occurs between the late teens and mid-twenties (Wainryb et al., 2001). Social identity formation (i.e., the exploration of which particular social roles one values) is a key developmental task for young adults (Benson & Elder, 2011). Given the disruption to this process that illness onset can engender, social inclusion is thought to be particularly important for young adults with SMI (Killackey et al., 2013). While relevant studies have begun to emerge (e.g., Berry & Greenwood, 2018a), this cohort remains under-researched in the social inclusion and mental health literature (Evans-Lacko et al., 2014).

Notwithstanding a potential under-emphasis on these developmental aspects, the literature has progressed towards the measurement of social inclusion among people with SMI.

Measuring Social Inclusion among People with Serious Mental Illness.

As the first decade of the 21st Century drew to a close, studies seeking to develop psychometric measures of social inclusion began to appear in the literature (e.g., Hacking & Bates, 2008; Huxley et al., 2006; Marino-Francis & Worrall-Davies, 2010; Secker et al., 2009; Stickley & Shaw, 2006). Many were developed for unique purposes within circumscribed settings. For example, Secker et al. (2009) developed the Social Inclusion Scale (SIS) to evaluate the impact of participating in a community arts project on a sample of middle-aged mental health service users. Stickley and Shaw (2006) developed a measure to assess the social inclusion experiences of people with chronic SMI who were relocating from a 12-bed supported accommodation service into the community. A common methodological issue across many of these studies was sample size. For

example, Marino-Francis and Worrall-Davies (2010) developed a tool to measure social inclusion in a community mental health service. The sample size ($n=69$) may have been too small to justify the principal components analysis they conducted. While there are no strict rules, Tabachnik and Fidell (2012) suggest that a sample size ≥ 150 may be required in most cases to conduct a factor and/or principal components analysis.

Another common methodological issue relates to item creation. A number of studies adopted items from existing scales of theoretically related constructs (e.g., Lloyd, Waghorn, Best, & Gemmell, 2008). Others relied heavily on the input of participants within small and unique samples, without incorporating wider and more comprehensive methods such as literature reviews (e.g., Stickley & Shaw, 2006). Despite these methodological issues, some of the measures were employed in subsequent empirical studies (possibly due to a lack of established instruments, and the exigency of measuring social inclusion). For example, in a cross-sectional study, Killaspy et al. (2014) investigated retrospectively perceived change in social inclusion after the development of a psychotic illness among middle-aged people with SMI. Wilson and Secker (2015) sought to further develop the SIS (Secker et al., 2009) in a sample of mature-aged university students. Arguably, this sample was not representative of the general population because all participants were currently participating in education (a putative indicator of social inclusion).

In the second decade of the 21st Century, a number of reviews have evaluated psychometric properties of social inclusion measurement tools. Coombs, Nicholas and Pirkis (2013) conducted a scoping review of the suitability of available social inclusion measures for use in Australian public sector mental health services. Shortly thereafter, Baumgartner and Burns (2014) published a review with a similar aim but more global focus. The authors of both reviews suggested that existing instruments need to be adapted, or new ones specifically designed, for use in mental health services. Most recently, Cordier et al., (2017) published a systematic review evaluating the psychometric

properties of social inclusion measures in any population group. They called for improved study designs using adequate sample sizes and appropriate statistical analyses. All three reviews were united in their conclusion that, of the few available psychometric social inclusion measures, some have shown promise but none have been sufficiently developed.

Summary of Introduction

Social inclusion involves subjective belongingness in relation to satisfaction with opportunities to participate in valued social roles across multiple dimensions (e.g., employment/education, leisure activities, housing and accommodation, financial situation, family and social relationships, and health). This phenomenon likely has an evolutionary basis: human beings appear to have an innate need to belong. Empirical support for this position comes from evidence of a relationship between diverse indicators of social inclusion (e.g., quantity and quality of social relationships) and positive health outcomes (e.g., reduced mortality risk). Despite increasing awareness of this relationship, social inclusion has historically been conceived as an ideological and political concept. Efforts to operationalise it as an empirical construct (i.e., develop psychometric tools to measure it directly) emerged in the early 21st Century. Such efforts were concentrated on putatively excluded populations, particularly people with chronic SMI. There remains a lack of conceptual clarity and specificity in the social inclusion and mental illness literature. Some have suggested that this may be overcome by focusing on more precise populations of interest, perhaps defined by developmental phase (Hayes et al., 2008). Young adulthood is one such phase that may influence social inclusion trajectories, given that social identity formation is a key task during this period. Illness onset can negatively disrupt this process for young adults with SMI, who are therefore an important population to focus on. Despite this, there remains a lack of developmental perspectives in the mental health and social inclusion literature. Nonetheless, some psychometric tools have been developed to measure social inclusion among people with SMI. Methodological issues have hampered the applicability of these measures, and reviews have

concluded that no existing measure has undergone sufficient psychometric development (i.e., employed appropriate study designs or demonstrated applicability across diverse settings). In the context of this background, the importance of considering social inclusion within the population of interest (i.e., young adults with SMI) will be elucidated in the published narrative review of the following chapter.

CHAPTER TWO: A REVIEW OF THE LITERATURE ON SOCIAL INCLUSION AMONG YOUNG ADULTS WITH SERIOUS MENTAL ILLNESS

Preamble

People with chronic SMI (e.g., schizophrenia) have long been considered socially excluded (Killaspy et al., 2014). Chronic SMI typically develops over many years and is characterised by an enduring syndrome, i.e., recurrent episodic or continuous symptomatology (Hope & Keks, 2015). However, there are different stages of SMI, each of which may involve unique needs, entail different levels of functional impairment, and require different treatment approaches (McGorry et al., 2006). The onset of SMI typically occurs between the early-to-mid teens and the mid-twenties (i.e., in adolescence and young adulthood [Baldwin et al., 2005]). The term ‘young people’ has been used to describe adolescence and young adulthood as combined, overlapping developmental stages (Gulliver et al., 2010; Rickwood et al., 2007). The putative social exclusion of people with chronic SMI cannot be assumed to exist among young people with a recent onset of SMI. Also, any social exclusion that may be experienced by young people with SMI cannot be assumed to be identical to that experienced by older people with SMI.

There is a growing literature seeking to empirically examine social inclusion in chronic SMI populations (e.g. Mezey et al., 2013; Turner et al., 2017), but this is under-researched among young people with SMI (Evans-Lacko et al., 2014). The paper presented in this chapter, which was accepted for publication in the *Australian & New Zealand Journal of Psychiatry* in September 2018, aims to address this gap. It offers a narrative review of the literature on social inclusion among young people with SMI (population search terms included: “youth” OR “adolescen*” OR “young people” OR “young adult” OR “young person”). These broader terms were applied in recognition of the paucity of published studies examining social inclusion specifically among young adults with SMI. The chapter concludes with a brief overview of findings from the review.

The social inclusion of young people with serious mental illness: A narrative review of the literature and suggested future directions

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Abstract

Background: Social inclusion involves objective participatory (e.g. education/employment) and subjective (e.g. sense of belonging/acceptance) elements across multiple domains. It has been associated with enhanced physical and mental wellbeing yet is a novel construct in the empirical literature (i.e. measures have not been sufficiently developed).

Aims: Young people with serious mental illness are reported to be socially excluded. It is unclear whether this is reflected in the social inclusion/exclusion literature. The aim of this narrative review is to determine whether such literature permits a comprehensive (i.e. multi-dimensional, objective and subjective) understanding of social inclusion among young people with serious mental illness.

Methods: Searches to identify studies related to the social inclusion and/or exclusion of young people with serious mental illness were conducted on 16 February 2016, 24 August 2016, 16 February 2017, 24 August 2017 and 16 February 2018 in PsycINFO, MEDLINE, the Cochrane Library, SCOPUS, Open Grey, Web of Science, Google and Google Scholar.

Results: There is a paucity of research in the explicit social inclusion literature involving young people either with or without serious mental illness as participants. Literatures exist in related independent areas of research (e.g. employment, social networks), but such studies employ heterogeneous methodologies.

Conclusion: Multi-dimensional measures of social inclusion incorporating objective and subjective indicators must be developed for young people with and without serious mental illness. This will enable the generation of normative and clinical data. Existing evidence for the social exclusion of young people with serious mental illness comes from objective indicators in isolated domains (e.g. unemployment). Subjective indicators continue to be under-researched. The above-described measures must be employed to further understanding of the apparent discrepancies between young people with serious mental illness and those without serious mental illness. This will elucidate the relationships between objective and subjective elements of social inclusion and the relationships between these elements and the psychological distress that young people with serious mental illness often experience. This has implications for intervention.

Keywords

Social inclusion, early intervention, youth, young people, mental illness, psychosis

Background

Social inclusion is an emergent construct in the empirical literature, yet elements of social inclusion (e.g. social and community connections) have long been associated with positive health outcomes (Berkman and Syme, 1979). Although it is frequently assumed to be a self-evident concept (i.e. is often not explicitly defined), a number of domains are commonly thought to underlie social inclusion. These include employment/education, social networks, housing, neighbourhood

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accessibility and amenities, finances, health/wellbeing and leisure activities (Filia et al., 2018). Despite increasing recognition of its importance, there is no consensus definition of social inclusion (Brown et al., 2015). Such conceptual issues (e.g. definitional controversies, overlap with other constructs) have been discussed elsewhere (Cordier et al., 2017) and are beyond the scope of this review. One may argue that until such consensus exists, empirical examination of the construct is of limited value. There are a number of well-established constructs that lack a consensus definition yet remain widely used. A consistent definition of quality of life (QoL) has not been established, yet it is used across a range of practical and policy contexts, including by the World Health Organization who have developed their own quantitative measure (The WHOQoL Group, 1995). Social inclusion is distinct from such related constructs, and reluctance to translate it into practice and policy impedes the ability to improve outcomes for those who are socially excluded (Brown et al., 2015).

There is some agreement that social inclusion involves objective participation in social activities, interconnected with subjective experiences of belonging and acceptance (Morgan et al., 2007). However, the nature of the interconnections is unclear – does subjective inclusion necessarily increase in the same direction or at the same rate as objective participation for all individuals? (Australian Mental Health Outcomes Classification Network, 2016). The terms social inclusion and social exclusion are intimately related; it is difficult to discuss one without the other. In this review, we follow the examples of other researchers (e.g. Hayes et al., 2008; Ryan and Sartbayeva, 2011), who have switched between the two terms and conceived them as opposite ends of the same continuum. Here, social inclusion will be defined as the experience of belonging/acceptance and satisfaction in relation to opportunities to participate in valued social roles across the above-mentioned domains (Gardner et al., 2017). Social exclusion will be defined as the experience of loneliness/isolation and dissatisfaction in relation to the involuntary absence of such opportunities. It is important to acknowledge that an individual may voluntarily eschew opportunities to participate in some social roles: a lack of objective social participation does not necessarily indicate social exclusion. It is also important to distinguish between active and passive processes of inclusion and/or exclusion. The likely detrimental effects and neural correlates of ostracism (i.e. active social exclusion) have been experimentally demonstrated (Eisenberger, 2012), but less is known about the effects of more passive forms of exclusion such as ignoring. It is possible that passive inclusion and passive exclusion each have harmful effects on health and wellbeing.

Gender differences are apparent in some domains of social inclusion. The median earnings of full-time employed men are 14% higher than those of full-time employed women in developed countries (OECD, 2018). Evidence is

more tentative regarding differences on subjective indicators. It has been reported that, compared to males, females have more emotionally intimate social connections, solicit more social support in times of stress and more frequently provide social support to others (Kawachi and Berkman, 2001). Na and Hample (2016) found that binary gender (male/female) significantly predicted sense of belonging, but did not report the direction of the effect and so it is unclear whether males or females experienced a greater sense of belonging. The social inclusion of gender fluid and diverse (i.e. non-binary) individuals is increasingly recognised as an important and under-explored area of research (Divan et al., 2016). Given evolving conceptualisations of gender and the relative novelty of social inclusion as a unified empirical construct, more research is needed in this area.

Social inclusion is thought to become salient in adolescence, which is a biopsychosocial process through which young people develop the skills to successfully transition to adulthood (Morrison et al., 2012). If social inclusion is not fostered through this sensitive period, it can be difficult to attain in later life (Social Exclusion Unit, 2005). Some have stated that adolescence occurs between 10 and 19 years of age (World Health Organization, 2017), although it may be defined as the phase between puberty onset and the attainment of adult independence (Blakemore and Mills, 2014). In this review, the terms ‘adolescence’, ‘youth’ and ‘young people’ will each refer to this phase and may be used interchangeably. ‘Young adult’ is a related term that will be applied to people who meet legal requirements of adulthood (i.e. ≥ 18 years old) but may have not yet completed the above-described phase of adolescence. Significant literatures exist within some domains of social inclusion for young people (see Mawn et al., 2017, for a systematic review and meta-analysis of youth unemployment). Empirical research on a more comprehensive conceptualisation of the construct (i.e. multi-dimensional, incorporating objective and subjective indicators) is lacking in this population. This is due, in part, to a lack of psychometrically sound measures of social inclusion (Baumgartner and Burns, 2014; Coombs et al., 2013; Cordier et al., 2017).

Young people with serious mental illness (SMI) are thought to be especially vulnerable to social exclusion (Social Exclusion Unit, 2005), and this may be the case regardless of specific diagnostic group (Caruana et al., 2017). The term SMI is somewhat interchangeable with the term psychiatric disability and may be defined as a mental illness that makes it difficult for an individual to complete everyday activities without assistance (ABS, 2015). There are inconsistencies in the literature regarding which mental disorders may be classified as SMI. Many definitions include non-organic psychotic disorders and only those affective disorders that severely impact function, such as bipolar I disorder and major depressive disorder (Ruggeri et al., 2000). In practice, SMI usually refers to psychotic

illness (McGorry et al., 2006), although it may refer to any mental illness requiring intensive recurrent treatment and/or hospitalisation (Carlat, 2005).

SMI typically emerges during adolescence and young adulthood; up to two-thirds of affected people experience their first episode of psychosis before 25 years of age (Morgan et al., 2012). Suicide is the leading cause of death for Australians in this stage of life (ABS, 2017). The Interpersonal Theory of Suicide (Van Orden et al., 2012) posits subjective social exclusion (i.e. thwarted belongingness) as a key determinant of adolescent suicidal behaviour. This notion has received empirical support: there is meta-analytic evidence that peer victimisation is a risk factor for adolescent suicidal ideation and attempts (Van Geel et al., 2014). For young people with SMI, many of whom feel stigmatised by social reactions to illness onset, the relationship between exclusion and suicide may be even stronger (Tarrier et al., 2007). Suicide rates are 7–10 times higher for people with SMI than those from the general population (Tanney, 2000), and meta-analytic evidence suggests that completed suicides usually occur near illness onset (Tarrier et al., 2007). Fortunately, there is evidence that social inclusion may protect against suicide risk in this cohort (Masten and Powell, 2003).

Compared to the emergent social inclusion literature, youth suicide and mental illness-related stigma are relatively well-established areas of research. There is a large body of work devoted to understanding stigma processes, whereas most publications referring to social inclusion do not formally define the construct (Evans-Lacko et al., 2014). The apparent relationships between suicide, social exclusion and stigma among young people with SMI are likely complex and demand further attention. However, this very important area of research is beyond the scope of the present review, which aims to further understanding of social inclusion/exclusion as a preliminary step in that direction.

The social exclusion of young people with SMI is also costly in economic terms. Many young people with SMI begin receiving government payments following illness onset and continue to do so for the rest of their life (Killackey et al., 2013). The cost of psychotic illness alone to society and government has been estimated at AUD\$4.91 billion and AUD\$3.52 billion per annum, respectively (Neil et al., 2014). Despite these personal and societal costs, social inclusion has not been rigorously examined in this population due to the previously mentioned focus on isolated domains (e.g. un/employment) and lack of tools that have been explicitly developed to measure social inclusion.

Public health policy has increasingly been concerned with social inclusion. Improving social connection has recently been advanced as a public health priority in the United States (Holt-Lunstad et al., 2017). Increasing the social inclusion of young people with SMI in particular is a key indicator of *Australia's Fourth National Mental Health*

Plan (Department of Health, 2009). Yet the social exclusion of this cohort does not appear to be decreasing, despite evidence for improved access to services (Morgan et al., 2012). In order for policies to successfully target social inclusion, they must be able to effectively identify individuals or groups who are socially excluded and thoroughly assess the dimensions of exclusion (Hayes et al., 2008). Such identification and assessment are not presently feasible for young people with or without SMI, for reasons already stated. Further research seeking to measure and examine the barriers and facilitators to social inclusion for young people, particularly those with SMI, is therefore warranted in order to better inform policies and interventions (Stain et al., 2012).

Overview

In this paper, we conduct a narrative review of the literature on social inclusion among young people with SMI. The review is organised into two sections: (1) an outline of evidence of the potential benefits of social inclusion, and the importance of measuring social inclusion for young people, particularly those with SMI and (2) a review of evidence for the reported social exclusion of young people with SMI relative to those without SMI, and the introduction of a useful theoretical framework for interpreting such group differences.

Literature search strategy

Searches were conducted on 16 February 2016, 24 August 2016, 16 February 2017, 24 August 2017 and 16 February 2018 in PsycINFO, MEDLINE, the Cochrane Library, SCOPUS, Open Grey and Web of Science. Searches were also conducted in Google Scholar and the general Google search engine. Initially, searches were conducted separately within three areas: social inclusion, SMI and adolescence. Search terms used for the literature relating to social inclusion are as follows: 'social* inclu*' OR 'social* exclu*'. Search terms used for the literature relating to SMI are as follows: 'mental health' OR 'mental* ill*' OR 'severe mental illness' OR 'serious mental illness' OR 'disorder' OR 'psychot*' OR 'psychosis' OR 'psychoses' OR 'schizo*' OR 'bipolar'. Search terms used for the literature relating to young people are as follows: 'youth' OR 'adolescen*' OR 'young people' OR 'young adult' OR 'young person' OR 'first-episode' OR 'early intervention' OR 'at risk' OR 'at-risk' OR 'high risk' OR 'ultra high risk' OR 'ultra-high risk' OR 'ultrahigh risk'. Results from the three independent searches were then combined (e.g. 'social* inclu*' OR 'social* exclu*' AND 'mental* ill*' OR 'mental health' AND 'youth' OR 'adolescen*').

Article titles and abstracts were scanned to determine relevance. Given the small number of citations using the

terms social inclusion/exclusion in the youth SMI literature, any article that discussed social inclusion in relation to people of any age group with SMI was deemed relevant. Snowballing techniques were also applied by perusing the reference lists of relevant articles to locate further articles of relevance.

Getting the measure of social inclusion

Why measure it? Relationships to mental and physical health

Social inclusion (i.e. a combination of objective participation and subjective belonging/acceptance) is likely to have a protective relationship with mental health (Davies et al., 2008). Structural (e.g. objective social integration) and perceived (e.g. satisfaction with social support) inclusion may help buffer against psychological distress through the availability of opportunities for meaningful social engagement and emotional support (Kawachi and Berkman, 2001). However, a bi-directional relationship is possible: mental health may also influence social inclusion. A large study recently published in the *Australian and New Zealand Journal of Psychiatry* ($N=21,227$ adults randomly selected from the New Zealand electoral roll) found that psychological distress and subjective feelings of social acceptance predicted each other longitudinally (Saeri et al., 2018). The authors found that feelings of acceptance were a stronger and more consistent predictor of decreased psychological distress over time than decreased psychological distress was of feelings of acceptance. This suggests that increased subjective social inclusion contributes to decreased psychological distress, although causality cannot be inferred from this finding. Replications in controlled observational longitudinal studies are required. The finding highlights the need for further research incorporating objective and subjective indicators of social inclusion and examining their relationships to psychological distress.

Social inclusion also appears to have a protective relationship with physical health: meta-analytic evidence suggests that internationally and across sexes, an increase in objective (e.g. participation in social activities, living with others) and subjective (e.g. feelings of belonging) social inclusion is associated with reduced mortality risk (Holt-Lunstad et al., 2017). Conversely, objective and subjective indicators of social exclusion (e.g. infrequent contact with friends/family, perceived isolation) are related to deteriorated physical health (Cacioppo et al., 2015). Despite these apparent benefits, empirical research seeking to explicitly examine social inclusion at the individual and group level has not emerged until the past 10–15 years (Morgan et al., 2007). Such research has typically focused on marginalised adult populations such as those with chronic schizophrenia (e.g. Killaspy et al., 2014). A developmental

perspective on social inclusion has not been well established in this literature.

Considering the developmental perspective on social inclusion

Social inclusion and exclusion are dynamic processes across the lifespan (Morgan et al., 2007); the experience of social inclusion at age 18 is likely to be objectively and subjectively different to that at age 50. Adolescence is a sensitive period for both functional and emotional aspects of social development, as young people transition to adult roles (Killackey et al., 2013). Many of the processes involved in this normative transition require the navigation of increasingly complex interpersonal relationships in an evolving social environment (Blakemore and Mills, 2014). There is evidence for an increased sensitivity to peer inclusion and exclusion in adolescence (Blakemore and Mills, 2014; Vanhalst et al., 2015); social cognition, which involves information processing about the self and others in social contexts, develops significantly during this developmental phase (Kilford et al., 2016). Forming a sense of identity, which involves simultaneously cultivating autonomy and connectedness, is another developmental task of adolescence (Pfeifer and Berkman, 2018). There is evidence that the more developed a young person's self-identity is, the stronger their sense of community connection is likely to be (Cicognani et al., 2014). Understanding social inclusion and related processes during transitional phases such as adolescence is therefore important and more research is needed in this respect (Hayes et al., 2008).

Adolescence is also the developmental phase during which the onset of most forms of mental illness usually occurs (McGorry et al., 2013). Young people with SMI sometimes have social cognitive deficits that may make it difficult for them to successfully negotiate interactions with peers (Healey et al., 2016), although there is tentative evidence that such deficits may not necessarily relate to social inclusion (Gardner et al., 2017). Young people sometimes have intolerant attitudes regarding mental health issues and may even target those with SMI for maltreatment (Sholl et al., 2010). The onset of SMI is often marked by peer harassment, loss of friendships, isolation and loneliness (O'Driscoll et al., 2015). Young people who have developed SMI may be particularly vulnerable to social exclusion (Lau et al., 2010). For these young people, there is an absence of long-term illness effects and secondary processes (e.g. medication side-effects, recurrent hospitalisation, entrenched marginalisation) that may impact social inclusion in chronic populations. Research in the early phase of illness may therefore afford a clearer understanding of the processes of inclusion and exclusion in SMI by minimising confounds related to illness chronicity (Sullivan et al., 2013). As such, it may facilitate more valid measurement.

The current status of measurement development

Explicit and direct measures of social inclusion ought to contain objective and subjective indicators (Shepherd and Parsonage, 2011). Objective indicators measure observable elements of the social environments within which people live, and subjective indicators measure the ways people evaluate and perceive their living conditions within such environments (Lee and Marans, 1980). However, the majority of research on social inclusion has been conceptual and has not incorporated objective and subjective indicators, which has hampered measurement progress (Good Gingrich and Lightman, 2015). Work towards the creation of reliable and valid measures of social inclusion began relatively recently (e.g. Huxley et al., 2012), with few studies directly measuring the construct (Baumgartner and Burns, 2014). There is currently no ‘gold standard’ measure of social inclusion (Wilson and Secker, 2015), and two preliminary reviews concluded that no measure has been adequately developed or tested (Baumgartner and Burns, 2014; Coombs et al., 2013). This conclusion was also reached by the authors of a recent systematic review evaluating the psychometric properties of social inclusion measures (Cordier et al., 2017). It is important to note that there are measurement tools outside of the social inclusion literature that may partially capture relevant themes. For example, the *Interpersonal Needs Questionnaire* (Van Orden et al., 2012) assesses risk factors for suicide such as thwarted belongingness. However, it also assesses suicide risk factors that are not necessarily related to inclusion (e.g. ‘*the people in my life would be happier without me*’). Given the present paper aimed to review the explicit social inclusion/exclusion literature, such overlapping measures from distinct literatures were not captured by the search terms used.

There are no measures of social inclusion specific to young people, either with or without SMI. Hence, researchers have not had the optimal tools with which to explicitly examine social inclusion in these populations. A comprehensive (i.e. objective, subjective, and multi-dimensional) account of the degree of social inclusion among young people from the general community has yet to be well established. Consequently, gross discrepancies in social inclusion between young people with SMI and those in the general community are often assumed while there is a lack of clarity regarding granular similarities and differences.

Future directions in measurement development

Measures of social inclusion must be developed among young people both with and without SMI, but some thought must be given as to how this may best be achieved. Nomothetic approaches emphasise generalizability, whereas idiographic approaches emphasise individuality: combining

these approaches may be optimal in clinical and research settings (Hayes and Hoffman, 2018). Measures can be administered through observation and/or employed via self-report. Given the centrality of subjective experience to social inclusion, self-report measures incorporating objective and subjective indicators are appropriate (Coombs et al., 2016). Such indicators should measure levels of connectedness and participation (Cordier et al., 2017) across previously mentioned domains of social inclusion. For young people, items related to vocational achievement and peer networks will be especially important (Van Schalkwyk et al., 2015; Vanhalst et al., 2015). Measures that produce summary scale scores can help simplify assessment in clinical practice, and data analysis in research settings. However, mixed-measurement approaches (i.e. a combination of nominal, ordinal, interval and ratio variables) may more meaningfully facilitate a combined nomothetic-idiographic approach. As such, they would better capture the complexity of social inclusion in both clinical and research contexts. Item-level analysis of mixed-measurement indicators can help clinical services target-specific areas of social inclusion that their clients may want help with (Australian Mental Health Outcomes Classification Network, 2016). Researchers ought not to assume that complex constructs such as social inclusion are homogeneous (Portney and Watkins, 2009). Mixed-measurement tools may allow researchers to better examine the heterogeneity and multidimensionality of social inclusion, thus maximising the ecological validity of findings.

In the United Kingdom, the Social and Community Opportunities Profile (SCOPE; Huxley et al., 2012) is a relatively established mixed-measurement tool for assessing the social inclusion of adults. Psychometric development of the SCOPE included a principal components analysis for data reduction/dimension identification, and examination of internal consistency, test-retest reliability and validity. Measures of social inclusion for young people with and without SMI will benefit from similar psychometric development. It will be important for the design, planning, and implementation of such research to occur in consultation with a variety of young people.

Understanding social inclusion for young people with SMI

What is the evidence?

Young people with SMI are often described as at risk of social exclusion (Lau et al., 2010) and among the least included groups in society (Social Exclusion Unit, 2005). Yet the consensus in the social inclusion literature is that, of the few existing measures, some have shown promise but none have undergone sufficient psychometric assessment (Baumgartner and Burns, 2014; Coombs et al., 2013; Cordier et al., 2017). If empirical research has been impeded

by such issues, it is necessary to consider the evidence on which reports of social exclusion in this population are based (i.e. if explicit measures of social inclusion have not been feasible, which proxy measures have been used?). Furthermore, a review of research on social exclusion in mental illness reported that 1% of $N=97$ studies incorporated participants who were young people (Evans-Lacko et al., 2014). If the assertion that young people with SMI are socially excluded does not come from an evidence-base in the social inclusion literature, which literature(s) does it come from? Much of the evidence suggesting the social exclusion of young people with SMI comes from research on objective indicators in independent domains in the first-episode psychosis literature.

Employment and education

Employment is perhaps the single strongest contributor to social inclusion in SMI (Evans and Repper, 2000). This is especially pertinent to young people with SMI, for whom education is linked to employment and may be equally important (Caruana et al., 2017). Unemployment rates for young people with SMI have been estimated at 40–50%, compared to rates as low as 3.5–4.5% in healthy same-aged peers, and the estimate rises to between 70% and 90% unemployment for those who develop chronic SMI (Killackey et al., 2013). Young people with SMI also appear to have poor outcomes in educational settings, which are the foundation for future employment opportunities and higher wages (ABS, 2015). There is evidence that as few as one-quarter of young people with SMI complete high school compared to an 84% completion rate among their healthy same-aged peers (Killackey et al., 2013). In addition, young people with SMI are chronically excluded in educational settings as measured by number of friends and frequency of exposure to peer harassment (O'Driscoll et al., 2015).

Social networks

Social networks, including both formal and informal supports, are an integral component of social inclusion for young people with SMI: social support positively predicts functional outcomes in this population (Jaracz et al., 2007). Formal supports may be defined as those individuals and/or services that provide support in a professional capacity (e.g. GPs, social workers). Many young people with SMI struggle to maintain engagement with formal supports (Gulliver et al., 2010). This may occur for a variety of reasons, such as unsatisfactory previous experiences with services, or concerns about being misunderstood by treatment professionals (Van Schalkwyk et al., 2015). Informal supports may be defined as those individuals and/or groups who provide personal and emotional support within the social network (e.g. friends/family). The authors of a

systematic review concluded that there was evidence for reduced social networks and support in early psychosis, but that a greater number of comparable studies are needed due to the heterogeneity of methodologies to date (Gayer-Anderson and Morgan, 2013).

Housing and neighbourhood amenities

Safe housing in accessible, well-served neighbourhoods is an important factor in the social inclusion of young people. It has been estimated that up to 42% of the homeless Australian population are young people (Flatau et al., 2015). It is also estimated that between 50% and 75% of homeless Australian youth have experienced a mental illness (Costello et al., 2013) and that 14% have SMI (Flatau et al., 2015). This compares to an estimated SMI prevalence rate of approximately 1% in the general youth population (Kamieniecki, 2001). As such, lack of adequate housing is a major factor relating to the social exclusion of young people with SMI (Bradshaw et al., 2007).

Living in disadvantaged neighbourhoods with limited amenities and services (e.g. lack of public transport, no library) is associated with a range of poor physical and mental health outcomes, as well as reduced employment and education prospects for young people (Hayes et al., 2008). Young people with SMI tend to experience more of these disadvantaged living arrangements than their healthy same-aged peers (Morgan et al., 2008). There is evidence that young people with SMI spend less time participating in leisure or social activities in their local community than their unemployed peers who do not have a history of mental illness (Hayes and Halford, 1996).

Finances

Access to financial resources makes an obvious and considerable contribution towards an individual's social inclusion. Young people with SMI experience significant financial problems, partly due to unemployment, but also due to constricted social networks which limit access to potential sources of financial aid (Singer et al., 2014). Data suggest that during the 2010/2011 financial year, Australians aged 15–34 years earned an average annual wage/salary of \$40,055 compared to the national average of \$51,923 (ABS, 2015). A 2009 financial survey of 371 Australians living with SMI revealed that 38% of respondents had an annual income less than \$20,000 and that 53% of respondents regularly went into debt (e.g. relied on credit cards) in order to make ends meet (SANE, 2009). A similar survey of 559 Australians with SMI suggested that 75% of respondents received government payments (SANE, 2010). Given that up to 60% of people with SMI apply for low-income disability support pensions within 5 years of illness onset, it is important to address financial issues as early as possible in SMI to promote social inclusion (Krupa et al., 2012).

Physical health

Good physical health contributes to social inclusion by enabling people to be mobile and active enough to participate in valued social activities. Unfortunately, people who suffer from SMI, including those with a recent illness onset, have experienced poorer physical health than the general population (Gates et al., 2015). For example, it has been estimated that the life expectancy of an individual with schizophrenia is reduced by 15 years compared to the general population (Hjorthøj et al., 2017). Much of the increased mortality risk in chronic SMI may be attributed to physical health issues such as cardiovascular disease and sedentary lifestyle (McNamee et al., 2013). Physical health has been posited as an especially important element of social inclusion for young people, particularly those with SMI whose already complicated transition to adulthood may be made more difficult by physical ill-health (Social Exclusion Unit, 2005). Srihari et al. (2013) found a significant increase in cardiovascular risk factors (i.e. nicotine consumption and markers of obesity) among young people with SMI over 12 months after service entry. They also found that such young people were indistinguishable from controls regarding these same cardiovascular risk factors upon service entry. Furthermore, there is meta-analytic evidence that young people with SMI (especially those on antipsychotic medication) are at increased risk of metabolic syndrome relative to the general population (Vancampfort et al., 2015).

Multi-dimensional complexity and challenges

The above sections briefly reviewed diverse sets of evidence for the social exclusion of young people with SMI in distinct domains. It is highly likely that there are complex interrelationships across domains, and it is important to reflect on some of the challenges that this complexity poses. For example, there is robust evidence that youths who are not in employment, education or training (NEET) have negative economic outcomes (Mawn et al., 2017). Superficially, this may be interpreted as higher levels of employment/education contributing to higher income. However, there is evidence that intergenerational socioeconomic factors (e.g. familial history of dependence on income support) are strongly related to NEET for young people with SMI (Ryan and Sartbayeva, 2011). This suggests that distal social network and financial factors contribute to proximal employment/education status for young people with SMI, complicating interpretations of the direction of effects. This highlights the difficulty of modelling cross-sectional paths between domains of social inclusion in this population. Longitudinal research designs that can adequately model reciprocal relationships and directional influences between domains of social inclusion over time may help address these challenges. Indeed, an article recently published in this journal used cross-lagged panel

analysis to examine bi-directional relationships between social connectedness and mental health across time (Saeri et al., 2018). Future research will also need to disentangle any effect that individual differences in, e.g., belongingness needs may have. Such needs are likely to be stronger in some young people than in others (Verhagen et al., 2018). Understanding this variation could help explain, e.g., differential responding to objectively equivalent improvements in un/employment status among young people with SMI.

The importance of multi-dimensional measurement

Objective indicators of inclusion are among the social determinants of wellbeing, and young people with SMI appear to have poor outcomes in this respect. Relative to their peers from the general community, young people with SMI have less employment/education, reduced social support, more housing problems while living in less advantaged neighbourhoods, with access to fewer leisure activities, fewer financial resources and poorer physical health. However, these findings come from studies that primarily examine first-episode psychosis and are situated within largely independent literatures. As noted above, this is problematic because many proposed domains of social inclusion are theoretically interrelated, and these interrelationships may come to bear on group differences. In a study of physical health and lifestyle factors among young people with SMI, Samele et al. (2007) found that differences between this clinical population and healthy controls were accounted for by unemployment status in the clinical group. Of the few studies examining social inclusion among young people with SMI, many are not comparable due to heterogeneity of methodologies, even within individual domains (Gayer-Anderson and Morgan, 2013). This makes it difficult to examine the potential interrelationships among domains, and how these may impact group differences. It will be helpful for future research seeking to understand discrepancies in social inclusion between young people with and without SMI to employ well-developed, explicit, multi-dimensional measures of the construct. This would add simplicity and consistency to pre- and post-testing of social inclusion, which has clinical and research applications (e.g. at service entry and discharge, or before and after interventions). It would also be helpful for such research to consider other forms of SMI in addition to psychosis.

Despite the need for a more integrated and consistent approach to measuring social inclusion, it seems clear that young people with SMI ought to be offered interventions to improve objective inclusion across the above-mentioned domains. Indeed, interventions such as Individual Placement and Support (IPS) for education/employment are well-established and efficacious (Mueser et al., 2016). However, it is the opportunity to participate in those

particular social roles that are valued by the individual that characterises social inclusion (Huxley et al., 2012). The above findings do not necessarily provide information regarding subjective experiences of belonging/acceptance, nor which forms of social participation are individually valued. Subjective indicators are valid measures of outcome in SMI and ought to be used alongside objective indicators (Lloyd et al., 2010). This will help determine which social roles are meaningful to young people with SMI, in which domains of social inclusion they may like to increase participation, and whether subjective (e.g. psychological) interventions are indicated to help improve social inclusion.

How do young people with SMI subjectively experience social inclusion/exclusion?

There are two broad aspects to the subjective experience of social inclusion: feelings of belonging/acceptance and subjective satisfaction with opportunities to participate in valued social roles (Gardner et al., 2017). Subjective indicators of social inclusion are under-researched among young people with SMI (Sündermann et al., 2014). A recent systematic review of loneliness in psychosis found just 10 studies that were suitable for inclusion and concluded that loneliness in psychosis remains poorly understood (Lim et al., 2018). There is some qualitative evidence that young people with SMI value a sense of belonging (Perry et al., 2007), although this need appears to be unmet. Tarrier et al. (2007) found that 77% of participants with first-episode psychosis felt they had suffered loss or disruption to their social life and 50% felt socially excluded due to illness onset. There is some cross-sectional evidence that young people at ultra-high risk for psychosis experience lower perceived social support and higher levels of loneliness than healthy controls (Robustelli et al., 2017). It is unclear whether these variables predicted a longitudinal transition to first-episode psychosis. Nonetheless, such findings suggest that subjective social exclusion is worthy of exploration as a potential aetiological factor in the emergence of SMI. Given that many young people with SMI appear to experience low levels of belonging/acceptance and high levels of loneliness, emerging interventions (e.g. smart phone applications) are seeking to target these areas (Lim et al., 2016).

The subjective value that one assigns to particular social roles is a personal and individualised matter, but some common themes emerge when young people with SMI are asked about their treatment goals and preferences. Ramsay et al. (2011) surveyed 100 young people in the United States who had been hospitalised for first-episode psychosis and asked them about their life and treatment goals. The most frequently stated goals involved employment, education, relationships, housing, health and transportation, with vocational and educational services being the most desired service type. Similarly, Iyer et al. (2011) asked 68 young people with

first-episode psychosis in India to identify three treatment goals and rank them according to importance. Employment, family and interpersonal relationships, and education were identified as the top 3 priorities, in that order. In Australia, Cotton et al. (2011) explored the reasons why young people with SMI were referred to group interventions, and the young peoples' goals in attending such interventions. They found considerable overlap between referral reasons and client goals, both of which primarily centred on improving interpersonal relationships and vocational issues.

The treatment goals of young people with SMI appear to map onto a number of proposed social inclusion domains (e.g. employment/education, social networks, housing, health). This suggests that such young people value social roles in these domains and may be dissatisfied with existing levels of engagement (i.e. that there is a discrepancy between subjectively desired and objectively available opportunities to participate). At present, such propositions remain speculative and require further examination with explicit measures of social inclusion that adequately integrate objective and subjective indicators.

The relationship between objective and subjective indicators of social inclusion

Increased objective participation seems to contribute to greater subjective sense of inclusion in the general population (Na and Hamble, 2016), including young people (Newman et al., 2007). Objective participation and subjective sense of inclusion may not share an identical relationship in SMI populations to that encountered in the general community, though (Australian Mental Health Outcomes Classification Network, 2016). There is some evidence that increased objective community integration is positively related to subjective sense of recovery in SMI (Lloyd et al., 2010). However, Lloyd and colleagues used a measure of community integration that seems to capture more subjective than objective elements of social inclusion (e.g. '*I feel like part of this community*'). Also, the most common diagnosis among their middle-aged sample (age in years $M=41$, standard deviation [SD]=12.8) was schizophrenia, suggesting that participants suffered long-term illness and might experience entrenched exclusion. Empirical data are lacking regarding the relationship between objective and subjective indicators of social inclusion for young people with SMI. In the next section, we offer a theoretical account which may permit the generation and testing of hypotheses about the relationship between objective and subjective indicators of social inclusion in this population.

Perceptions of social rank/status after illness onset

While there are no theories that have been specifically developed to explain social inclusion (Baumgartner and

Burns, 2014), evolutionary accounts are applicable. Baumeister and Leary (1995) proposed that humans have an innate need to belong, requiring regular objective social contact that promotes a subjective sense of connection. The integration of these objective and subjective elements is theorised to have greater evolutionary value than either element on its own. The need to belong has received significant empirical support over the past 20 years (Verhagen et al., 2018). Social Rank Theory, an evolutionary account seeking to explain aspects of the need to belong, has been advanced specifically as a framework for understanding the psychosocial changes that occur for affected young people after SMI onset. Thoughts, emotions and behaviour are postulated to be affected by an individual's subjective perception of their social rank or status within the group (Birchwood et al., 2005). This seems particularly applicable to adolescence and early adulthood, where social comparison (i.e. 'ranking' oneself compared to peers) proliferates (Vanhalst et al., 2015). Indeed, developmental researchers often ask adolescent participants to explicitly rank the popularity of individuals in their peer group as a measure of social status (e.g. Loflin and Barry, 2016).

The impact of SMI onset may be significantly influenced by illness appraisals, especially those related to interpersonal (e.g. social networks) and achievement (e.g. employment/education) domains (Birchwood et al., 2005). We have reviewed evidence for the objective social exclusion of young people with SMI relative to those without SMI from various domain-specific literatures (e.g. reduced social network size, unemployment, inadequate housing, poor physical health, financial difficulties). Social Rank Theory suggests that these objective markers of exclusion are likely to be salient and strongly linked to a subjective perception of decreased social rank/status (i.e. inclusion) for young people with SMI. It is plausible that this link between objective and subjective markers is important yet weaker for young people from the general community, whose social functioning is likely intact and perhaps taken for granted. That is, there may be satiation effects (Baumeister and Leary, 1995) whereby those with sufficient objective connections are less likely to continue seeking such connections as a means of increasing their sense of belonging/acceptance. This has implications for intervention: increasing opportunities for participation may contribute to a disproportionate increase in subjective inclusion for young people with SMI relative to those from the general community.

Here, it is relevant to acknowledge that community perceptions of, and responses to, people with SMI are integral. Some have argued for a greater emphasis on 'mutual recovery', whereby the responsibility for increasing social inclusion shifts from the individual with SMI to a shared cross-community approach (Saavedra et al., 2018). This is an important related area of research, but is outside the scope of the present review.

Social rank/status, social exclusion and psychological distress

The onset of SMI may often be associated with shame, loss and hopelessness, in relation to a perceived decrease in social rank/status (Birchwood et al., 2005). Depression and anxiety are highly prevalent among young people after SMI onset (Cotton et al., 2012), and there is some evidence that a subjective sense of exclusion may contribute to such psychopathology. For example, Iqbal et al. (2000) found that approximately 50% of people diagnosed with first-episode psychosis subsequently experienced symptoms of depression. They also found that perceived loss of social role and status was related yet antecedent to the depressive symptoms, which were not an epiphenomenon of psychotic symptomatology. Using Social Rank Theory as a framework, Birchwood et al. (2005) have stated that subjective appraisals of SMI onset are the primary factor contributing to whether or not affected young people develop depression and/or anxiety. This suggests that subjective perceptions of exclusion may have a stronger relationship to psychological distress than do objective indicators of exclusion for young people with SMI. We have found tentative support for this hypothesis in our own work. In a cross-sectional exploration of social factors and psychopathology in first-episode psychosis, we found that subjective measures of social inclusion (e.g. *I felt accepted by my neighbours*) were more strongly related to symptoms of depression than was a measure of objective social functioning (Gardner et al., 2017). This finding was correlational and causality cannot be inferred. However, it is consistent with the notion that interventions aimed solely at increasing social networks for young people with SMI, rather than changing subjective perceptions of social support, may not be accurately weighting treatment targets (Sündermann et al., 2014). Lim et al. (2018) have suggested that addressing cognitions about social interactions (e.g. perceived exclusion) may alleviate psychological distress for young people with SMI. They also note that this should occur within appropriate social environments, highlighting the interconnections between subjective and objective elements of social inclusion. This points to the need for further research examining the relative strength of relationships between subjective and objective indicators of social inclusion and psychological distress for young people with SMI.

Conclusion and future directions

Adolescence is the crucible of social inclusion; a transitional stage where young people forge their sense of identity, and start to develop the social roles they hope to inhabit in adulthood. It is a period of unprecedented biopsychosocial change that demands significant adaptation for any young person. Those who experience SMI during this crucial developmental phase are burdened with additional demands related to the onset and management of their illness, which may negatively impact processes of social inclusion. Clinicians and

researchers alike are aware of the need to focus on the social inclusion of young people with SMI. Arguably, though, they have been deprived of the evidence-based tools required to comprehensively assess the social inclusion of young people with SMI. This is a logical first step towards creating tailored social inclusion interventions. In this review, we have argued that explicit multi-dimensional measures of social inclusion incorporating objective and subjective indicators must be developed for young people both with and without SMI. We have also argued that such measures must be used in order to develop a better understanding of reported group differences in social inclusion between young people with SMI and those from the general community. We have posited Social Rank Theory as a useful framework for interpreting any such group differences. To extend these suggested future directions, scoping reviews may be required to identify a range of evidence-based interventions to improve the social inclusion of young people with SMI.

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CHAPTER TWO: A REVIEW OF THE LITERATURE ON SOCIAL INCLUSION AMONG YOUNG ADULTS WITH SERIOUS MENTAL ILLNESS

Overview of Findings

The narrative review presented in this chapter identified significant gaps in the literature regarding the empirical examination of social inclusion among young adults with SMI. There are a number of research areas that address unidimensional aspects of social inclusion without explicitly using the term (e.g., un/employment, social networks). The explicit social inclusion literature includes studies which offer formal operationalisations of the construct that engage its complexity. As a group with developmentally specific psychosocial needs, young adults in general have been largely overlooked in this literature. There is evidence that young adults with SMI are socially excluded relative to same-aged peers from the general community on some objective indicators (e.g., higher unemployment). Subjective perceptions are theorised to be a significant component of social inclusion, but subjective indicators (e.g., loneliness) are under-researched among young adults with SMI. Psychometric measures are useful because they combine objective and subjective indicators. No such measures of social inclusion have been developed specifically for young adults with SMI, nor young adults from the general community. Hence the relevant dimensions and indicators of social inclusion within these cohorts remain unclear, and no comparisons on psychometric measures exist between these two groups. Such comparisons would provide a more comprehensive understanding of any social exclusion experienced by young adults with SMI relative to same-aged peers from the general community. These findings inform the aims of the research program described in the next chapter.

CHAPTER THREE: AIMS OF THE RESEARCH PROGRAM

The empirical work presented in this thesis represents significant advances towards addressing the gaps identified in the above literature review. The overarching purposes of this research program were to clarify dimensions and indicators of social inclusion among young adults with SMI, and to better characterise the putative social exclusion of this cohort relative to same-aged peers in the community. The research program comprises three separate but related empirical studies designed to address this purpose: (i) an exploration of psychometric properties of a social inclusion measure for young adults with SMI; (ii) an exploration of psychometric properties of a social inclusion measure among young adults in the general community; and (iii) establishment of any group differences on a psychometric measure of social inclusion between young adults with SMI and those from the general community. The aims of the three studies are listed below.

Preliminary Psychometric Properties of a Measure of Social Inclusion for Young Adults aged 18 to 25 with Serious Mental Illness (Chapter 5)

There are no psychometrically validated measures of social inclusion for young adults with SMI. Therefore, the relevant dimensions and indicators of social inclusion remain unclear, and it is difficult to empirically examine the putative social exclusion of this cohort. Exploratory methods are indicated for such under-developed research areas (Shields & Rangarajan, 2013). Thus, in this exploratory study, the aim was to test the psychometric properties of a novel social inclusion measure among young adults aged 18–25 years with SMI. Specific aims were to:

- i. Perform data reduction to identify dimensions of a novel measure of social inclusion
- ii. Examine the reliability of dimensions (i.e., internal consistency), and items (i.e., stability of measurement)

- iii. Explore convergent validity relative to established measures of social inclusion, loneliness, social functioning, QoL, and psychological distress
- iv. Explore face validity

Preliminary Psychometric Properties of a Measure of Social Inclusion Among Young Adults aged 18 to 25 from the General Community (Chapter 6)

Psychometrically validated measures of social inclusion are also lacking for young adults in the general community. Therefore, it is difficult to ascertain what the developmental norm for social inclusion in young adulthood is. In this exploratory study, the purpose was to test the psychometric properties of a novel social inclusion measure among young adults aged 18–25 years in the general community. Specific aims were to:

- i. Perform data reduction to identify dimensions of a novel measure of social inclusion
- ii. Examine the reliability of dimensions (i.e., internal consistency), and items (i.e., stability of measurement)
- iii. Explore convergent validity relative to established measures of social inclusion, loneliness, social functioning, QoL, and psychological distress
- iv. Explore face validity

Group Differences in Social Inclusion Between Young Adults aged 18 to 25 with Serious Mental Illness and Same-aged Peers from the General Community (Chapter 7)

The previous two studies will establish preliminary psychometric properties of a measure of social inclusion in young adults with SMI and those from the general community. In so doing, they will generate observational data that will permit comparisons of social inclusion between the two

groups. The aim of this cross-sectional, correlational study was to identify particular dimensions and individual indicators of social inclusion that discriminated between groups.

In the following Chapter, the methodology that was employed in the research program to address the aims of the three studies is described in more detail than what is provided in the manuscripts.

CHAPTER FOUR: EXTENDED METHODOLOGY

In this Chapter a more detailed description of the methodology is provided; this supplements what is offered in each of the individual papers. The methodology for the first two studies was identical; the only difference between these studies being the population that was sampled. To avoid repetition, the methodology of these two studies is described concurrently. The methodology for the third study, which shared some of the procedures with the first two studies (e.g., data collection), is then described separately.

Preliminary Psychometric Properties of a Measure of Social Inclusion

These two studies were correlational, non-experimental, and exploratory repeated measures studies over two weeks within two cohorts of young adults aged 18–25 years: those with SMI and those from the general community. Pooling the samples (i.e., combining young adults with and without SMI) and using tests of metric invariance to examine whether indicators and/or dimensions of social inclusion differed between groups was initially considered. Metric invariance testing involves conducting confirmatory factor analyses to determine whether the same underlying construct is being measured across groups (Schnabel et al., 2015). As such, it assumes continuous observed variables. This assumption could not be met in the present research program, because the primary measure of interest (outlined below) was primarily comprised of categorical observed variables. Alternative metric invariance methods for modelling categorical data are in development (Svetina et al., 2020). However, these methods require that the number of indicator categories be equal across groups, and that there be no groups with few observations in a given category (Rutkowski et al., 2019). It was anticipated that these assumptions would not be met in the present research program (i.e., that few young adults from the general community would endorse some items that are highly relevant to social inclusion for those with SMI). For example, items assessing the impact of mental illness on community participation and belongingness would produce few

observations in the community sample relative to the SMI sample. Hence it was ultimately decided to separate the cohorts, so that social inclusion could be examined specifically among young adults with SMI. As discussed in the literature review, Social Rank Theory suggests that illness-related disruptions may contribute to the emergence of unique aspects of social inclusion for young adults with SMI. It is therefore plausible that in each of the two samples, different underlying dimensions of social inclusion may emerge.

The specific age range (18–25 years) was selected because, as discussed earlier, young adulthood appears to be a sensitive period for social inclusion in developed countries (Wood et al., 2018). A pragmatic advantage of conducting research in this age range is that people aged 18 years or older are usually considered to be the primary decision makers about their participation, i.e., additional consent from parents is not necessarily required (Nijhawan et al., 2013). Two weeks is a commonly used and sufficient test-retest time interval for measures that have clinical and research applications (DeVon et al., 2007). A two week test-retest time interval has previously been used in the development of social inclusion measures (e.g., Huxley et al., 2012; Marino-Francis & Worrall-Davies, 2010).

Setting and Sample.

Serious mental illness.

SMI among older adults is often defined by specific diagnosis (e.g., schizophrenia), but such specificity may be inappropriate in younger cohorts where diagnostic instability is common (Menezes & Milovan, 2000). For young adults, transdiagnostic conceptualisations of SMI with a focus on specific symptoms (e.g., psychosis, difficulties in interpersonal functioning) have been offered (Hartmann et al., 2017). Consistent with the concept of psychiatric disability, SMI may be defined as any mental illness that limits an individual's ability to complete everyday activities without assistance (Australian Bureau of Statistics, 2015) and/or has necessitated hospitalisation

(Carlat, 2007). Young adults aged 18 to 25 with SMI were recruited from two sources, specifically: Orygen, a tertiary public mental health service for people aged 15–25 in the northwest of Melbourne, Australia, and Mind Australia, which provides short- and long-term psychosocial rehabilitation services for people aged 16–25 across greater Melbourne, Australia. Study inclusion criteria were based on service entry criteria, which take into account the severity and complexity of the young person's mental illness (regardless of any specific diagnoses). For a young adult to be accepted into either of these services their mental illness must be persistent, unresponsive to primary and secondary care previously provided by alternative agencies, and have affected many aspects of their life (including their safety). Since these are public, government-funded services, they prioritise young people with the greatest clinical needs. Exclusion criteria were acute mental illness (i.e., symptom severity precluding informed consent) as assessed by clinical staff, and lack of fluency in English (due to pragmatic reasons).

General community.

Young adults aged 18 to 25 years were recruited from a variety of settings in the general community (e.g., youth employment and support services, public housing, libraries, sports clubs/gymnasiums, retail outlets, cafés/restaurants/bars, educational institutions). The study was advertised through social media, posters/flyers, and snowballing (i.e., non-probability) recruitment techniques. Exclusion criteria for the general community sample were lack of fluency in English (determined by whether or not an interpreter was required), and diagnosis of SMI (i.e., a mental illness that makes it difficult to complete every day activities without assistance). As this was a general community sample, and not a sample of so-called ‘healthy controls,’ a diagnosis of mental illness per se did not necessarily exclude participants. Mental disorders such as anxiety and depression are common in the general population of young adults, with prevalence estimates of 20% among young men and 32% among young women (Gustavson et al., 2018). Participants from the general community who reported a lifetime diagnosis of mental illness were asked followup

questions to determine whether this ought to be considered SMI (e.g., whether they had ever used psychiatric services). Those who reported impairment in functioning due to mental illness were considered for inclusion in the SMI group.

Measurement.

This section provides a rationale for, and description of, the measures selected to address the specific aims of studies within the research program. Particular attention is given to the Filia Social Inclusion Measure (F-SIM), the psychometric properties of which were examined in the first two studies. The other measures described below were included so as to examine the construct validity of the F-SIM in the first two studies.

Tests of construct validity are important in measurement development studies because they examine the degree to which an instrument generalises to the construct it purports to measure (Portney & Watkins, 2009). Convergent validity is a subtype of construct validity that examines the degree to which two measures of constructs that ought to be related, based on theory or conceptual overlap, are in fact related (Campbell & Fiske, 1959). Convergent validity can be assessed by determining whether bivariate correlations between measures of theoretically related constructs are statistically significant (Swank & Mullen, 2017). Correlation coefficients that are statistically significant may be interpreted as indicating weak ($.10$), moderate ($.30$), or strong ($\geq .50$) associations between constructs (Cohen, 1992), with stronger associations reflecting superior convergent validity. This is readily interpretable when the correlation between two measures is positive (i.e., when both variables move in the same direction, they converge). However, construct validity may also be inferred from statistically significant negative correlations, or inverse relationships where one variable increases as another variable decreases (i.e., the variables diverge in the literal sense of moving in different directions). These have been labelled ‘divergent associations’ in the emotion regulation literature (Appleton et al., 2014) and also in the social connectedness literature (Ahn &

Shin, 2016). Confusingly, this is not always what is meant by the term ‘divergent validity.’ That term is sometimes used interchangeably with the term ‘discriminant validity,’ another subtype of construct validity that examines the degree to which two measures of constructs that ought *not* to be related are in fact unrelated (Krabbe, 2017). Given this ambiguity in the literature, it is important to clarify precisely which aspects of construct validity are under consideration here. In this research program, convergent validity of the F-SIM will be assessed by determining the statistical significance and strength of association of both positive and negative bivariate correlations with measures of theoretically related constructs.

Discriminant validity as defined above (not to be confused with the degree to which a measure can differentiate between known groups) was not assessed in this research program. This was done to minimise burden on participants (i.e., so as to not increase the time taken to complete participation, which may have contributed to attrition). Furthermore, this research program involves an examination of psychometric properties of a preliminary version of the F-SIM. Discriminant validity may be assessed in future research seeking to validate a definitive version of the measure.

Convergent validity has been examined in the few published social inclusion measurement studies (see Cordier et al., 2017 for a review). However, the specific constructs that have been employed vary across studies (perhaps in part due to different conceptualisations of social inclusion across research groups). Secker and colleagues (2009) used measures of empowerment and mental health, Huxley and colleagues (2012) used measures of social capital and participation, and Mezey and colleagues (2013) used measures of quality of life (QoL) and mental health. Even where the same constructs are employed, different measures are often used. Secker and colleagues (2009) used the Clinical Outcomes in Routine Evaluation instrument to measure mental health difficulties, whereas Mezey and colleagues (2013) used the Brief Psychiatric Rating Scale to measure psychopathology.

Given the absence of a uniform approach to construct validity in the literature, the constructs measured in this research program were selected for their theoretical relationship to social inclusion. Social functioning was selected because, similar to social inclusion, it involves participation in societally defined age-appropriate roles (Mueser & Tarrier, 1998). Unlike social inclusion, it does not necessarily involve subjective satisfaction with such roles. To the extent that social participation is integral to both constructs, it was expected that they would share a moderate-to-strong positive association. Quality of life (QoL) was selected because social inclusion likely contributes to this more global construct (Huxley et al., 2012), which involves independence, physical and psychological health, personal beliefs, relationships to other people, and relationships to salient features of the environment (The WHOQoL Group, 1995). It was expected that these constructs would share a moderate-to-strong positive association. Loneliness is an aversive psycho-emotional state experienced when an individual's perceived level of social connection is less than their desired level of social connection (Russell, 1996). As such, it was selected for its theoretical overlap with subjective social exclusion and was expected to share a moderate-to-strong negative association with social inclusion. Psychological distress involves poor mental health characterised by symptoms of depression and anxiety (Kessler, Andrews & Colpe, 2002). This construct was selected based on the theoretical (e.g., Baumeister & Leary, 1995) and increasingly empirical (e.g., Holt-Lunstad et al., 2017) relationship between objectively and subjectively impoverished social connections and poor mental health. It was expected that psychological distress would share a moderate-to-strong negative association with social inclusion.

Based on the above rationale, the below measures were included in the research program. The F-SIM is described first, followed by measures of social inclusion, social functioning (i.e., activity and participation), QoL, loneliness, and psychological distress that were included to assess the convergent validity of the F-SIM.

Measurement Instruments.

Social inclusion.

The Filia Social Inclusion Measure (F-SIM) is a novel self-report measure of objective and subjective social inclusion over the past month. It was the primary measure of interest in the research program (see Appendix 1 for the full preliminary version that was completed by participants). Unlike most existing measures (see Cordier et al., 2017), the development of the F-SIM did not involve adopting items from established measures of related constructs (e.g., Lloyd et al., 2008). Rather, the following iterative empirical approach was employed. A thematic analysis of the literature identified 90 conceptual contributors to social inclusion across 13 domains (Filia et al., 2018, see Appendix 2). In a subsequent study (Filia et al., 2019a, see Appendix 3), the 90 conceptual contributors were transformed into 147 individual items across 11 domains. A Delphi methodology was applied, sampling 32 people with SMI, 32 carers of people with SMI, and 40 general community members. Through this approach, the researchers sought to attain consensus across groups regarding which of the 147 items and 11 domains ought to be included in an initial version of the measure. After removal of items and domains about which there was a lack of consensus, the result was a 126-item instrument (plus two demographic items assessing gender and age, resulting in 128 total items). Items were grouped into five consensus domains of social inclusion: housing/neighbourhood factors, social relationships/activities, employment and education, financial factors, and health factors (Filia et al., 2019b, see Appendix 4). These domains are broadly consistent with other studies that have taken an empirical approach to identifying latent domains underlying social inclusion (e.g., Huxley et al., 2012). Preliminary testing of the F-SIM was conducted among 30 people with SMI, 30 family members/carers of a person with SMI, and 30 general community members (Filia et al., 2019b, see Appendix 4). People with SMI were less socially included than those without mental illness, and family members/carers of people with SMI were less socially included than general community members. That is, the F-SIM demonstrated the

ability to discriminate between groups. The F-SIM had good acceptability and face validity to participants. During this initial development phase of the F-SIM, some young adults with and without SMI were included in the samples for the Delphi and pilot-testing studies (the youngest participant was 21 years old). However, young adults aged 18–25 years were not the sole population of interest. The process was intentionally broad and inclusive, so as to capture as global a conceptualisation of social inclusion as possible.

When assessing complex processes in clinical research, it is helpful to adopt a mixed-measurement approach (Hayes & Hoffman, 2018). Accordingly, the F-SIM incorporates items with binary (e.g., *Is your accommodation unstable?* [Yes/No]), ordinal (e.g., *I often feel unwelcome, like I don't belong* [Not at all/A little bit/Very much so]), and continuous (e.g., *How much nett income do you receive each week?*) response options. At this stage of its development, the F-SIM does not provide a numerical summary or total score but rather uses percentages and simple frequencies to examine aggregate responses to individual items. This provides clinical utility in enabling services to focus on specific, targeted areas of social inclusion that clients identify as problematic (Australian Mental Health Outcomes Classification Network, 2016). It is also consistent with other measures of social inclusion (e.g., Coombs, Reed & Rosen, 2016). Self-reported mental disorder diagnosis was also obtained via the F-SIM. Self-report methods of recording mental disorder diagnosis have been used reliably in large genome-wide studies of depression (Hyde et al., 2016). Participants were asked whether they had ever received a diagnosis from the following Diagnostic and Statistical Manual for Mental Disorders, 5th edition (American Psychiatric Association, 2013) categories: depressive disorders, anxiety disorders, schizophrenia spectrum & other psychotic disorders, bipolar and related disorders, eating disorders, obsessive-compulsive and related disorders, trauma-related disorders, substance-related and addictive disorders, or personality disorders. Four user-experience questions were included at the end of the questionnaire in order to

provide participants with the opportunity to give feedback on the F-SIM (e.g., *How well do you think this questionnaire actually measures social inclusion?*).

The Social Inclusion Scale (SIS [Secker et al., 2009]) is a 19-item self-report measure of social inclusion over the past two weeks. Items are measured on Likert-type scales from 1 (*Not at all*) to 4 (*Yes, definitely*). A SIS total score (range of 19 to 72, higher scores indicate greater social inclusion) is computed by summing all items, five of which are reverse-scored (e.g., *I have felt insecure about where I live*). There are no established clinical cut-off scores or guides for interpretation for the SIS. Subscales of Social Relations (score range of 8 to 32, higher scores indicate better social relations) and Social Acceptance (score range of 5 to 20, higher scores indicate greater social acceptance) can be computed. Social Isolation subscale scores (range of 5 to 20) can also be computed, but there is some ambiguity as to whether higher scores indicate more or less isolation. In this research program, the subscale was computed such that higher scores indicated more social isolation (i.e., items such as *I have felt accepted by my friends* were reverse-scored). As one of the relatively established existing measures of social inclusion (Cordier et al., 2017), the SIS was included in order to assess the construct validity of the F-SIM. The SIS has demonstrated reliability and validity in a sample of $n = 103$ university students (Wilson & Secker, 2015) and in a sample of $n = 88$ middle-aged adults diagnosed with mental illness attending mental health services (Secker et al., 2009). No psychometric measures have been validated specifically within young adult samples, but we have previously used the SIS to measure social inclusion among those with SMI (Gardner et al., 2019a). In that study, the SIS demonstrated good internal consistency (Cronbach's $\alpha = .73$) and was positively associated with the Social and Occupational Functioning Assessment Scale (SOFAS) among people aged 15–25 years with first-episode psychosis.

In light of the above, it may be argued that the SIS is a suitable measure for further development in the present research program. However, a novel measure such as the F-SIM is

needed. Existing measures of social inclusion such as the SIS were created by adopting items from established measures of related constructs (e.g., social capital), and then tested in circumscribed psychiatric populations (Secker et al., 2009). Conversely, as described above, the F-SIM was based on a literature search and thematic analysis of social inclusion in broad terms, as well as an examination of what it means to be socially included for people both with and without lived experience of SMI. That is, the conceptual basis of the F-SIM and the process for its item creation were theoretically sound and empirically driven.

Social Functioning.

The *Activity and Participation Questionnaire* (APQ-6 [Stewart et al., 2010]) is a six-item self-report measure of social functioning (i.e., educational, vocational, and social/recreational activity and participation) over the past week. Questions are measured on dichotomous (e.g., *Last week, did you have a full-time or part-time job of any kind? Yes/No*) and continuous (e.g., *How many hours per week do you spend attending class and studying?*) scales. The APQ-6 may be scored according to number of hours spent working, number of hours spent attending classes and studying, and number of hours spent on social/recreational activities. A higher number of hours spent participating in such activities indicates superior social functioning. The APQ-6 was selected because it was identified as an appropriate measure of objective social functioning/participation in a review of social inclusion measures (Coombs et al., 2013). It is routinely used in Australian public mental health settings, including among young adults with SMI (e.g., Howe, Batchelor & Coates, 2017). The APQ-6 has demonstrated good test-retest reliability and construct validity in an adult psychiatric population (Stewart et al., 2010).

Quality of Life (QoL).

The *Australian Quality of Life instrument, eight dimensions* (AQoL-8D [Maxwell, Özmen, Iezzi & Richardson, 2016]) is a 35-item self-report measure of QoL over the past week. Items are

measured on Likert-type scales with varying anchor points e.g., 0 (*I need daily help*) to 3 (*I need no help at all*). Example items are, *How much energy do you have to do the things you want to do?* and, *How often do you have trouble sleeping?* Items can be summed for a total score with a range of 0 to 100 (higher scores indicate greater QoL). Subscale scores (Independent Living, Happiness, Mental Health, Coping, Relationships, Self-Worth, Pain, Senses) can also be computed with a range of 0 to 100 (higher scores indicate greater quality of life within each domain). The AQoL-8D can also be used as a multi-attribute utility measure with weighted responses that can be summed as a measure of quality-adjusted life years from 0 to 1 (e.g., *How often do you feel sad?* 0=*Nearly all the time*, .20=*Often*, .58=*Some of the time*, .86=*Rarely*, and 1=*Never*). The utility scores are computed via SPSS syntax for each subscale and for an overall index of QoL-related health state utility. This instrument was selected because its items more adequately address the social dimensions of QoL than alternative instruments (e.g., *How often do you feel socially excluded or left out?*). The AQoL-8D has demonstrated excellent reliability (i.e., internal consistency and test-retest reliability) and construct (i.e., convergent and discriminant) validity in various populations including young adults with and without SMI (Maxwell et al., 2016; Richardson, Chen, Iezzi & Khan, 2011; Richardson, Iezzi, Khan & Maxwell, 2014).

Loneliness.

The Revised UCLA Loneliness Scale (Russell et al., 1980) is a 20-item self-report measure of subjective feelings of loneliness and isolation over the past week. Items are measured on Likert-type scales from 1 (*I never feel this way*) to 4 (*I often feel this way*). Example items are, *I feel isolated from others*, and, *I feel part of a group of friends*. Ten items are reverse scored. Items are summed for a total score with a range of 20 to 80. Higher scores indicate more severe loneliness and isolation. This instrument was selected because it is one of the most established and widely used measures of loneliness. It has demonstrated excellent reliability (i.e., internal consistency) and

construct validity in samples of young people with SMI (Lim et al., 2019) and those from the general population (Goossens et al., 2013).

Psychological Distress.

The Kessler-10 Psychological Distress Scale (K10 [Kessler et al., 2002]) is a 10-item self-report measure of psychological distress (i.e., symptoms of anxiety and depression) in the past month. Items are measured on Likert-type scales from 1 (*None of the time*) to 5 (*All of the time*). Example items are, *During the last 30 days, about how often did you feel hopeless?* and, *During the last 30 days, about how often did you feel so nervous that nothing could calm you down?* Individual item scores are summed to create a total score with a range of 10 to 50. Higher scores indicate more severe psychological distress. In healthcare settings, cut-off scores are available to indicate likely presence or absence of mild (20–24), moderate (25–29), or severe (30–50) mental disorders (Australian Bureau of Statistics, 2015). This instrument was selected because it is widely used in public healthcare settings, including among young adults with SMI (e.g., Howe et al., 2017). The K10 has demonstrated reliability and validity in adolescent and young adult populations (Chan & Fung, 2013).

The five measures used to assess the convergent validity of the F-SIM are summarised in Table 1 below.

Table 1

Summary of Five Measures Included in the Research Program to Examine the Convergent Validity of the Filia Social Inclusion Measure (F-SIM)

Instrument	Abbreviation	What it measures	Administration method	Scale type	Number of items	Score range	Source
Social Inclusion Scale	SIS	Subjective social inclusion over the past two weeks	Self-report	Likert: 1 (<i>Not at all</i>) to 4 (<i>Yes, definitely</i>)	19	19–72, higher scores indicate greater social inclusion	Secker et al., (2009)
Activity and Participation Questionnaire	APQ-6	Participation in employment, education, social relationships and recreational activities over the past week	Self-report	Mixed categorical (e.g., <i>Did you work in the past 7 days?</i>) and continuous (e.g., <i>How</i>	6	NA – a higher number of hours of social participation indicates	Stewart et al., (2010)

				<i>many hours did</i>		greater social	
				<i>you work in the</i>		functioning	
				<i>past 7 days?)</i>			
Australian Quality of Life instrument, 8 Dimensions	AQoL-8D	Quality of Life globally, and in eight specific domains (Independent Living, Happiness, Mental Health, Coping, Relationships, Self Worth, Pain, Senses) over the past week	Self-report	Likert-type scales with varying anchor points	35	0–100 with higher scores indicating greater QoL, or, quality adjusted life years from .00 (death) to 1.00 (optimal health)	Maxwell et al. (2016)

Revised UCLA Loneliness Scale	NA	Loneliness over the past week	Self-report	Likert: 1 (<i>Never</i>) to 4 (<i>Often</i>)	20	20–80, higher scores indicate greater loneliness	Russell et al., (1980)
Kessler-10 Psychological Distress Scale	K10	Psychological distress over the past week	Self-report	Likert: 1 (<i>None of the time</i>) to 5 (<i>All of the time</i>)	10	10–50, higher scores indicate greater psychological distress	Kessler et al. (2002)

Procedure.

The Melbourne Health Human Research and Ethics Committee (HREC) approved the research project (HREC/16/MH/325). Ethical approval was also received from the Monash University HREC. The Mind Research and Evaluation Committee and Orygen's Research Review Committee and Human Ethics Advisory Group (HEAG) also supported the project.

The importance of incorporating service user perspectives in youth mental health research is increasingly being acknowledged (Orlowski et al., 2015). The Youth Research Council (YRC) at Orygen was consulted as part of the HREC application process for this research program. Consultation consisted of a series of meetings prior to HREC application, wherein members of the YRC provided feedback (e.g., on wording and design of participant information and consent forms). The YRC also appointed two of its members to act as ongoing liaisons, with whom the student researcher maintained periodic contact. As such, there was input from young adults with and without a lived experience of mental illness throughout the course of this research program. Participants from the general community sample were approached in the manner previously described (e.g., social media, advertisements). Participants with SMI were approached in consultation with clinical staff from Orygen and Mind (to ensure that the young people were well enough to provide informed consent).

Design.

Data were collected via an online survey platform (Qualtrics®) at two time points that were two weeks apart. Survey questions comprised the six distinct measures outlined above. An email comprising a link to the survey was distributed to individual participants. Surveys took approximately 45–60 minutes to complete in total (i.e., including both time points). Participants were given the option to complete the surveys alone in their own time, or with the support of a

study team member. Consent to participate was implied by completion and submission of the surveys, and this was clearly communicated to participants (e.g., on the recruitment flyer, in the preamble to the surveys, in person for those participants who completed the surveys in the presence of a study team member). After completing all six measures during the first survey (T1), which took approximately 30–45 minutes, participants completed only the F-SIM, which took approximately 10–15 minutes, two weeks later (T2). Participants received a \$20 (AUD) retail voucher to compensate them for their overall time.

Data analyses.

Data screening.

Statistical analyses were conducted using IBM® SPSS® Version 25. Recommendations from the ‘Checklist for Screening Data’ (Tabachnik & Fidell, 2012, p. 125) were followed. Online survey platforms such as Qualtrics® can be configured to prevent data entry errors (e.g., pre-defining acceptable value ranges). Regardless, descriptive statistics were inspected for accuracy of input. All variables were assessed for the extent and nature of missing data, using Little’s Missing Completely at Random (MCAR) test. Where data were assessed as MCAR, imputation was conducted using the expectation maximisation method for continuous variables (Tabachnik & Fidell, 2012). Mode replacement was used for categorical variables (Linting & van der Kooij, 2012). Continuous variables deviating from a Gaussian distribution were identified and transformed where applicable. Transformed variables were used in subsequent analyses, where it was feasible to do so (i.e., where transformations did not obfuscate interpretation). Where it was not feasible to do so, non-parametric methods were used (e.g., Spearman’s rho correlation coefficients, r_s).

Psychometric Theory.

There are two common approaches to examining the psychometric properties of tests/measurements. Classical Test Theory (CTT) assumes that an observed test/measurement score is the sum of the true score and error (Novick, 1966). Item Response Theory (IRT) is a model-based approach which assumes that there is a relationship between the observed test/measurement score and some unobservable latent characteristic (Hambleton, Swaminathan, & Rogers, 1991). There is some debate as to which of these approaches is optimal. The CTT approach has the advantage of being better established, more widely used, and more familiar to clinicians (Jabrayilov, Emons, & Sijtsma, 2016). The IRT approach has the advantage of evaluating responses based on latent characteristics, without depending on the particular items contained in the test/questionnaire (Zanon, Hutz, Yoo, & Hambleton, 2016). Latent-variable approaches such as IRT require larger sample sizes than observed-variable approaches such as CTT (Hardouin, Amri, Feddag & Sébille, 2012). A number of studies have found that CTT and IRT approaches produce comparable results (Fan, 1998; Petrillo, Cano, McLeod, & Coon, 2015). It has been suggested that both CTT and IRT should be considered, with the ultimate choice of test theoretical approach being dependent on factors such as intended audience (Petrillo et al., 2015) and type of test/measure being developed (Cappelleri, Jason Lundy, & Hays, 2014). Given the clinical focus of this research program, and pragmatic concerns regarding sample size (i.e., lack of time and resources to recruit enough participants for an IRT approach), a CTT approach was adopted. A CTT approach is consistent with previous clinical research seeking to develop measures of social inclusion (e.g., Huxley et al., 2012; Secker et al., 2009).

Principal Components Analyses.

Although it is widely agreed that social inclusion is dynamic and relative (Huxley et al., 2006), previous measurement studies have not examined whether underlying dimensions differ between community and SMI samples (e.g., Huxley et al., 2012). This may be because such studies

have not necessarily sought to develop measures of social inclusion for use in the general community. In this research program, it was not assumed that the dimensional structure of the F-SIM would be the same in the general community and SMI samples. Analysis of the underlying dimensions of the F-SIM was conducted separately within each sample (to examine its internal structure). The majority of items on the F-SIM employ categorical measurement (i.e., dichotomous, ordinal, or nominal). Exploratory factor analysis requires continuous observed variables, and is therefore an inappropriate technique for such mixed-measurement variables. Categorical Principal Components Analysis (CATPCA) is the optimal statistical technique for determining the underlying dimensional structure of mixed-measurement variables (Linting et al., 2007a). As part of the CATPCA process, mixed-measurement variables are transformed via optimal scaling. The transformed variables may then be entered into a rank-order correlation matrix. In the CATPCA output, the terms, 'component,' and, 'dimension,' are used interchangeably. In the literature, the terms 'component,' 'dimension,' 'domain,' and, 'factor,' are used somewhat interchangeably. In this thesis, the term 'dimension' will primarily be used.

It is helpful to incorporate a priori theory into exploratory component analysis, as the number of components selected can impact both the interpretation and analysis of the underlying structure in CATPCA (Linting & van der Kooij, 2012). As noted previously, the initial version of the F-SIM posits five theoretical domains of social inclusion (Filia et al., 2019b). Hence, a five-component solution was assumed as the starting point of the exploratory analysis for the two separate groups. Further analyses were undertaken to determine the appropriateness of this assumption within each group. The adequacy of the above-mentioned correlation matrix of transformed variables for principal components analysis was assessed, with the requirement being correlations $\geq .30$ (Tabachnik & Fidell, 2012). Techniques such as the Parallel Test (Schmitt, 2011) are not applicable within CATPCA methodology, as they make incompatible statistical assumptions about the data being analysed (e.g., continuous measurement). Scree plots were examined, as this is

one of the most established and widely used methods for determining the appropriate number of components to use (Costello & Osborne, 2005). Scree plots are the recommended method for determining number of components when conducting a CATPCA (Linting & van der Kooij, 2012). To assist interpretation of the structure, a rotation of components was performed. Initial oblique rotations via the Direct Oblimin method were conducted to determine whether components were significantly correlated. Where no such correlations existed, orthogonal rotations were then conducted via the Varimax method (Tabachnik & Fidell, 2012).

The terms ‘data reduction’ and ‘item reduction’ are both used in the factor/component analysis literature, and it is important to operationalise these terms in the context of the present research program. Data reduction involves reducing a large set of variables into a smaller and more manageable set by determining whether the information can be summarised more efficiently by underlying dimensions, e.g., via factor analysis of a psychometric measurement tool (VandenBos, 2007). The identification of such dimensions does not necessarily entail the permanent removal from the psychometric instrument of items that load weakly on its underlying dimensions. Such a process of item reduction is often used to shorten, and thus produce more definitive and practically applicable versions of, psychometric measures (e.g., Jensen & Burlingame, 2018). Given that this research program involved the preliminary exploration of a novel psychometric measure of social inclusion, CATPCA was used primarily for data reduction (i.e., to identify underlying dimensions). No items were permanently removed from the F-SIM based on the results of these exploratory studies. However, the CATPCA was used for item reduction in the limited sense that only F-SIM items with rotated component/dimension loadings $\geq .32$ were reported in the relevant studies (Tabachnik & Fidell, 2012). That criterion was adopted because it signifies that $>10\%$ of variance overlaps with other items loading on the same dimension (Costello & Osborne, 2005). Cross-loading items (i.e., items that loaded $\geq .32$ on two or more components) were not necessarily viewed

as problematic, as some overlap across domains (e.g., employment/education, and finances) was expected.

Component scores seek to estimate what scores participants would have received on an underlying dimension if it could be measured directly. They are regression-like coefficients computed by taking the standardised score on each variable, multiplying by the corresponding component loading of the variable for the given component, and summing these products (Tabachnik & Fidell, 2012). Component scores were computed for each case and were used where applicable in subsequent analyses.

Reliability.

As is common among measures of complex social characteristics, items on the F-SIM were not assumed to be homogenous: reliability was tested by examining correlational relationships between items within each dimension (Portney & Watkins, 2009). Cronbach's α coefficient is a measure of internal consistency that can be applied to scales with dichotomous, continuous, or ordinal items (Portney & Watkins, 2009). Hence, Cronbach's α coefficient was calculated to assess the internal consistency of F-SIM dimensions and was interpreted as follows: $.70 \leq \alpha < .80$ = acceptable, $.80 \leq \alpha < .90$ = good, $.90 \leq \alpha$ = excellent (Portney & Watkins, 2009). The Intraclass Correlation Coefficient (ICC) provides the optimal measure of test-retest reliability because it uses an analysis of variance approach to determine both agreement among ratings and degree of correspondence (Portney & Watkins, 2009). The ICC is superior to the Pearson's product-moment correlation (r) coefficient, which provides an index of association but not agreement. Another advantage of the ICC is that it can be applied to interval/ratio, ordinal, and dichotomous data (Portney & Watkins, 2009). There are three ICC models and two ICC forms. Model 3 and form 2 (ICC_{3,2}) is the most appropriate for test-retest reliability, where the goal is to document that a tool has clinical applications (Trevethan, 2017). Stability of measurement was therefore assessed via

ICC_{3,2} for F-SIM items at T1 and T2. As recommended by Cicchetti (1994), an ICC_{3,2} ranging from .60–.74 was considered good and an ICC_{3,2} $\geq$.75 was considered excellent test-retest reliability.

Validity.

As described earlier, convergent validity was assessed in terms of the extent to which dimension/component scores on the F-SIM positively correlated with SIS, APQ-6, and AQoL-8D scores, and negatively correlated with K-10, and UCLA Loneliness Scale scores. Spearman's rho correlation coefficients (r_s) were calculated between these six measures at T1. Correlation coefficients were interpreted as indicative of weak (.10), moderate (.30), or strong ($\geq$.50) relationships among variables (Cohen, 1992). Previous measurement development studies (e.g., Huxley et al., 2012; Mezey et al., 2013; Secker et al., 2009) reported positive correlations ranging from .25 to .65 between measures of social inclusion, community participation, and QoL. While these studies used older samples and different measures to those employed here, a similar range of moderate-to-strong positive correlations was expected between F-SIM component scores and SIS, APQ-6, and AQoL-8D scores in the present studies. Also reported in these previous studies were negative correlations ranging from $-.15$ to $-.60$ between measures of social inclusion and measures of social isolation and mental ill-health. A similar range of moderate-to-strong negative correlations was expected between F-SIM component scores and K-10 and UCLA Loneliness Scale Scores in the present research program.

Face validity (i.e., the extent to which participants subjectively view an instrument as capturing what it purports to measure) was explored through the examination of responses to user experience questions (e.g., by calculating frequency counts and percentage responses to the question *How well do you think this questionnaire actually measures social inclusion?*). Effect sizes and 95% confidence intervals were calculated for relevant parameter estimates.

Power and sample size.

There is a lack of empirical evidence for strict rules regarding adequate sample sizes in factor and principal component analyses (Costello & Osborne, 2005). Where loadings are $\geq .60$ with at least four variables loading on each factor or component, sample sizes may be as low as 50 (Guadagnoli & Velicer, 1988). With lower loadings and less variables per factor or component, a sample size of 150 or more may be required (Guadagnoli & Velicer, 1988; Tabachnik & Fidell, 2012). In questionnaire validity studies, statistical power is largely a function of measurement reliability (Heo et al., 2015). The reliability of the F-SIM has not yet been assessed, but minimum sample sizes of 80 have provided meaningful estimates in clinical questionnaire validity research (Hobart, Cano, Warner, & Thompson, 2012). A minimum sample size of 64 is required to detect a moderate bivariate correlation with power ($1-\beta$) of .80 and α (type I error) = .05 (Cohen, 1992). Each of the first two studies in the research program included data from > 150 participants, thus we contend that there is adequate power for each of the above statistical analyses.

Having described the methodology of the first two studies, which will generate observational F-SIM data in the two groups, it is now possible to outline the methodology of the third and final study, which involves examination of group differences on the F-SIM. This will represent the first time a psychometric measure of social inclusion has been employed to examine differences between young adults with and without SMI. With the caveat that neither the F-SIM nor any other measure of social inclusion has been definitively validated (i.e., criterion validity has not been established [Cordier et al., 2017]), this study will help elucidate the putative social exclusion experienced by those with SMI.

Group Differences in Social Inclusion

Design.

This was a cross-sectional between-subjects study of two groups: young adults aged 18 to 25 years with and without SMI. The settings and samples, measures, procedure, and data screening processes used in this study were identical to those outlined above for the first two studies; however, only T1 data was used in the third study.

Data analyses.

A hierarchical logistic regression was conducted to predict membership to one of two groups: young adults aged 18–25 from the general community (GC=0), and young adults aged 18–25 with serious mental illness (SMI = 1). Logistic regression was chosen because it is the optimal technique for using mixed-measurement (i.e., nominal-, ordinal-, interval-, and/or ratio-level) variables to discriminate between categories of a binary outcome variable. Further, it provides a single measure of effect size (odds ratios) to depict contributions of individual variables. It was also chosen because the primary function of this technique is to determine the dimensions that discriminate between groups, which matched the aims of the study. Logistic regression performs this function better than alternative approaches such as discriminant function analysis, because it is more flexible in terms of distributional assumptions (Tabachnik & Fidell, 2012). It has been applied in previous social inclusion measurement development studies (e.g., Huxley et al., 2016). A hierarchical method was used to examine whether each dimension of the F-SIM made a statistically significant contribution to the prediction of group membership while accounting for the effect of other F-SIM dimensions.

The F-SIM was the predictor variable of interest and group membership was the outcome variable of interest in this study. As discussed earlier, Social Rank Theory suggests that young

adults with SMI are likely to have illness-related social experiences not shared by those from the general community (Birchwood et al., 2005). These may contribute to partially idiographic manifestations of social inclusion in each population. It is therefore possible that a different constellation of F-SIM dimensions and/or indicators will emerge among young adults with SMI in study one relative to those from the general community in the second study. Such an occurrence is not uncommon in the factor analytic literature. Buck and colleagues (2016) reported different factor structures of social cognition for people with psychosis compared to healthy controls. It was decided that, should this occur in the present research program, the F-SIM dimensions and indicators identified in the primary population of interest (i.e., young adults with SMI) would be used in this study. Each F-SIM dimension identified in the previous study was allocated its own block in the logistic regression model (i.e., individual items from a given dimension were grouped together and entered as a block). In terms of ordering the entry of the blocks, demographics (age and gender) were entered as control predictors in block one. The F-SIM dimension blocks were then entered hierarchically, in the order that they were identified in the principal components analysis of the previous study.

The contribution of each block in the logistic regression model to the explanation of group differences was determined as follows. Omnibus tests of model coefficients were examined to determine chi-square change between blocks (χ^2_{Δ}). Chi-square (χ^2) and Hosmer-Lemeshow tests were conducted to assess the overall goodness-of-fit of each of the steps of the model, as well as the final model. Nagelkerke pseudo R^2 values were generated to indicate the amount of variation in group membership that was explained by the cumulated blocks of variables (Tabachnik & Fidell, 2012). Classification tables were generated to examine the ability of each of the steps in the model to accurately identify group membership. The relative contribution of individual predictors in the models was tested with the Wald χ^2 statistic. Odds ratios (OR) and their 95% confidence intervals

[95%CI] were calculated to assess the effect size of individual predictors. Effect sizes were interpreted as being small, OR = 1.5, medium, OR = 2.0, or large, OR = 3.0 (Sullivan & Feinn, 2012).

Power and sample size.

There is very little research using psychometric measures to examine group differences in social inclusion (Huxley et al., 2016). This complicates efforts to undertake power analyses. However, Filia et al. (2019b, Appendix 4) pilot-tested the F-SIM and found statistically significant differences between groups suggesting that people with SMI ($n = 30$) were significantly more likely to experience social exclusion than people from the general population ($n = 30$). For example, 53% of people with SMI responded, 'Yes,' to the item, '*I often feel unwelcome, like I don't belong,*' compared to 7% of general community members. This equates to a large effect size, OR=16.00 (95%CI = 3.22, 79.56). A sample size of 21 is required to detect a comparable effect, with power ($1-\beta$) of .80 and α (type I error) = .05 (Chow, Wang, & Shao, 2007). However, this data comes from an older cohort and may be an overestimate of differences between young adults with and without SMI. We are not aware of any previous studies comparing these cohorts on psychometric measures of social inclusion. Though not strictly a measure of social inclusion, Macdonald et al. (2000) found that $n = 26$ young adults with SMI reported having significantly fewer friends than $n = 26$ young adults from the general community, $t(48) = -3.61, p = .001$. This equates to a large effect size, Cohen's $d = 1.02$ (95%CI = 0.20, 3.79). Given that data from $n = 150$ young adults with SMI and $n = 150$ young adults from the general community were used, it is reasonable to assume that this study had adequate power for the above statistical analyses. With respect to the logistic regression technique, it is recommended that there be ≥ 10 cases for every predictor variable included in a logistic regression model (Vittinghoff & McCulloch, 2007). With $N = 300$, this would allow for the inclusion of up to 30 predictor variables. Only 23 predictor variables were included, as a conservative means to avoid over-fitting the model to the data.

Summary

In this chapter, a methodology was described for the three individual studies within the thesis. The first two studies involved preliminary examination of psychometric properties of the F-SIM in, (i) a cohort of young adults aged 18–25 years with SMI, and, (ii) a sample of young adults aged 18–25 years from the general community. The samples were examined separately (as opposed to being pooled) so as to enable a clearer examination of social inclusion specifically among young adults with SMI, and to acknowledge the possibility of different dimensional structures underlying the F-SIM in each group. Apart from sampling different populations, the two studies were methodologically identical. Categorical Principal Components Analyses (CATPCA) were conducted to identify underlying dimensions of the F-SIM. Internal consistency of dimensions was examined via Cronbach's α . Item-level test-retest reliability over two weeks was examined via ICC_{3,2} with absolute agreement. Convergent validity was assessed in terms of whether F-SIM dimension scores were positively associated with SIS, APQ-6, and AQoL-8D scores, and whether they were negatively associated with UCLA Loneliness Scale and K10 scores. Face validity of the F-SIM was examined via user acceptability and experience questions.

The third and final study involved an examination of group differences in social inclusion (i.e., on the F-SIM) between young adults aged 18–25 years with SMI and same-aged peers from the general community. In the event that different dimensional structures of the F-SIM emerged in studies one and two, the structure reported among young adults with SMI was used here (because that was the primary population of interest in the research program). A hierarchical logistic regression was conducted with group membership (SMI or general community) as the outcome variable. Age and gender were entered as predictors in the first regression block, to control for the potentially confounding effect of these variables. Subsequent regression blocks were populated with predictor items from each of the F-SIM dimensions. Those blocks were entered hierarchically into

the logistic regression model, based on the order in which the F-SIM dimensions emerged in the principal components analysis of study one. The ability of each block within the regression model, and each individual item within each block, to discriminate between groups was examined. This method was employed to permit the identification of broad dimensions and specific indicators of social inclusion that differentiated between young adults with SMI and those from the general community.

Having now outlined the methodology that was used across the three studies in this research program, subsequent chapters will present and discuss the results of the program. The focus of the next chapter is on measuring social inclusion among young adults aged 18 to 25 years with SMI.

CHAPTER FIVE: MEASURING SOCIAL INCLUSION AMONG YOUNG ADULTS WITH SERIOUS MENTAL ILLNESS

Preamble

A number of existing psychometric measures of social inclusion have been designed for SMI populations, but the samples used to develop them have been comprised of middle-aged people with chronic SMI (e.g., Huxley et al., 2012; Mezey et al., 2013; Secker et al., 2009). For young adults with SMI, social inclusion is less likely to be impacted by factors related to illness chronicity (e.g., recurrent hospitalisation, entrenched marginalisation [Sullivan et al., 2013]). Furthermore, young adulthood is a transitional period wherein people ‘try on’ various social identity roles they may hope to inhabit in adulthood (Benson & Elder, 2011). This suggests developmentally unique social inclusion needs for young adults with SMI relative to older SMI populations. The empirical paper presented in this chapter is the first to examine the psychometric properties of the F-SIM among young adults aged 18 to 25 years with SMI. In the paper, F-SIM dimensions and relevant individual indicators are identified, which helps refine our understanding of social inclusion in this population. The paper also provides preliminary psychometric data to inform further development of the F-SIM for use in clinical and research settings. It was accepted for publication in *Psychiatric Rehabilitation Journal* in May 2019.

This chapter concludes with a brief overview of results from the study.

Preliminary Psychometric Properties of a Measure of Social Inclusion for Young Adults Aged 18 to 25 With Serious Mental Illness

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Objective: Young adults with serious mental illness (SMI) are reported to be socially excluded, but social inclusion measures are untested in this population. The aim of this study was to test the Filia Social Inclusion Measure (F-SIM) in this population. **Method:** Categorical principal components analysis of F-SIM data from $N = 159$ young adults with SMI aged 18–25 was conducted. Cronbach's alpha (α) examined internal consistency. Intraclass Correlation Coefficients ($ICC_{3,2}$) examined 2-week test–retest reliability. Spearman's rho correlation coefficients (r_s) examined construct validity. **Results:** Cronbach's alpha was .94 for Dimension 1 (*Interpersonal Connections*), .87 for Dimension 2 (*Vocational and Financial Security*), and .82 for Dimension 3 (*Healthy Independent Lifestyle*). $ICC_{3,2}$ coefficients ranged from .20–.99. Dimension 1 scores correlated with measures of social inclusion ($r_s = .69, p < .01$), Quality of Life (QoL [$r_s = .63, p < .01$]), hours of social/leisure activities last week ($r_s = .32, p < .01$), loneliness ($r_s = -.76, p < .01$), and psychological distress ($r_s = -.42, p < .01$). Dimension 2 scores correlated with measures of social inclusion ($r_s = .27, p < .01$) and hours working ($r_s = .67, p < .01$) and studying last week ($r_s = .47, p < .01$). Dimension 3 scores correlated with measures of social inclusion ($r_s = .25, p < .01$), QoL ($r_s = .40, p < .01$), psychological distress ($r_s = -.33, p < .01$), and loneliness ($r_s = -.26, p < .01$). **Conclusions and Implications for Practice:** The F-SIM demonstrated excellent reliability and validity among young adults aged 18–25 with SMI. This represents a preliminary step toward evidence-based assessment and intervention to help increase social inclusion for this vulnerable population.

Impact and Implications

This study presents the Filia Social Inclusion Measure (F-SIM), a new tool for measuring social inclusion among young adults with a lived experience of serious mental illness. The F-SIM is a promising measure of social inclusion that will benefit from ongoing development. These findings are relevant to clinicians and policymakers, who need reliable and valid measurement tools for an evidence-based approach to improving the social inclusion of vulnerable groups.

Keywords: measurement, mental illness, psychometric, social inclusion, young people

In recent years, social inclusion has shifted from a primarily ideological concept to a health-related empirical construct. There are no specific theories of social inclusion (Baumgartner & Burns, 2014), although evolutionary accounts are applicable (Gardner,

Filia, Killackey, & Cotton, 2019). Humans have a basic need for interpersonal contact that promotes a subjective sense of belonging (Baumeister & Leary, 1995). This theoretical foundation assumes that social inclusion entails objective (e.g., community participa-

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tion) and subjective (e.g., sense of acceptance) experiences (Wright & Stickley, 2013). Various dimensions underlying social inclusion have been posited. Employment/education, finance factors, social networks, health, and housing/neighborhood factors are among the most commonly cited dimensions (Filia, Jackson, Cotton, Gardner, & Killackey, 2018). There is no unanimously agreed definition of social inclusion, and such conceptual issues have been examined elsewhere (Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007). Here we define social inclusion as a sense of belongingness/acceptance in relation to opportunities to participate in valued social roles (Gardner et al., 2019). Social exclusion is commonly viewed as the dimensional opposite: a sense of loneliness/isolation in relation to dissatisfaction with opportunities to participate (Hayes, Gray, & Edwards, 2008; Ryan & Sartbayeva, 2011).

Social inclusion theoretically overlaps with constructs such as social functioning and quality of life (QoL). A key element of social functioning is participation in societally defined age-appropriate roles (Mueser & Tarrier, 1998), though not necessarily subjective satisfaction with such roles. An individual who works in a job they find isolating and unfulfilling may be socially functional but not included (Secker, 2009). On the other hand, someone who is not participating socially may not necessarily feel excluded (Groth-Marnat, 2009). Quality of life incorporates an individuals' level of independence, physical and psychological health, personal beliefs, relationships to other people, and relationships to their environment (The WHOQOL Group, 1995). Social inclusion is distinct from QoL but contributes to it (Huxley et al., 2012). Empirically examining relationships between these variables may help clarify the construct validity of social inclusion, thus improving its measurement.

Given the complex, multidimensional nature of social inclusion, policies and interventions must target well-specified subgroups of interest (Evans-Lacko et al., 2014; Hayes et al., 2008). Young adulthood is a sensitive period for social inclusion as young people transition to adult roles (Álvarez-Jiménez et al., 2012). Most forms of mental illness typically have their onset during this stage, which can disrupt the transitional process (Killackey, Jackson, Gleeson, Hickie, & McGorry, 2006). Young adults with serious mental illness (SMI) are widely reported to be socially excluded (Social Exclusion Unit, 2005). Definitions of SMI are often limited to diagnoses, for example, schizophrenia (Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). However, there is significant diagnostic instability in the early stages of SMI and some have proposed transdiagnostic conceptualizations (Hartmann et al., 2017). Here SMI is defined as any mental illness that makes it difficult for a person to manage their daily activities without assistance (Australian Bureau of Statistics, 2015).

Existing evidence that young adults with SMI are socially excluded primarily comes from objective indicators in distinct domains. For example, unemployment rates are higher (Ramsay, Stewart, & Compton, 2012) and social network sizes are smaller (Gayer-Anderson & Morgan, 2013) for young adults with SMI compared with those from the general community. Subjective indicators are underresearched in this population (Sündermann, Onwumere, Kane, Morgan, & Kuipers, 2014). Also, as Gayer-Anderson and Morgan note, different methodologies are often applied (even within domains). A systematic review of psychometric properties concluded that measures of social inclusion have

not been sufficiently developed (Cordier et al., 2017): there is no gold standard measure of this construct (Wilson & Secker, 2015). A number of studies report the development of social inclusion measures among adults aged 18–65 with SMI. The age-in-years of participants in these studies tends to range from midthirties to midfifties (e.g., Huxley et al., 2012; Mezey et al., 2013; Secker, Hacking, Kent, Shenton, & Spandler, 2009). The social inclusion of middle-aged people with SMI may be impacted by long-term illness effects (e.g., entrenched marginalization) that are absent among young adults with SMI (McCleery, Horan, & Green, 2014). Further, young adults experience unique developmental processes including independence from parents and the emergence of the peer group as the dominant social concern (Blakemore & Mills, 2014). These factors suggest the need for a novel measure of social inclusion among young adults with SMI. To-date, no such measures have been psychometrically tested in this population (Gardner et al., 2019). This makes it difficult to assess the efficacy of interventions in terms of social inclusion.

Evidence-based interventions to improve social inclusion among young adults with SMI are needed for at least two reasons. First, there is evidence that social exclusion contributes to the psychological distress often experienced by young adults with SMI as they adjust to illness onset (Singer, Addington, Dobson, & Wright, 2014). Second, increased social inclusion (e.g., improving interpersonal relationships, addressing vocational issues) is a common treatment goal for young adults with SMI (Cotton et al., 2011; Iyer, Mangala, Anitha, Thara, & Malla, 2011; Ramsay et al., 2011). The development of such interventions requires reliable and valid measurement of social inclusion (i.e., to assess efficacy in research trials). Succinct measures are also required in clinical services (e.g., to assess levels of social inclusion at service entry and discharge). The overarching aim of the present study was to test the psychometric properties of a social inclusion measure among young adults aged 18 to 25 with SMI. Specific aims were to:

1. Perform data/item reduction on a novel measure of social inclusion;
2. Identify underlying dimensions of the measure;
3. Examine the internal consistency and test-retest stability of the measure;
4. Explore construct validity relative to established measures of social inclusion, loneliness, social activity/participation, QoL, and psychological distress
5. Explore face validity.

Method

Setting and Sample

Participants were 18–25 years old and were recruited from two sources, specifically: Orygen Youth Health, a public mental health service for people aged 15–25 in the northwest of Melbourne, Australia, and Mind Australia, which provides short- and long-term psychosocial rehabilitation services for people aged 16–25

across Melbourne, Australia. Both services support young people with SMI. Participants were approached in consultation with clinical staff from these services. Diagnoses of mental illness were recorded via self-report, a method that has been used in large genome-wide studies of depression (Hyde et al., 2016). Exclusion criteria were acute mental illness (i.e., symptom severity precluding informed consent) and lack of fluency in English (due to pragmatic reasons).

Measures

The Filia Social Inclusion Measure (F-SIM) is a novel self-report measure of social inclusion over the past month. Item creation was based on a thematic analysis of key contributors to social inclusion (Filia et al., 2018). A literature search using the terms, *social inclusion* and *social exclusion* was conducted. Papers wherein either construct was defined and was a primary focus were considered appropriate. This identified $n = 25$ peer-reviewed papers from the non-population-specific social inclusion literature, $n = 26$ peer-reviewed papers from the social inclusion and mental illness literature, and $n = 20$ pieces of gray literature (e.g., publications from services aiming to improve social inclusion for various groups). Qualitative coding and categorization were applied (Braun & Clarke, 2006) to identify individual contributors to, and domains of, social inclusion that were commonly cited across these literatures. Themes were considered relevant if they involved putative causes of social inclusion/exclusion, the increase or decrease of social inclusion/exclusion, and barriers/facilitators of an individual's social inclusion. Ninety individual contributors were identified across 13 domains (Filia et al., 2018).

A Delphi methodology sampling $n = 25$ adults with SMI, $n = 25$ carers of adults with SMI, and $n = 33$ adults from the general community was then applied. The aim was to reach consensus regarding which individual contributors identified in the thematic analysis ought to inform item creation for the F-SIM. Consensus individual contributors were converted into items with varying measurement levels, depending on the concept being measured. For example, *Do you have a current drivers license?* required dichotomous (Yes/No) coding. Some indicators (e.g., *I often feel unwelcome, like I do not belong*) were better suited to ordinal measurement (*Not at all/A little bit/Very much so*). Others were clearly ratio (e.g., *What is your net weekly income?*). This process produced 128 mixed-measurement items across five domains of social inclusion (housing/neighborhood, relationships and social activities, employment/education, finances, and health/wellbeing). Like other social inclusion measures (Coombs, Reed, & Rosen, 2016), frequencies/percentages can be used to examine responses to individual F-SIM items. This maximizes clinical utility by targeting specific areas of social inclusion (Australian Mental Health Outcomes Classification Network, 2016). Pilot and preliminary testing of the measure were conducted among middle-aged people from the general community and those with SMI (Filia, 2014). User-experience questionnaires were distributed to participants, and chi-square analyses or one-way ANOVAs were conducted to examine group differences on F-SIM items. Results suggested that the measure was acceptable and face-valid to users, and was able to discriminate between groups. The psychometric properties of the F-SIM are yet to be established among young

adults with SMI. Age, gender, and presence/absence of lifetime mental disorder diagnosis were obtained via the F-SIM.

The Social Inclusion Scale (SIS; Secker et al., 2009) is a 19-item self-report measure of social inclusion over the past two weeks. Items (e.g., *I have felt accepted by my neighbors*) are measured on Likert-type scales from 1 (*Not at all*) to 4 (*Yes, definitely*). Five items are reverse scored. Scores on three subscales can be computed: Social Isolation (range 5–20, higher scores indicate more social isolation), Social Relations (range 8–32, higher scores indicate better social relations), and Social Acceptance (range 5–20, higher scores indicate greater social acceptance). All items are summed for total scores (range 19–72, higher scores indicate greater social inclusion). Although there is currently no gold standard measure of social inclusion, the SIS has relatively strong psychometric properties (Cordier et al., 2017), and has demonstrated reliability and validity in psychiatric samples (Secker et al., 2009).

The Activity and Participation Questionnaire (APQ-6; Stewart et al., 2010) is a six-question self-report measure of participation in employment, education, and social/leisure activities in the past week. Questions are measured on nominal (e.g., *Last week, did you have a full-time or part-time job of any kind?*) and continuous (e.g., *How many hours per week do you spend attending class and studying?*) scales. The APQ-6 is scored according to number of hours participating in employment, education, and social/leisure activities. A higher number of hours indicate superior social functioning. The APQ-6 has demonstrated reliability and validity in psychiatric samples (Stewart et al., 2010).

The Revised UCLA Loneliness Scale (Russell, 1996) is a 20-item (e.g., *I feel isolated from others*) self-report measure of subjective feelings of loneliness and isolation. Items are measured on Likert-type scales from 1 (*Never*) to 4 (*Often*) and summed for a total score with a range of 20 to 80. Higher scores indicate more severe loneliness and isolation. The UCLA Loneliness Scale has demonstrated reliability and validity in psychiatric samples (Robustelli, Newberry, Whisman, & Mittal, 2017).

The Australian Quality of Life instrument–8 Dimensions (AQoL-8D [Maxwell, Özmen, Iezzi, & Richardson, 2016]) is a 35-item (e.g., *How often do you have trouble sleeping?*) self-report measure of QoL over the past week. Items are measured on Likert-type scales with varying anchor points. The AQoL-8D produces total and subscale (e.g., Independent Living) utility scores to measure quality-adjusted life years ranging from *0/death* to *1/optimal health*. The AQoL-8D has demonstrated reliability and validity among psychiatric samples (Richardson, Iezzi, Khan, & Maxwell, 2014).

The Kessler-10 Psychological Distress Scale (K10; Kessler et al., 2002) is a 10-item (e.g., *During the last 30 days, about how often did you feel hopeless?*) self-report measure of anxiety and depression symptomatology in the past month. Items are measured on Likert-type scales from 1 (*None of the time*) to 5 (*All of the time*) and summed to create total scores with a range of 10–50. Higher scores indicate greater psychological distress (<20 suggests an individual is likely to be well). In health care settings, cut-off scores indicate a likely mild (20–24), moderate (25–30), or severe (≥ 30) mental disorder (Australian Bureau of Statistics, 2015). The K10 has demonstrated reliability and validity in youth and psychiatric samples (Chan & Fung, 2014).

Ethics Approval, Youth Consultation, and Consent Procedures

This exploratory observational study received ethical approval from the Melbourne Health Human Research and Ethics Committee (HREC/16/MH/325) and endorsement by the Mind Australia Research and Evaluation Committee. The Youth Research Council at Orygen, the National Centre of Excellence in Youth Mental Health were consulted during the planning, design, and implementation of the study. Data were collected via online surveys at two time points (T1 and T2) two weeks apart. Surveys were created in Qualtrics and distributed via e-mail. Informed consent was implied by submission of survey responses, and this was explained via the participant information and consent form. Participants were provided with a small retail voucher following completion of their participation.

Data Analyses

Analyses were conducted using IBM SPSS Version 25. Recommendations from the Checklist for Screening Data (Tabachnik & Fidell, 2012, p. 125) were followed. Descriptive statistics were inspected for accuracy of input, Little's Missing Completely at Random (MCAR) test was used to assess missing data, and non-normal variables were identified and transformed where applicable.

Classical test theory (CTT) approaches to psychometric measurement are familiar to clinicians and are most widely used (Jabrayilov, Emons, & Sijtsma, 2016). Consistent with previous social inclusion measurement development (e.g., Huxley et al., 2012; Secker et al., 2009), this study adopted a CTT approach. Underlying dimensions were identified to reduce data and examine internal structure of the F-SIM. Categorical Principal Components Analysis (CATPCA) facilitates these statistical procedures when using mixed-measurement variables (Linting & van der Kooij, 2012), such as those on the F-SIM. A full explanation of CATPCA methodology is available elsewhere (Linting & van der Kooij, 2012). Briefly, CATPCA does not assume normality or linearity and uses optimal scaling to transform nonquantitative (e.g., nominal) variables into quantitative variables (Linting & van der Kooij, 2012). Rank-order correlations between transformed variables were examined to ensure suitability of the data for PCA, with a criterion of correlations $\geq .30$ among items.

The thematic analysis (Filia et al., 2018) and Delphi methodology for F-SIM item creation suggested five dimensions of social inclusion. A five-component solution was therefore assumed as the starting point of the exploratory analysis. Statistical procedures for determining the appropriate number of factors (e.g., Horn's Parallel Analysis) are not applicable within CATPCA; however, the Scree plot helps make such determinations (Linting & van der Kooij, 2012). To assist interpretation of the structure, a rotation of components was performed. Items with component loadings $< .32$ were removed from the analysis (Costello & Osborne, 2005). Component scores (based on regression-like coefficients) were computed for each case and used where applicable in subsequent analyses.

Items on the F-SIM were not assumed to be homogenous. Relationships between items within each component were examined via Cronbach's alpha to test internal consistency. Cronbach's

alpha can be applied to scales with dichotomous, continuous, or ordinal items (Portney & Watkins, 2009).

Two weeks is a sufficient test-retest time interval for measures that have clinical and research applications (DeVon et al., 2007). This interval has been used in the development of other social inclusion measures (Huxley et al., 2012; Marino-Francis & Worrall-Davies, 2010). The intraclass correlation coefficient (ICC) is the optimal measure of test-retest reliability and can be applied to interval/ratio, ordinal, and dichotomous data (Portney & Watkins, 2009). There are three ICC models and two ICC forms. Model 3 and form 2 (ICC_{3,2}) are most appropriate for test-retest reliability (Trevethan, 2017). Stability of measurement was therefore assessed via ICC_{3,2} with absolute agreement for F-SIM items over two weeks.

Construct validity was assessed in terms of how component scores on the F-SIM covaried with SIS, APQ-6, AQoL-8D, UCLA Loneliness Scale, and K10 scores. It was expected that component scores would converge (i.e., be positively associated) with SIS, APQ-6, and AQoL-8D scores, and diverge from (i.e., be negatively associated with) UCLA Loneliness Scale and K-10 scores. Spearman's rho correlation coefficients (r_s) were calculated between these measures. Correlation coefficients were interpreted as depicting weak (.10), moderate (.30), or strong ($\geq .50$) relationships among variables (Cohen, 1992). Face validity was explored through frequencies/percentage responses to user experience questions (e.g., *How well do you think this questionnaire actually measures social inclusion?*).

Results

Participants

Between April 2017 and August, 2018, 159/174 consenting participants completed surveys at T1. Of the 159 T1 respondents, 46 completed surveys at T2. Missing data analysis at T1 included all measures outlined above. Little's MCAR test suggested that missing data at T1 were ignorable, $\chi^2(128) = 111.18, p = .86$. Only F-SIM data were collected at T2, where Little's MCAR test suggested that missing data were also ignorable, $\chi^2(155) = 122.42, p = .98$. Given that no variables were missing more than 10% of data, imputation was conducted via expectation-maximization for quantitative variables (Tabachnik & Fidell, 2012) and via CATPCA mode replacement for categorical variables (Linting & van der Kooij, 2012). Seven F-SIM items demonstrated insufficient variance and were deleted. The AQoL-8D utility scores, APQ-6 scores, weekly income, and weekly rent/mortgage payments were not normally distributed. Transformations either did not improve normality or obfuscated interpretation. Nonparametric methods (e.g., r_s coefficients, Mann-Whitney U tests) were used where appropriate. Baseline demographic comparisons were made between participants who provided T2 data and those who did not. There were no significant differences in age, $t(158) = -0.48, p = .63$, gender, $\chi^2(n = 160) = 6.31, df = 3, p = .10$, weekly income, Mann-Whitney $U = 2363, p = .44$, Internet access at home $\chi^2(n = 160) = 1.45, df = 1, p = .23$, or

Table 1

Demographics and Other Characteristics of a Sample of Young People Aged 18–25 With Serious Mental Illness

Characteristic	Total sample (<i>N</i> = 159)
Demographics	
Gender, % (<i>n</i>)	
Female	48.40 (77)
Male	42.80 (68)
Transgender	4.40 (7)
Do not identify as female, male, or transgender	4.40 (7)
Age in years, <i>M</i> (<i>SD</i>)	21.13 (2.21)
Living situation	
<i>Where are you currently living?</i> , % (<i>n</i>)	
Homeless, living on the streets (no roof over your head)	1.30 (2)
Homeless shelter, boarding house, hostel, or transitional housing	6.90 (11)
Public housing	3.10 (5)
Nursing home or supported accommodation	9.40 (15)
Private rental	32.70 (52)
Own home (paying off mortgage, or own outright)	1.30 (2)
Family home (with your parents or other family members)	45.30 (72)
<i>Who do you currently live with?</i> , % (<i>n</i>)	
Parents	58.50 (93)
Siblings	31.40 (50)
Partner	8.80 (14)
Children	2.50 (4)
Other family members	6.90 (11)
Friend	8.20 (13)
Flatmate	10.70 (17)
Other residents	13.20 (21)
Self alone including pets	8.20 (13)
<i>How many dollars (AUD) per week do you personally spend on rent or mortgage payments?</i> , <i>M</i> (<i>SD</i>)	96.28 (122.78)
<i>Do you have access to the internet at home?</i> (% Yes [<i>n</i>])	92.50 (147)
<i>Do you have a current drivers license?</i> (% Yes [<i>n</i>])	56.00 (89)
Finances	
Net weekly income in dollars (AUD), <i>M</i> (<i>SD</i>)	317.87 (239.23)
<i>Where do you currently receive an income from?</i> (% Yes [<i>n</i>])	
Payment from work or study (e.g., scholarship)	32.70 (52)
Government payment (e.g., youth allowance, newstart allowance, single parent payment, disability support pension)	61.60 (98)
Spouse or other family member provides money	15.10 (24)
I don't receive an income/I have no money	11.30 (18)
Employment/education	
<i>Did you work or study at any time over the past 12 months?</i> (% Yes [<i>n</i>])	77.40 (123)
<i>Are you currently:</i> (% Yes [<i>n</i>])	
Working for pay?	33.30 (53)
Working for payment other than monetary?	7.50 (12)
Working in a voluntary capacity?	15.10 (24)
Studying at a formal institution leading to a qualification (e.g., university, TAFE)?	27.70 (44)
Unemployed with no activity?	56.00 (88)
<i>Did you complete the highest year of secondary school?</i> (% Yes [<i>n</i>])	65.40 (104)
Mental health	
<i>Have you ever received a diagnosis of a mental illness from a health professional?</i> (% Yes [<i>n</i>])	96.20 (153)
<i>DSM-V category</i>	
Depressive disorders	52.83 (84)
Anxiety disorders	43.40 (69)
Schizophrenia spectrum and other psychotic disorders	30.20 (48)
Personality disorders	25.79 (41)
Bipolar and related disorders	18.87 (30)
Trauma-related disorders	17.61 (28)
Eating disorders	10.06 (16)
Obsessive-compulsive and related disorders	6.29 (10)
Substance-related and addictive disorders	4.40 (7)
Kessler Psychological Distress Scale (K10) score, <i>M</i> (<i>SD</i>)	31.47 (9.42)

Note. *M* = mean; *SD* = standard deviation; *n* = number of participants; AUD = Australian Dollars; TAFE = Technical and Further Education; *DSM-V* = *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition.

Table 2

Characteristics of a Sample of 159 Young People Aged 18–25 With Serious Mental Illness on Established Measures of Social Inclusion, Social Functioning, Loneliness, and QoL

Measure	<i>M (SD)</i>	Minimum	Maximum
Social Inclusion Scale			
Sum total score	44.71 (10.24)	20	71
Social Isolation Scale	13.41 (3.83)	5	20
Social Relations Scale	17.49 (4.65)	8	31
Social Acceptance Scale	12.68 (3.33)	5	20
Activity and participation questionnaire			
<i>Last week how many hours did you work?</i>	5.99 (11.09)	0	55
<i>How many hours per week do you spend attending classes and studying?</i>	3.50 (7.92)	0	50
<i>How many hours did you spend on other social activities in the last week (e.g., socializing with friends/family, sports or physical activity, leisure activities)?</i>	13.37 (14.49)	0	80
UCLA Loneliness Scale			
Sum total score	52.48 (12.94)	24	76
Australian Quality of Life Instrument (AQoL-8D)			
Sum total utility score	.42 (.21)	.13	.99
Independent Living Scale utility score	.77 (.17)	.39	1
Happiness Scale utility score	.52 (.19)	.21	1
Mental Health Scale utility score	.43 (.15)	.19	.97
Coping Scale utility score	.53 (.18)	.28	1
Relationships Scale utility score	.57 (.15)	.47	1
Self-Worth Scale utility score	.53 (.20)	.25	1
Pain Scale utility score	.71 (.26)	.11	1
Senses Scale utility score	.74 (.18)	.31	1

Note. *M* = mean; *SD* = standard deviation; *n* = number of participants; Minimum = minimum observed value; Maximum = Maximum observed value.

having engaged in work/study at any time in the past 12 months $\chi^2(n = 160) = .81, df = 1, p = .37$.

Sample Characteristics

Table 1 shows sample characteristics ($N = 159$). Gender was approximately evenly distributed: $n = 77$ female (48.4%), $n = 68$ male (42.8%), $n = 7$ transgender (4.4%), $n = 7$ do not identify as male, female or transgender (4.4%). Age range was 18 to 25 years ($M = 21.13, SD = 2.21$). Family home (45%) and private rental (33%) were common living arrangements, where participants tended to live with parents (58.50%) and/or siblings (31.40%). Net weekly income in AUD varied considerably ($M = \$317.87, Mdn = \$280, SD = \$239.23, range = 0–1600$), and was lower than the current adult mean weekly earning estimate of \$1,653.00 AUD (Australian Bureau of Statistics, 2015). Weekly AUD personally spent on rent/mortgage also varied considerably ($M = \$96.28, Mdn = \$60, SD = \$128.78, range = 0–590$). Most participants were unemployed with no current activity (56%) and receiving payments from the government (61.60%), whereas 32.70% received payment from work or study. The most commonly reported diagnostic categories were depressive disorders ($n = 84, 53\%$), anxiety disorders ($n = 69, 43\%$), and schizophrenia spectrum disorders ($n = 48, 30\%$). Comorbidity was common: $n = 103$ (64%) participants reported more than one diagnosis of mental illness. Psychological distress measured by the K10 ($M = 31.47, SD = 9.42, range = 12–50$) suggested that on average participants were experiencing severe distress (Australian Bureau of Statistics, 2015). This is consistent with K10 mean scores for young people with SMI reported elsewhere (e.g., Rickwood et al., 2015).

Table 2 shows characteristics for established measures of social inclusion, social activity/participation, loneliness, and QoL. The mean SIS score was 44.71 ($SD = 10.24$), which is lower than university students in the U.K. ($M = 60.27, SD = 7.92$ [C. Wilson, personal communication, August 6, 2018]), and comparable with data from a first-episode psychosis sample (Gardner et al., 2019). Over the past week, on average, participants spent 5.99 hr working ($Mdn = 0, SD = 11.09, range = 0–55$), 3.50 hr attending classes/studying ($Mdn = 0, SD = 7.92, range = 0–40$), and 13.37 hr on other social/leisure activities ($Mdn = 10, SD = 14.49, range = 0–80$). The mean UCLA loneliness scale score ($M = 52.48, SD = 12.94$) was elevated compared with normative data for young adults (Knight, Chisholm, Marsh, & Godfrey, 1988) and similar to other data from young people with SMI (Liebke et al., 2017). The various AQoL-8D utility scores were comparable with data from psychiatric samples (Richardson et al., 2014) and lower than normative data estimates (Maxwell et al., 2016).

Underlying Dimensions and Internal Consistency

A CATPCA was run on $N = 159$ responses to 128 mixed-measurement variables from the F-SIM. All variables were transformed into quantitative data via optimal scaling. A rank-order correlation matrix revealed the presence of correlations $\geq .30$. A sample size of 150 has been suggested as sufficient for PCA (Tabachnik & Fidell, 2012). Based on review of the scree plot, the final solution assumed three dimensions explaining 28% of total variance (Dimension 1 = 15.64%, Dimension 2 = 7.21%, Dimension 3 = 5.43%). Other solutions were trialed (1–7 dimensions) but none were as parsimonious as the three-dimension solution.

Table 3

Rotated Component Loadings for n = 72 F-SIM Items That Loaded $\geq .32$ on the Three Dimensions (Interpersonal Connections, Vocational and Financial Security, and Healthy Independent Lifestyle) Among Young People Aged 18–25 With Serious Mental Illness (N = 159)

Abbreviated item	Rotated component loadings		
	Interpersonal connections	Vocational and financial security	Healthy independent lifestyle
How satisfied are you with your social life?	.80	.19	.14
How satisfied are you with the social activities that you take part in?	.73	.15	.20
I don't have a group of friends to call on to do anything with socially ^a	.70	.07	.16
How often do you catch up with a friend for dinner or a movie or some other social activity?	.67	.26	.11
Do you have friends who would call on you in a crisis?	.65	.17	-.04
Do you have good friends who you see or speak to regularly?	.64	.08	.06
Do you have friends who would call on you to discuss their everyday experiences?	.64	.08	-.00
Do you have good friends who you can count on to talk through stuff and be there for you in a crisis?	.63	.13	.04
Do you have friends with whom you share common interests and values?	.62	.20	.01
I feel excluded or not part of the group when taking part in new activities or joining new groups ^a	.61	-.02	.34
I haven't participated in any social or community activities for a long time, I don't know where to start ^a	.61	.05	.03
I often feel unwelcome, like I don't belong ^a	.59	.01	.40
How often do you connect with someone via SMS text message or social media?	.58	-.01	-.25
I don't have very good self-confidence or self-esteem (I'm shy, find it hard to meet people etc.) ^a	.56	.00	.24
I don't enjoy social activities due to fear, anxiety, not having the right people to share them with ^a	.55	.02	.25
I've had so many bad things happen to me, why should I expect that anything would improve? ^a	.54	.08	.41
How often do you talk to a family member or friend on the telephone?	.54	-.20	-.15
I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things ^a	.53	-.01	.33
I don't know what I need to do to improve my circumstances ^a	.51	-.03	.38
Do you have someone (family/friends) you can chat to about daily activities, feelings, or events?	.45	-.02	.05
Do you drop in to a neighbor's house or chat with them (at least weekly)?	.43	-.13	.07
How often do you share everyday activities with others such as watching television together?	.43	-.15	-.22
Do you feel that you have a best friend with whom you share your thoughts and feelings?	.41	.17	.01
I feel like I am bullied by others ^a	.41	.04	.33
How often do you have a meal with someone else?	.41	-.05	.17
Do you feel that your emotional health interferes in your ability to achieve all you would like in your life? ^a	.39	-.08	.25
Would you be able to raise money from sources other than your family or friends in case of an emergency?	.34	.22	.03
Do you find that you don't venture out much because of fear of crime or personal attack in your neighborhood? ^a	.33	.06	.16
There aren't any social activities that I know of that I'm interested in taking part in ^a	.33	.07	.02
How often would you currently take part in physical exercise?	.33	.00	-.06
I belong to a number of minority groups ^a	.32	.06	.15
Do you feel that your emotional health interferes in your ability to access services that would help to improve your life or circumstances (e.g. health services, public transport, Internet)? ^a	.32	.03	.26
Are you currently unemployed with no activity? ^a	.04	.80	-.06
Are you currently working for pay?	.03	.77	-.08
How many of the past 12 months did you work or study for?	.01	.72	-.01
Over the past 12 months did you work or study at any time?	.06	.59	.09
Have you been enrolled in any formal studies in the past 12 months?	-.00	.52	.07
Are you currently studying at a formal institution, leading to a qualification (i.e., TAFE or University)?	.07	.51	.06
Of the household members over the age of 18, are all currently employed or attending formal education?	-.04	.48	.09
Are public transport services in your local neighborhood or community easy to access?	.12	.45	.45
Do you receive enough income to cover your basic everyday costs?	.07	.45	.33
Is your income so low that you suffer from financial strain? ^a	.13	.44	.33
Are retail services in your local neighborhood or community easy to access?	.06	.43	.42
Has not having skills/qualifications required for employment limited you in your current employment situation? ^a	.23	.43	.08
Are you currently working in a voluntary capacity?	.09	.42	-.11
Do you currently live with other residents?	.03	.40	.39
Did you complete the highest year of secondary school education?	.19	.39	.24
Have poor employment opportunities (e.g. lack of suitable roles) limited you in your current employment situation? ^a	.16	.38	.37

(table continues)

Table 3 (continued)

Abbreviated item	Rotated component loadings		
	Interpersonal connections	Vocational and financial security	Healthy independent lifestyle
What is the highest year of primary or secondary schooling that you have completed?	.19	.37	.24
Do you work/study under good conditions (e.g., appropriate pay, leave entitlements, without bullying/harassment)?	.16	.36	.20
Do you feel that you earn considerably less or suffer more financial strain than others in your community? ^a	.29	.36	.15
I have not completed any additional qualifications since leaving primary or secondary school ^a	.10	.33	-.09
I have completed a degree since leaving primary or secondary school	-.03	.33	.10
Do you currently live with your parents?	-.03	-.04	-.69
Are local health services in your local neighborhood or community of a good standard?	.05	-.13	.56
I don't have the time to do what I think I should do. I have other things I have to do. I need more time in the day. ^a	.22	-.03	.54
Is your accommodation unstable (e.g. Are you worried about eviction or losing accommodation in the near future?) ^a	.16	.12	.48
How many alcoholic beverages (e.g., glass/cup, small bottle, or can) do you drink per week?	-.05	-.14	-.47
Are you living in a location other than where you would like (e.g. away from friends/family)? ^a	.17	.19	.47
Do you currently use illegal substances? ^a	.10	.13	.46
Are public transport services in your local neighborhood or community of a good standard?	.14	.19	.45
Are general community services in your local neighborhood or community easy to access?	.12	.28	.45
How much money per week (in dollars) do you personally spend on rent or mortgage payments?	-.18	.21	-.43
Do you currently live with siblings?	-.09	-.08	-.41
How many meals a week do you buy fast food or takeaway food on average (Including breakfast, lunch and dinner)?	.04	-.11	-.39
Do you find your neighborhood lacking in some way? (e.g. Is your neighborhood disadvantaged?) ^a	.01	-.00	.37
Are retail services in your local neighborhood or community of a good standard?	.05	.03	.35
Do you have an illness that has previously impaired your ability to obtain skills or qualifications necessary for employment (e.g. not being able to concentrate properly or having to have time off studying or withdraw from courses due to illness)? ^a	.11	.04	.35
How many times per week do you eat a homemade balanced meal (i.e., including vegetables and meat or other protein) for your main meal of the day?	.11	-.02	.34
Do you currently consume tobacco (e.g., smoke cigarettes, chew tobacco)? ^a	-.05	.24	.34
Do you currently live with a flatmate?	-.04	-.27	.34
Is your housing lacking in any way that makes it difficult to live in (e.g. No heating, not enough rooms for the number of people living there)? ^a	.30	.14	.33

Note. Bold text highlights component loadings $\geq .32$, which was the criterion used to determine whether items would be retained in a given dimension. For the sake of brevity, item wording has been abbreviated. Loadings are based on an orthogonal rotation via Varimax with Kaiser Normalization.

^a Denotes items where a negative response (e.g., No, or, Not at all) to a categorical item corresponds to a positive component loading.

To assist interpretation, the solution was rotated. Oblique rotation using direct oblimin revealed low correlations (ranging from $r = .11$ to $r = .18$) between the three dimensions. Orthogonal rotation using the varimax method was therefore employed. Table 3 shows component loadings for $n = 72$ items that loaded $\geq .32$. Cronbach's alpha was .94 for Dimension 1, .87 for Dimension 2, and .82 for Dimension 3. Dimension 3 shared $n = 6$ items with Dimension 1, and $n = 6$ items with Dimension 2.

Test-Retest Reliability

On average participants ($n = 46$) completed the T2 survey 17.80 days after T1 ($SD = 7.18$, $Mdn = 15$, range = 14–52). Table 4 shows ICC_{3,2} coefficients along with 95% confidence intervals and corresponding F test value for each F-SIM item that loaded $\geq .32$. The ICC_{3,2} for $n = 72$ items ranged from .20 to .99, and $n = 61$ of those items (82.43%) had an ICC_{3,2} $\geq .70$.

Construct Validity

Table 5 shows r_s correlations between F-SIM dimension scores and other variables. Dimension 1 scores had a moderate positive

correlation with the pain subscale of the AQoL-8D ($r_s = .26$, $p < .01$). They had moderate-to-strong positive correlations with number of hours spent on social/leisure activities last week ($r_s = .32$, $p < .01$) and the AQoL-8D subscale scores for senses ($r_s = .33$, $p < .01$), mental health ($r_s = .43$, $p < .01$), and independent living ($r_s = .44$, $p < .01$). They had strong positive correlations with AQoL-8D self-worth ($r_s = .57$, $p < .01$), happiness ($r_s = .60$, $p < .01$), coping ($r_s = .61$, $p < .01$), relationships ($r_s = .68$, $p < .01$), and AQoL-8D total ($r_s = .63$, $p < .01$) scores. Dimension 1 scores were also strongly and positively correlated with SIS total ($r_s = .69$, $p < .01$), social relations ($r_s = .58$, $p < .01$), and social acceptance ($r_s = .59$, $p < .01$) scales. They had a moderate-to-strong negative correlation with K10 score ($r_s = -.42$, $p < .01$), and strong negative correlations with SIS social isolation subscale ($r_s = -.76$, $p < .01$) and UCLA Loneliness scale ($r_s = -.76$, $p < .01$) scores.

Dimension 2 scores had weak-to-moderate positive correlations with SIS social relations ($r_s = .22$, $p < .01$) and social acceptance ($r_s = .20$, $p < .05$) subscale scores. They had a moderate positive correlation with SIS total score ($r_s = .27$, $p < .01$), and strong positive correlations with number of hours per week studying/

Table 4

Test-Retest Reliability Over Two Weeks of 72 Items on the F-SIM for n = 46 Young People Aged 18–25 With Serious Mental Illness

Abbreviated item	ICC _{3,2}	95% CI for ICC	F(45, 45) Test value
How satisfied are you with your social life?	.83	[.70, .91]	6.06***
How satisfied are you with the social activities that you take part in?	.77	[.59, .87]	4.52***
I don't have a group of friends to call on to do anything with socially	.79	[.62, .88]	4.64***
How often do you catch up with a friend for dinner or a movie or some other social activity?	.79	[.62, .88]	4.65***
Do you have friends who would call on you in a crisis?	.89	[.80, .94]	8.93***
Do you have good friends who you see or speak to regularly?	.80	[.63, .89]	4.96***
Do you have very good self-confidence or self-esteem (I'm shy, find it hard to meet people etc.)	.78	[.60, .88]	4.56***
Do you have good friends who you can count on to talk through stuff and be there for you in a crisis?	.79	[.61, .88]	4.63***
Do you have friends with whom you share common interests and values?	.73	[.52, .85]	3.83***
I feel excluded or not part of the group when taking part in new activities or joining new groups	.68	[.41, .82]	3.05***
I haven't participated in any social or community activities for a long time, I don't know where to start	.58	[.25, .77]	2.41**
I often feel unwelcome, like I don't belong	.80	[.64, .89]	4.95***
How often do you connect with someone via SMS text message or social media?	.87	[.76, .93]	7.59***
I don't have very good self-confidence or self-esteem (I'm shy, find it hard to meet people etc.)	.81	[.65, .90]	5.16***
I don't enjoy social activities due to fear, anxiety, not having the right people to share them with	.71	[.48, .84]	3.42***
I've had so many bad things happen to me, why should I expect that anything would improve?	.75	[.55, .86]	3.97***
How often do you talk to a family member or friend on the telephone?	.89	[.79, .94]	9.21***
I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things	.76	[.57, .87]	4.17***
I don't know what I need to do to improve my circumstances	.73	[.51, .85]	3.73***
Do you have someone (family/friends) you can chat to about daily activities, feelings, or events?	.79	[.61, .88]	4.58***
Do you drop in to a neighbor's house or chat with them (at least weekly)?	.66	[.38, .81]	2.89***
How often do you share everyday activities with others such as watching television together?	.89	[.81, .94]	9.24***
Do you feel that you have a best friend with whom you share your thoughts and feelings?	.79	[.63, .89]	4.92***
I feel like I am bullied by others	.75	[.55, .86]	4.00***
How often do you have a meal with someone else?	.66	[.38, .81]	2.91***
Do you feel that your emotional health interferes in your ability to achieve all you would like in your life?	.20	[−.46, .56]	1.24
Would you be able to raise money from sources other than your family or friends in case of an emergency?	.76	[.56, .87]	4.05***
Do you find that you don't venture out much because of fear of crime or personal attack in your neighborhood?	.89	[.80, .94]	8.93***
There aren't any social activities that I know of that I'm interested in taking part in	.67	[.33, .83]	3.69***
How often would you currently take part in physical exercise?	.88	[.78, .93]	8.01***
I belong to a number of minority groups	.80	[.62, .89]	5.53***
Do you feel that your emotional health interferes in your ability to access services that would help to improve your life or circumstances (e.g. health services, public transport, Internet)?	.45	[.01, .70]	1.83*
Are you currently unemployed with no activity?	.91	[.83, .95]	10.30***
Are you currently working for pay?	.92	[.85, .96]	12.20***
How many of the past 12 months did you work or study for?	.91	[.83, .95]	10.56***
Over the past 12 months did you work or study at any time?	.87	[.76, .93]	7.88***
Have you been enrolled in any formal studies in the past 12 months?	.93	[.87, .96]	14.71***
Are you currently studying at a formal institution, leading to a qualification (i.e., TAFE or University)?	.90	[.83, .95]	10.48***
Of the household members over the age of 18, are all currently employed or attending formal education?	.78	[.61, .88]	4.58***
Are public transport services in your local neighborhood or community easy to access?	.72	[.50, .85]	3.60***
Do you receive enough income to cover your basic everyday costs?	.82	[.67, .90]	5.44***
Is your income so low that you suffer from financial strain?	.73	[.51, .85]	3.87***
Are retail services in your local neighborhood or community easy to access?	.42	[.05, .68]	1.72*
Has not having skills/qualifications required for employment limited you in your current employment situation?	.85	[.73, .92]	6.68***
Are you currently working in a voluntary capacity?	.78	[.61, .88]	4.71***
Do you currently live with other residents?	.65	[.37, .81]	2.83***
Did you complete the highest year of secondary school education?	.97	[.95, .98]	34.24***
Have poor employment opportunities (e.g. lack of suitable roles) limited you in your current employment situation?	.86	[.74, .92]	6.87***
What is the highest year of primary or secondary schooling that you have completed?	.99	[.98, .99]	93.28***
Do you work/study under good conditions (e.g., appropriate pay, leave entitlements, without bullying/harassment)?	.78	[.57, .88]	4.65***
Do you feel that you earn considerably less or suffer more financial strain than others in your community?	.76	[.56, .87]	4.25***

(table continues)

Table 4 (continued)

Abbreviated item	ICC _{3,2}	95% CI for ICC	F(45, 45) Test value
I have not completed any additional qualifications since leaving primary or secondary school	.93	[.88, .96]	14.37***
I have completed a degree since leaving primary or secondary school	.95	[.90, .97]	18.78***
Do you currently live with your parents?	.96	[.92, .98]	22.96***
Are local health services in your local neighborhood or community of a good standard?	.68	[.41, .82]	3.05***
I don't have the time to do what I think I should do. I have other things I have to do. I need more time in the day.	.61	[.29, .78]	2.52***
Is your accommodation unstable (e.g. Are you worried about eviction or losing accommodation in the near future?)	.75	[.55, .86]	4.05***
How many alcoholic beverages (e.g., glass/cup, small bottle, or can) do you drink per week?	.92	[.85, .96]	12.00***
Are you living in a location other than where you would like (e.g. away from friends/family)?	.82	[.68, .90]	5.57***
Do you currently use illegal substances?	.94	[.89, .97]	16.46***
Are public transport services in your local neighborhood or community of a good standard?	.70	[.45, .83]	3.24***
Are general community services in your local neighborhood or community easy to access?	.40	[.09, .67]	1.66*
How much money per week (in dollars) do you personally spend on rent or mortgage payments?	.90	[.81, .95]	10.42***
Do you currently live with siblings?	.89	[.81, .94]	9.11***
How many meals a week do you buy fast food or takeaway food on average (Including breakfast, lunch and dinner)?	.82	[.67, .90]	5.53***
Do you find your neighborhood lacking in some way? (e.g. Is your neighborhood disadvantaged?)	.75	[.55, .86]	4.04***
Are retail services in your local neighborhood or community of a good standard?	.70	[.45, .83]	3.27***
Do you have an illness that has previously impaired your ability to obtain skills or qualifications necessary for employment (e.g. not being able to concentrate properly or having to have time off studying or withdraw from courses due to illness)?	.72	[.48, .84]	3.47***
How many times per week do you eat a homemade balanced meal (i.e., including vegetables and meat or other protein) for your main meal of the day?	.56	[.19, .76]	2.26**
Do you currently consume tobacco (e.g., smoke cigarettes, chew tobacco)?	.95	[.91, .98]	20.77***
Do you currently live with a flatmate?	.76	[.57, .87]	4.19***
Is your housing lacking in any way that makes it difficult to live in (e.g. No heating, not enough rooms for the number of people living there)?	.88	[.79, .94]	8.51***

Note. Wording of items is abbreviated for the sake of brevity. ICC (3,2) = Intraclass Coefficient model 3 and type 2. Method of ICC was *absolute agreement*. 95% CI = 95% confidence interval for ICC (3,2).

* $p < .05$. ** $p < .01$. *** $p < .001$.

attending classes ($r_s = .47, p < .01$) and number of hours working last week ($r_s = .67, p < .01$). Dimension 2 scores had a weak-to-moderate negative correlation with SIS social isolation scale scores ($r_s = -.23, p < .01$). There was also a weaker but significant positive correlation with number of hours spent on social/leisure activities last week ($r_s = .18, p < .05$).

Dimension 3 scores had weak-to-moderate positive correlations with SIS social acceptance subscale ($r_s = .20, p < .05$) and SIS total scale ($r_s = .25, p < .01$) scores, as well as AQoL-8D happiness subscale scores ($r_s = .22, p < .01$). They had moderate positive correlations with the AQoL-8D senses ($r_s = .26, p < .01$) and pain ($r_s = .27, p < .01$) subscale scores. Dimension 3 scores had moderate-to-strong positive correlations with the AQoL-8D total score ($r_s = .40, p < .01$) and subscale scores of mental health ($r_s = .33, p < .01$), coping ($r_s = .33, p < .01$), relationships ($r_s = .33, p < .01$), self-worth ($r_s = .34, p < .01$), and independent living ($r_s = .36, p < .01$). There was a weaker but significant correlation with SIS social relations subscale scores ($r_s = .19, p < .05$). Dimension 3 scores had a moderate negative correlation with UCLA Loneliness Scale scores ($r_s = -.26, p < .01$) and a moderate-to-strong negative correlation with K10 score ($r_s = -.33, p < .01$).

Acceptability and Face Validity

The average self-reported completion time of the F-SIM was 20.29 min ($SD = 10.22$). In response to the question *Do you think*

the F-SIM took too long to complete? $n = 102$ (64.2%) participants selected *No*, $n = 39$ (24.5%) selected *Maybe a little*, and $n = 18$ (11.3%) selected *Yes*. In response to the question *How well do you think that the F-SIM actually measures social inclusion?* $n = 70$ (44%) said *Very Well*, $n = 84$ (52.8%) selected *Somewhat*, $n = 4$ (2.5%) selected *Not very well*, and $n = 1$ (0.6%) selected *Doesn't seem to measure social inclusion at all*. In response to the question *Did you find the F-SIM difficult to complete in any way?* $n = 133$ (83.6%) selected *No* and $n = 26$ (16.4%) selected *Yes*. Reasons offered by those who specified what they found difficult involved the wording of questions being difficult to understand, $n = 13$ (8.2%), and perceived sensitivity of information being requested, $n = 13$ (8.2%).

Discussion

The aim of this study was to psychometrically test a novel measure of social inclusion (the F-SIM) among young adults aged 18–25 with SMI. The key finding is that social inclusion is a multidimensional construct in this population. We found three dimensions: (a) *Interpersonal Connections*; (b) *Vocational and Financial Security*; and (c) *Healthy Independent Lifestyle*. These dimensions overlap considerably with the treatment goals of young adults with SMI (Cotton et al., 2011; Iyer et al., 2011; Ramsay et al., 2011).

Items loading on *Interpersonal Connections* involved social relationships and activities with friends/family, or factors that may

Table 5
Spearman's Rho (R_s) Correlations Among Scores on Three Dimensions of the Filia Social Inclusion Measure (F-SIM) and Established Measures of Related Constructs (Social Activity/Participation, Loneliness, QoL, Social Inclusion, and Psychological Distress) for N = 159 Young People Aged 18–25 With Serious Mental Illness

Measure	IC scores	VFS scores	HIL scores	K10 scores	SIS total	SIS Social Isolation	SIS Social Relations	SIS Social Acceptance	Hours worked last week	Hours studied last week	Hours social/leisure activities last week	UCLA	Independent Living AQoL8D	Happiness AQoL8D	Mental Health AQoL8D	Coping AQoL8D	Relationships AQoL8D	Self Worth AQoL8D	Pain AQoL8D	Senses AQoL8D	AQoL8D total
IC scores	1	.01	.05	-.42**	.69**	-.76**	.58**	.59**	.07	.07	.32**	-.76**	.44**	.60**	.43**	.61**	.68**	.57**	.26**	.33**	.63**
VFS scores		1	-.01	.01	.27**	-.23**	.22**	.20*	.67**	.47**	.18*	-.14	.08	.08	-.05	.03	.07	.05	.01	.04	.02
HIL scores			1	-.33**	.25**	-.13	.19*	.20*	-.08	.02	-.01	-.26**	.36**	.22**	.33**	.33**	.33**	.34**	.27**	.26**	.40**
K10				1	-.52**	.47**	-.42**	-.43**	-.02	-.11	-.13	.53**	-.55**	-.67**	-.88**	-.74**	-.61**	-.79**	-.44**	-.39**	-.84**
SIS total					1	-.88**	.86**	.83**	.22**	.28**	.39**	-.77**	.54**	.64**	.47**	.66**	.72**	.60**	.22**	.37**	.67**
SIS Social Isolation						1	-.65**	-.75**	-.22**	-.23**	-.43**	.83**	-.42**	-.60**	-.42**	-.58**	-.76**	-.56**	-.26**	-.32**	-.64**
SIS Social Relations							1	.55**	.20*	.23**	.28**	-.60**	.49**	.63**	.42**	.64**	.53**	.53**	.14	.27**	.58**
SIS Social Acceptance								1	.09	.19*	.40**	-.66**	.41**	.48**	.35**	.47**	.66**	.45**	.17**	.35**	.53**
Hours worked last week									1	.23**	.13	-.09	.17*	.09	.01	.13	.05	.08	-.01	.05	.08
Hours studied last week										1	.22**	-.23**	.12	.24**	.09	.15	.18*	.014	.10	.11	.17*
Hours social/leisure activities last week											1	-.38**	.20*	.18*	.03	.13	.38**	.15	.07	.18*	.20*
UCLA												1	-.45**	-.67**	-.52**	-.66**	-.87**	-.65**	-.30**	-.36**	-.73**
Independent Living AQoL8D													1	.47**	.50**	.59**	.51**	.53**	.46**	.49**	.69**
Happiness AQoL8D														1	.74**	.82**	.68**	.78**	.29**	.39**	.84**
Mental Health AQoL8D															1	.78**	.59**	.80**	.48**	.38**	.89**
Coping AQoL8D																1	.64**	.80**	.37**	.39**	.88**
Relationships AQoL8D																	1	.68**	.38**	.44**	.81**
Self Worth AQoL8D																		1	.30**	.36**	.86**
Pain AQoL8D																			1	.38**	.56**
Senses AQoL8D																				1	.56**
AQoL8D total																					1

Note. IC = Interpersonal Connections dimension of F-SIM; VFS = Vocational & Financial Security dimension of F-SIM; HIL = Healthy Independent Lifestyle dimension of F-SIM; K10 = Kessler-10 Psychological Distress Scale Score; SIS = Social Inclusion Scale Score; UCLA = UCLA Loneliness Scale Score; AQoL-8D = Australian Quality of Life Instrument, 8 Dimension Version. ** $p < .05$. *** $p < .01$.

impact such connections. This highlights the need to focus on the underresearched area of loneliness (i.e., dissatisfaction with interpersonal connections) among young people with SMI (Lim, Gleeson, Alvarez-Jimenez, & Penn, 2018). Items loading on *Vocational and Financial Security* reflected level of involvement in employment and/or education, financial status, and factors related to these variables. This highlights the primacy of vocational (i.e., employment and/or education) recovery for young people with SMI (Álvarez-Jiménez et al., 2012). It also supports the ongoing implementation of evidence-based vocational interventions such as Individual Placement and Support (Killackey et al., 2017). Items loading on *Healthy Independent Lifestyle* tended to involve burgeoning adult independence across housing (e.g., neighborhood, living situation) and lifestyle (e.g., diet, alcohol and other drug consumption) domains. This supports an increasing focus on neighborhood factors (O'Donoghue, Roche, & Lane, 2016) and improving physical health (Gates et al., 2015) among young people with SMI.

There were a small number of cross-loading items, which is perhaps to be expected given complex social characteristics are rarely homogenous (Portney & Watkins, 2009). There were a relatively large number of items ($n = 72$) remaining after data reduction, compared with Huxley and colleagues' (2012) measure of social inclusion among older adults. This may be due to differences between populations: social inclusion may be a more complex phenomenon for young adults with SMI, requiring more variables to explain it. Consistent with various theoretical viewpoints (Morgan et al., 2007), there was a combination of objective and subjective indicators across all three dimensions.

Internal consistency within each dimension was good-to-excellent (Bernstein & Nunnally, 1994) and comparable with other measures of social inclusion (Huxley et al., 2012; Wilson & Secker, 2015). Stability of measurement over two weeks was good (Cicchetti, 1994). Although other studies tend to employ r or κ coefficients, these test-retest results appear comparable with those reported elsewhere (Huxley et al., 2012; Wilson & Secker, 2015).

There was evidence of construct validity for all three dimensions. *Interpersonal Connections* scores converged (i.e., were positively associated) with an established measure of social inclusion, a measure of QoL, and hours spent on social/leisure activities last week. They diverged from (i.e., were negatively associated with) measures of social isolation, loneliness, and psychological distress. *Vocational and Financial Security* scores converged with an established measure of social inclusion, hours spent attending classes/studying last week, and hours spent working last week. They diverged from the social isolation subscale of an established social inclusion measure. *Healthy Independent Lifestyle* scores converged with a measure of QoL, and the social relations and social acceptance subscales of an established social inclusion measure. They diverged from measures of loneliness and psychological distress.

In terms of acceptability/face validity, only a small number of participants thought the F-SIM did not measure social inclusion very well, or was difficult to complete. Almost one third of participants thought the 128 items of the F-SIM took too long to complete, which is perhaps to be expected at this stage of measurement development. The present study produced a 72-item version upon which further item-reduction may be based. A component-loading criterion of .45 would produce a 38-item ver-

sion while retaining enough variables to preserve the dimensional structure reported here. This may be a useful rationale for subsequent confirmatory analyses. Overall, the present findings suggest that the F-SIM will require further refinement but is broadly acceptable to young adults with SMI.

This is the first study we are aware of to psychometrically test a measure of social inclusion specifically among young adults aged 18 to 25 with SMI. Other strengths include the large sample size ($N = 159$), which provided adequate power to detect relationships among variables, and the use of statistical methods that can model mixed-measurement relationships. Limitations include the large number of items remaining after data reduction. Further data reduction will be required before practical applications in busy clinical settings are feasible. The relatively high attrition rate from T1 to T2 is another limitation. However, stability of measurement was good and demographic comparisons suggested that T2 participants were representative of the overall sample. The self-report of SMI is a limitation, although young adults must be experiencing a mental illness that significantly impacts their daily functioning to be eligible for treatment at the recruitment sites. The results of this exploratory study are preliminary; subsequent confirmatory studies are required to verify these findings.

Social inclusion is an emergent construct that has been increasingly linked to improved health and wellbeing, leading some to conclude it should be a public health priority. Young adults with SMI are widely thought to be socially excluded, and there is some evidence to support this, suggesting this population should be a target for any policy development. Yet no direct measures of social inclusion have been developed specifically for this population. Hence, there is an absence of the tools required for assessment and evaluation. This study offers the F-SIM as a novel measure of social inclusion for young adults aged 18–25 with SMI. We identified three dimensions underlying the F-SIM in this population (*Interpersonal Connections*, *Vocational and Financial Security*, and *Healthy Independent Lifestyle*). The internal consistency of all three dimensions was good-to-excellent, and the test-retest reliability of items on these dimensions was good. Construct validity for each dimension was good, and the measure was generally acceptable to participants. Future research may extend these findings by using the F-SIM to examine group differences between young adults with SMI and those from the general community. This will enable a more comprehensive understanding of the apparent social exclusion experienced by young adults with SMI. It will also establish normative and clinical data, which will provide useful reference points for future research and clinical practice involving young adults with SMI.

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CHAPTER FIVE: MEASURING SOCIAL INCLUSION AMONG YOUNG ADULTS WITH SERIOUS MENTAL ILLNESS

Overview of Results

The paper presented in this chapter explored preliminary psychometric properties of a novel measure of social inclusion (the F-SIM) among young adults aged 18–25 years with SMI. This included an examination of the F-SIM's dimensional structure, internal consistency of its dimensions, test-retest reliability of its items over two weeks, its convergent validity with respect to measures of theoretically related constructs, and its user acceptability/face validity.

Three dimensions of the F-SIM were observed (*Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*), suggesting that these are important aspects of social inclusion for young adults aged 18–25 years with SMI. The scree plot used to identify the three dimensions was omitted from the published paper, but is included in Appendix 5. Internal consistency of these dimensions was excellent, and test-retest reliability of F-SIM items was good. Each dimension exhibited convergent validity with measures of social inclusion, social functioning, QoL, psychological distress, and loneliness. The F-SIM was broadly acceptable and had face validity with participants. The relevant theoretical and clinical implications of these findings will be addressed in Chapter 8: Discussion.

Having now reported preliminary psychometric properties of the F-SIM in the primary population of interest, the following chapter will examine the psychometric properties of the F-SIM in a sample of young adults from the general community. This will allow for the detection of any similarities and/or differences between groups in terms of relevant dimensions and indicators of social inclusion. It will also generate community data to permit comparisons between groups in the third and final study.

CHAPTER SIX: MEASURING SOCIAL INCLUSION AMONG YOUNG ADULTS IN THE GENERAL COMMUNITY

Preamble

In the previous chapter, preliminary psychometric properties of the F-SIM were reported in a sample of young adults with SMI. In that population, social inclusion entailed dimensions of *Interpersonal Connection*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*. However, social inclusion is also not well understood among young adults from the general community: psychometric properties and dimensions of social inclusion measures have not been established in this population either. The paper presented in this chapter is the first to examine the psychometric properties of the F-SIM specifically among young adults aged 18 to 25 years from the general community. This enables inferences to be made about normative dimensions and indicators of social inclusion for young adults. It also facilitates a comparative discussion of findings from this community sample to those from the previous study, which sampled young adults with SMI. This will help elucidate any conceptual similarities and/or differences in dimensions of social inclusion between populations. The paper was submitted for peer review to the *Applied Research in Quality of Life* journal in February 2020.

This chapter concludes with a brief overview of results from the study.

**Preliminary Psychometric Properties of a Measure of Social Inclusion among
Young Adults Aged 18 to 25 in the General Community**

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Abstract

Aims: Social inclusion is primarily conceptualised in terms of putatively excluded groups, e.g., people with serious mental illness (SMI). It is less well understood in the general population. Young adulthood is a developmental stage with significant implications for social inclusion trajectories, yet measures of social inclusion have not been developed for this cohort. The aim of this study was to explore the psychometric properties of a preliminary version of the Filia Social Inclusion Measure (F-SIM) among young adults from the general community.

Methods: A categorical principal components analysis of the F-SIM among $N=152$ people aged 18–25 years from the general community was conducted. Internal consistency was assessed via Cronbach's α . To assess convergent validity, we examined Spearman's rho correlation coefficients (r_s) between F-SIM dimension scores and measures of social inclusion, social functioning, quality of life (QoL), loneliness and psychological distress, and two-week test-retest reliability via Intraclass Correlation Coefficients (ICC_{3,2}).

Results: Cronbach's α was .92 for Dimension 1 (*Interpersonal Connections*) and .87 for Dimension 2 (*Community Integration*). Item-level ICC_{3,2} coefficients ranged from .30–.93. *Interpersonal Connections* scores converged with measures of social inclusion ($r_s=.52, p<.001$), QoL ($r_s=.55, p<.001$), social/leisure participation ($r_s=.26, p=.001$), loneliness ($r_s=-.59, p<.001$) and psychological distress ($r_s=-.38, p<.001$). *Community Integration* scores converged with measures of social inclusion ($r_s=.27, p=.001$), QoL ($r_s=.18, p=.03$), vocational participation ($r_s=.33, p<.001$), loneliness ($r_s=-.31, p<.001$) and psychological distress ($r_s=-.24, p=.003$), but were weak-to-moderate associations.

Conclusions: A preliminary version of the F-SIM demonstrated reliability and validity among young adults in the community. Further development is required.

Keywords: *Social inclusion, social exclusion, measure, psychometric, young adults, mental health*

Social inclusion is an important contributor to positive health outcomes – particularly among marginalised groups, such as people with serious mental illness (SMI [Filia et al., 2019a]). Opportunities for participation in valued social roles, and subjective satisfaction with those opportunities, are integral to social inclusion (Huxley et al., 2012). Key domains are thought to include housing/neighbourhood factors, relationships/social activities, employment/education, finances, and health/wellbeing (Filia et al., 2018; Huxley et al., 2012). Social exclusion is typically considered the dimensional opposite of social inclusion (Baumgartner & Burns, 2014). In this paper, the latter term will be primarily used.

Social inclusion is a complex phenomenon that overlaps with a number of other constructs. Social functioning similarly involves participation in societally defined age-appropriate roles (Mueser & Tarrier, 1998). Unlike social inclusion, it does not necessarily involve subjective satisfaction with such roles. Social inclusion likely contributes to quality of life (QoL [Huxley et al., 2012]), which is a global construct involving independence, health, personal beliefs, relationships to other people, and relationships to the environment (The WHOQoL Group, 1995). Social exclusion theoretically involves loneliness, which is an aversive psycho-emotional state experienced when an individual's perceived level of social connection is less than their desired level of social connection (Russell, 1980). Psychological distress involves poor mental health characterised by symptoms of depression and anxiety (Kessler, Andrews & Colpe, 2002). Social exclusion and psychological distress are theoretically (e.g., Baumeister & Leary, 1995) and empirically (e.g., Holt-Lunstad et al., 2017) related. Although there is no uniform approach to assessing construct

validity in the social inclusion literature, measures of some combination of these constructs are typically included (Cordier et al., 2017).

The terms social inclusion/exclusion emerged in the 1970s in France to describe the social status of people from a range of marginalised groups, e.g., those with physical, psychiatric, and intellectual disabilities (Lenoir, 1974). Since then, these constructs have been continuously operationalised in terms of identifying those who are socially excluded, and seeking ways to promote their inclusion (Rawal, 2008). They have not typically been examined in the general population, and so normative experiences of social inclusion are not well understood. This makes it difficult to compare the social inclusion of general community members to that of marginalised groups, and thus to accurately describe the putative social exclusion of the latter relative to the former. Not only is there a need to establish normative social inclusion data, there is also a need to clearly describe target populations (Cordier et al., 2017).

Young adulthood (i.e., the period between late teens and mid-twenties) is a sensitive period wherein people cultivate social roles they hope to inhabit throughout adulthood (Benson & Elder, 2011). Given the implications of this process for social inclusion trajectories, young adults may constitute an appropriate target population within which to establish normative data. A systematic review of social inclusion measures in any population found that no instruments have undergone sufficient psychometric development, e.g., more adequate sample sizes and appropriate statistical analyses are needed (Cordier et al., 2017). None of the reviewed instruments specifically targeted young adults, and there does not appear to be any

that do so within the broader literature. The majority of instruments reviewed by Cordier and colleagues focused exclusively on SMI samples, and adopted items from existing measures of related constructs. The Filia Social Inclusion Measure (F-SIM) is a novel instrument based on an initial broad literature search to identify potential items (Filia et al., 2018). A consensus was reached on which specific items and domains to include in the measure, with significant input from people in the general community and with mental illness (Filia et al., 2019a). Preliminary testing revealed observable differences between these groups on F-SIM indicators across all five identified domains (Filia et al., 2019b).

We reported preliminary psychometric properties of the F-SIM among young adults aged 18–25 with SMI (Gardner et al., 2019). Three dimensions emerged (*Interpersonal Connections, Vocational & Financial Security, and Healthy Independent Lifestyle*). The F-SIM demonstrated excellent internal consistency, and good stability of measurement in that population. It demonstrated convergent validity with measures of social inclusion, social functioning, QoL, loneliness, and psychological distress. Results suggested that the measure was acceptable to young adults with SMI. However, the F-SIM remains untested in young adult community samples.

The broad aim of this paper was to explore the psychometric properties of a preliminary version of the F-SIM among young adults aged 18–25 from the general community. This will establish data to help better understand the relevant dimensions and indicators of social inclusion in this population. Findings can then be discussed with reference to those from the comparable previous study in a sample of young

adults with SMI (Gardner et al., 2019). Specific aims pertaining to psychometric properties of the F-SIM within the community sample of this study were to:

- i. Perform data reduction to identify dimensions underlying the measure
- ii. Examine the reliability of components/dimensions (i.e., internal consistency), and items (i.e., stability of measurement)
- iii. Explore convergent validity relative to measures of social inclusion, loneliness, social functioning, QoL, and psychological distress.
- iv. Explore face validity (i.e., the extent to which participants view the F-SIM as adequately assessing social inclusion)

Method

With the exception of setting and sample, the methods reported here replicate those previously described by Gardner et al. (2019) in a sample of young adults aged 18–25 with SMI.

Setting and Sample

Participants were 18-to-25-year-olds living in Melbourne, Australia recruited from various settings (e.g., universities, cafés/bars/restaurants, youth employment and support services, public housing complexes, shopping centres). Convenience-sampling techniques were used and the study was promoted using social media, flyers/posters, and snowballing. Exclusion criteria were lack of fluency in English and SMI. Diagnoses of mental illness were recorded via self-report, a method used in genome-wide studies of depression (Hyde et al., 2016). As this was a general community sample, not so-called ‘healthy controls,’ mental illness did not necessarily

exclude participants. Those reporting a lifetime diagnosis were asked followup questions to determine whether the diagnosis was considered SMI. For example, they were asked whether the illness made it difficult for them to manage everyday tasks by themselves, and whether they had ever accessed psychiatric services.

Measures

The Filia Social Inclusion Measure (F-SIM) is a self-report measure of social inclusion over the past month that was developed with input from people with mental illness and general community members (Filia et al., 2019b). Of 128 total items, two demographic items capture age and sex while the remaining 126 items are grouped into five domains: Housing, Neighbourhood & Services, Relationships, Activities & Setbacks, Employment & Education, Finances, and Health & Wellbeing (including self-reported mental disorder diagnosis). It employs mixed-measurement, including dichotomous (e.g., ‘*Do you have a drivers license?*’ [Yes/No]), ordinal (e.g., *I often feel unwelcome* [Not at all/A little bit/Very much so]), and ratio items (e.g., *What is your weekly income?*). Like other social inclusion measures (Coombs, Reed & Rosen, 2016), frequencies/percentages can be used to examine responses to individual items. This maximises clinical utility by targeting specific areas of social inclusion (Australian Mental Health Outcomes Classification Network, 2016). Four user-experience questions were included at the end of the F-SIM in order to assess acceptability and face validity of the measure. These questions were: (i) *How long in minutes did it take you to complete the questionnaire?* (ii) *Do you think that the questionnaire took too long to complete (Yes/No)?* (iii) *How well do you think this questionnaire actually measures social inclusion (Very well/somewhat/not very well/doesn’t seem to measure social inclusion at all)?* and (iv) *Did you find the*

questionnaire difficult to complete in any way (Yes/No)? Those responding in the affirmative to the last question were given the option to specify difficulties. The below measures were included to examine the convergent validity of the F-SIM.

The Social Inclusion Scale (SIS [Secker et al., 2009]) is a 19-item self-report measure of social inclusion over the past two weeks. Three items are specific to psychiatric populations (e.g., *My social life has been mainly related to mental health services*) and were removed as they were not relevant to this sample. Given the impact this would have on subscale scores (*Social Isolation, Social Relations, and Social Acceptance*), only a total scale score summing all 16 items was computed (range=16–64). A 16-item version of the SIS has been used previously to measure social inclusion among people aged 14–36 years in the community (Berry & Greenwood, 2018). There are no established clinical cut-off scores for the SIS. Higher scores indicate greater social inclusion.

The Activity and Participation Questionnaire (APQ-6 [Stewart et al., 2010]) is a six-question self-report measure of social functioning over the past week (e.g., *How many hours did you work?*). A higher number of hours indicate superior social functioning. The Australian Quality of Life instrument–8 Dimensions (AQoL-8D [Maxwell et al., 2016]) is a 35-item self-report measure of QoL over the past week. The AQoL-8D produces total and subscale (e.g., Pain) utility scores measuring quality-adjusted life years (range=0/death–1/optimal health). The Revised UCLA Loneliness Scale (Russell et al., 1980) is a 20-item self-report measure of loneliness/isolation over the past week. Items are measured on Likert-type scales from 1/*Never* to 4/*Often*, and summed for a total score with a range of 20–80. Higher scores

indicate greater loneliness/isolation. The Kessler-10 Psychological Distress Scale (K10 [Kessler et al., 2002]) is a 10-item self-report measure of psychological distress. Items are measured on Likert-type scales from 1/*None of the time* to 5/*All the time*, and summed to create total scores with a range of 10–50. Higher scores indicate greater distress. Cut-off scores indicate a likely mild (20–24), moderate (25–30), or severe (≥ 30) mental disorder (Australian Bureau of Statistics, 2012).

In terms of convergent validity, it was expected that the F-SIM would share moderate-to-strong associations with SIS, APQ-6, AQoL-8D, UCLA Loneliness Scale, and K10 scores.

Procedure

This exploratory observational study received approval from the Melbourne Health Human Research and Ethics Committee (HREC/16/MH/325), and the Research Review Committee at Orygen. Orygen’s Research Council provided input prior to HREC approval (e.g., suggesting youth-friendly language on participant information forms). They also remained in contact with a study team member for periodic consultations, ensuring that perspectives of young people were considered throughout the study. Data were collected via an online survey platform at two time points (T1 and T2) two weeks apart. Informed consent was implied by submission of survey responses, as explained via the participant information form. Participants were reimbursed with a small retail voucher for their time.

Data Analyses

Analyses were conducted using IBM® SPSS® Statistics Version 25.

Categorical Principal Components Analysis (CATPCA) was employed as the optimal method for examining the internal structure of mixed-measurement instruments (Linting & van der Kooij, 2012). A full description of CATPCA is beyond the scope of this paper, but briefly: the process transforms all mixed-measurement variables via optimal scaling, with the resulting transformed variables being entered into a rank-order correlation matrix (Linting & van der Kooij, 2012). These correlations among transformed variables were examined to ensure suitability of the data for CATPCA, with a criterion of correlations $\geq .30$ among items. In the CATPCA output, the terms, 'component,' and, 'dimension,' are used interchangeably. This convention is followed throughout this paper. A five-component/dimension solution was assumed for the F-SIM (Filia et al., 2019b), but had not been tested through data reduction techniques. The Scree plot helps determine the appropriateness of such assumptions in CATPCA (Linting & van der Kooij, 2012). Orthogonal and oblique methods of component rotation were explored, to assist interpretation of the structure. Only F-SIM items with component/dimension loadings $\geq .32$ were reported (Tabachnik & Fidell, 2012), because this suggests >10% of variance overlapping with other items on the same component/dimension (Costello & Osborne, 2005). Given the complexity of the social inclusion construct and likely interrelationships between e.g., employment and finance indicators, cross-loading items were not necessarily viewed as problematic. Component/dimension scores, based on regression-like coefficients, were computed for each case and used where applicable in subsequent analyses.

Relationships between items within each component/dimension were examined via Cronbach's α to test internal consistency. Cronbach's α was interpreted as follows: $.70 \leq \alpha < .80$ =acceptable, $.80 \leq \alpha < .90$ =good, $.90 \leq \alpha$ =excellent (Portney & Watkins, 2009). The Intraclass Correlation Coefficient (ICC) is the optimal measure of test-retest reliability (Portney & Watkins, 2009). There are three ICC models and two ICC forms. Model 3 and form 2 (ICC_{3,2}) is the most appropriate model for test-retest reliability (Trevethan, 2017). Stability of measurement was assessed via ICC_{3,2} with absolute agreement for F-SIM items over two weeks. As recommended by Cicchetti (1994), an ICC_{3,2} ranging from .60–.74 was considered good and an ICC_{3,2} $\geq .75$ was considered excellent test-retest reliability.

Convergent validity was assessed in terms of how F-SIM component/dimension scores correlated with SIS, APQ-6, AQoL-8D, UCLA Loneliness Scale, and K10 scores. Spearman's rho correlation coefficients (r_s) were calculated between measures, and were interpreted as depicting weak (.10), moderate (.30) or strong ($\geq .50$) relationships (Cohen, 1992). Face validity was explored through frequencies/percentage responses to the afore-mentioned user experience questions.

Results

Between April 2017 and February 2018, 157 participants completed surveys at T1 ($n=119$ completed surveys at T2). Five participants reported a lifetime diagnosis of a mental illness that made it difficult for them to complete everyday tasks unassisted, and for which they had attended psychiatric services. These cases were classified as SMI, and hence removed from the analyses. Table 1 shows sample characteristics of

T1 responders ($N=152$). Gender was approximately evenly distributed (51.00% female, $n=78$). Age range was 18–25 years ($M=21.36$, $SD=2.16$). Participants reported living with parents (37.50%, $n=57$), siblings (26.30%, $n=40$), and/or flatmates (20.40%, $n=31$), in private rental (46.00%, $n=70$) and family homes (41.00%, $n=62$). Nett weekly income in AUD varied considerably ($M=420.06$, $SD=322.45$, $range=0–1200$), as did weekly AUD spent on rent/mortgage ($M=121.32$, $SD=130.42$, $range=0–600$). Most participants were studying (84.00%, $n=120$) and receiving payment from work/study (58.00%, $n=89$). Seven participants (4.60%) reported a lifetime diagnosis of mental illness. None reported that the illness made it difficult for them to complete everyday tasks by themselves, or that they had ever accessed psychiatric services. Hence their data were retained for further analyses. K10 scores ($M=17.98$, $SD=6.00$, $range=10–37$) suggested that on average participants were not psychologically distressed (Australian Bureau of Statistics, 2012).

Baseline demographic comparisons were made between participants who provided T2 data and those who did not. There were no significant differences in age, $t(151)=-0.64$, $p=.51$, home internet access, $\chi^2(1, n=151)=0.57$, $p=.45$, or having engaged in work/study at any time over the past year, $\chi^2(1, n=151)=2.86$, $p=.09$. Females were more likely than males to respond at T2, $\chi^2(1, n=151)=15.67$, $p<.001$, and T2 responders reported lower weekly income than non-responders, *Mann-Whitney* $U=1237.00$, $z=-3.20$, $p=.001$.

Table 1

Demographics and other Characteristics of a Sample of Young Adults aged 18–25 from the General Community

Characteristic		Total sample (N = 152)	
Demographics	<i>Gender</i>		
	Female	% (n)	51.3 (78)
	Male	% (n)	48.0 (73)
	Transgender	% (n)	0.70 (1)
	<i>Age in years</i>	M (SD)	21.36 (2.16)
Living situation	<i>Where are you currently living?</i>		
	Homeless shelter, rooming/boarding house, hostel, or transitional housing	% (n)	2.0 (3)
	Public housing	% (n)	5.30 (8)
	Private rental	% (n)	46.1 (70)
	Own home (paying off mortgage, or own outright)	% (n)	5.9 (9)
	Family home (with your parents or other family members)	% (n)	40.8 (62)
	<i>Who do you currently live with?</i>		
	Parents	% (n)	37.50 (57)

	Siblings	% (<i>n</i>)	26.30 (40)
	Partner	% (<i>n</i>)	8.60 (13)
	Children	% (<i>n</i>)	0.70 (1)
	Other family members	% (<i>n</i>)	4.60 (7)
	Friend	% (<i>n</i>)	13.20 (20)
	Flatmate	% (<i>n</i>)	20.40 (31)
	Other residents	% (<i>n</i>)	9.90 (15)
	Self alone including pets	% (<i>n</i>)	9.20 (14)
	<i>How many dollars (AUD) per week do you personally spend on rent or mortgage payments?</i>	<i>M (SD)</i>	121.32 (130.42)
Finances	Nett weekly income in dollars (AUD)	<i>M (SD)</i>	420.06 (322.45)
	<i>Where do you currently receive an income from?</i>		
	Payment from work or study (e.g., scholarship) (% Yes)	% (<i>n</i>)	58.60 (89)
	Government payment (e.g., youth allowance, newstart allowance, single parent payment, disability support pension) (% Yes)	% (<i>n</i>)	19.70 (30)
	Spouse or other family member provides money (% Yes)	% (<i>n</i>)	40.10 (61)
	I don't receive an income – I have no money (% Yes)	% (<i>n</i>)	7.90 (12)
Employment/education			

<i>Are you currently:</i>			
Mental health	Working for pay? (% Yes)	% (<i>n</i>)	67.10 (95)
	Studying at a formal institution leading to a qualification (e.g., university, TAFE)? (% Yes)	% (<i>n</i>)	84.60 (120)
	Unemployed with no activity? (% Yes)	% (<i>n</i>)	11.20 (17)
	<i>Have you ever received a diagnosis of a mental illness from a health professional? (% Yes)</i>	% (<i>n</i>)	4.60 (7)
	DSM-V category:		
	Depressive Disorders	<i>n</i>	2
	Anxiety Disorders	<i>n</i>	4
	Obsessive-Compulsive and Related Disorders	<i>n</i>	1
	Trauma-related Disorders	<i>n</i>	1
	Eating Disorders	<i>n</i>	2
Kessler Psychological Distress Scale (K10) score		<i>M (SD)</i>	17.98 (6.00)

Note. *M* = mean; *SD* = standard deviation; *n* = number of participants; Minimum = minimum value; Maximum = Maximum value; AUD = Australian Dollars; TAFE = Technical and Further Education; DSM-V = Diagnostic and Statistical Manual of Mental Disorders, 5th Edition

Table 2 shows characteristics for measures of social inclusion, social functioning, loneliness and QoL. On a scale of 16–64, with no established clinical cut-off scores, the mean SIS score was 50.92 ($SD=7.20$). Over the past week, on average, participants spent 10.94 hours ($SD=13.73$) working, 22.11 hours ($SD=12.55$) attending classes/studying, and 20.25 hours ($SD=13.56$) on other social/leisure activities. The mean UCLA loneliness scale score was 36.78 ($SD=11.22$). The mean total AQoL-8D utility score, which reflects quality-adjusted life years, was 0.78 ($SD=0.17$).

Table 2

Characteristics of a Sample of 152 Young Adults aged 18–25 from the General Community on Established Measures of Social Inclusion, Social Functioning, Loneliness, and QoL

Measure				Minimum	Maximum
Social Inclusion Scale					
	Sum total score	<i>M (SD)</i>	50.92 (7.20)	30	64
Activity & Participation Questionnaire					
	<i>Last week how many hours did you work?</i>	<i>M (SD)</i>	10.94 (13.73)	0	60
	<i>How many hours per week do you spend attending classes and studying?</i>	<i>M (SD)</i>	22.11 (12.55)	0	53
	<i>How many hours did you spend on other social activities in the last week (e.g., socialising with friends/family, sports or physical activity, leisure activities)?</i>	<i>M (SD)</i>	20.25 (13.56)	0	70
UCLA Loneliness Scale	Sum total score	<i>M (SD)</i>	36.78 (11.22)	20	69

Australian Quality of Life Instrument (AQoL-8D)					
Sum total utility score	M (SD)	0.78 (.17)	0.29	1	
<i>Note.</i> M = mean; SD = standard deviation; n = number of participants; Minimum = minimum value; Maximum = Maximum value					

F-SIM CATPCA and Internal Consistency

A CATPCA was run on $N=152$ responses to 128 mixed-measurement variables from the F-SIM. A rank-order correlation matrix revealed the presence of correlations $\geq .30$. A sample size of 150 has been suggested as sufficient for PCA (Tabachnik & Fidell, 2012); thus, the data were deemed suitable for CATPCA. Based on review of the scree plot for the initial five-component/dimension solution (see Appendix), the final solution assumed two components/dimensions. These explained 18.82% of total variance, Dimension 1 (*Interpersonal Connections*)=11.82%, Dimension 2 (*Community Integration*)=7.00%. Although the scree plot clearly depicted two dimensions, other solutions were trialled (3–7 components/dimensions). None were as parsimonious as the two-component/dimension solution. That is, the items loading on the respective components/dimensions did not appear to form any coherent theme.

To assist interpretation, the solution was rotated. Oblique rotation using direct oblimin revealed a low correlation ($r=.14$) between components/dimensions. Orthogonal rotation using varimax was therefore employed. Table 3 shows component/dimension loadings for $n=47$ items that loaded $\geq .32$ on their respective dimension. Cronbach's α was .92 for Dimension 1 (*Interpersonal Connections*) and .87 for Dimension 2 (*Community Integration*).

Table 3

Rotated Component Loadings for n=47 F-SIM items that Loaded $\geq .32$ on the Two Dimensions (Interpersonal Connections, and Community Integration) among Young Adults aged 18–25 from the General Community (N=152)

Abbreviated Item	Rotated component loadings	
	Interpersonal Connections	Community Integration
How satisfied are you with your social life?	.85	-.07
How satisfied are you with the social activities that you take part in?	.81	-.03
Do you have good friends who you can count on?	.76	-.09
Do you have good friends who you see or speak to regularly?	.71	-.14
Do you have friends with whom you enjoy sharing time and look forward to seeing?	.66	-.06
Do you have friends with whom you share common interests and values?	.69	-.10
Do you have friends who would call on you to discuss their everyday experiences?	.62	.08
Do you have a best friend with whom you share your thoughts and feelings?	.59	-.06
Do you have friends who would call on you in a crisis?	.54	.15
Do you have someone (family/friends) you can chat to about daily activities, feelings, or events?	.51	-.11
Do you drop in to a neighbour's house or chat with them (at least weekly)?	.34	-.07

How often do you catch up with a friend for dinner or a movie or some other social activity?	.61	.11
How often do you have a meal with someone else?	.55	.19
How often do you share everyday activities with others such as watching television together?	.50	.43
How often do you talk to a family member or friend on the telephone?	.43	.15
How often do you connect with someone via SMS text message or social media?	.36	.34
*I don't enjoy social activities due to fear, anxiety, not having the right people to share them with	.70	.02
*I often feel unwelcome, like I don't belong	.69	.13
*I don't have very good self-confidence or self-esteem (I'm shy, find it hard to meet people etc.)	.66	.11
*I don't have a group of friends to call on to do anything with socially	.64	.15
*I feel excluded or not part of the group when taking part in new activities or joining new groups	.58	.14
*I haven't participated in any social or community activities for a long time, I don't know where to start	.57	.23
*There aren't any social activities that I know of that I'm interested in taking part in	.52	.21
*I don't know what I need to do to improve my circumstances	.62	.08
*I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things	.46	.08
*I don't have the time to do what I think I should do. I need more time in the day	.37	.04
*Does your emotional health interfere in your ability to achieve all you would like in your life?	.41	.14

Are the retail services in your local neighbourhood or community of a good standard?	.03	.66
Are the general community services in your local neighbourhood or community of a good standard?	-.01	.62
Are the health services in your local neighbourhood or community of a good standard?	.15	.54
Are the public internet services in your local neighbourhood or community of a good standard?	.13	.35
Are the local sports/youth/hobby groups in your neighbourhood or community of a good standard?	.09	.32
Have you assisted in planning, organising or running a community event (e.g. a local street party)?	.16	-.34
*I belong to a number of minority groups	.24	.56
*I experience either stigma or discrimination on a regular basis	.25	.42
*I feel like I am bullied by others	.21	.36
*I've had so many bad things happen to me, why should I expect that anything would improve?	.36	.37
*Do you feel that you earn considerably less than others in your community?	-.01	.47
*Is your income so low that you suffer from financial strain?	-.12	.40
Do you currently receive an income from work or study (e.g. scholarship)?	.06	.37
Are you currently working for payment other than monetary?	.06	-.36
*Are you currently unemployed with no activity?	-.07	.32
How many of the past 12 months did you work or study for?	.04	.32

*Do you have an illness that is likely to disrupt employment (e.g. having time off due to illness)?	-.08	.46
How often would you currently take part in physical exercise?	.20	.36
How many alcoholic beverages (e.g., glass/cup, small bottle, or can) do you drink per week?	.27	.33
*Do you have physical ailments that prevent you from accessing services to help improve your life?	-.04	.41
<i>Note.</i> For the sake of brevity, item wording has been abbreviated. Loadings are based on an orthogonal rotation via Varimax with Kaiser Normalization.		
*Denotes items where a negative response (e.g., 'No,' or 'Not at all') to a categorical item corresponds to a positive component loading		

Test-Retest Reliability of F-SIM Items

On average participants (78.29%, $n=119$) completed the T2 survey 15.21 days after T1 ($SD=3.32$, $median=14$, $range=14-40$). Table 4 shows $ICC_{3,2}$ coefficients along with 95% confidence intervals and F test value for F-SIM items loading $\geq .32$. The $ICC_{3,2}$ for $n=47$ items ranged from .30 (*Do you have an illness that is likely to disrupt employment?*) to .93 (*How many alcoholic beverages do you drink per week?*). Thirty-eight of these 47 items (80.85%) had an $ICC_{3,2} \geq .60$.

Table 4

Test-Retest Reliability over Two Weeks of 47 items on the F-SIM for n=119 Young Adults aged 18–25 from the General Community

Abbreviated Item	ICC_{3,2}	95%CI for ICC	F(118,118) Test value
How satisfied are you with your social life?	.82	[.74, .87]	5.47***
How satisfied are you with the social activities that you take part in?	.77	[.67, .84]	4.50***
Do you have good friends who you can count on?	.75	[.64, .83]	4.06***
Do you have good friends who you see or speak to regularly?	.83	[.76, .88]	5.95***
Do you have friends with whom you enjoy sharing time and look forward to seeing?	.67	[.53, .77]	3.02***
Do you have friends with whom you share common interests and values?	.85	[.79, .90]	6.66***
Do you have friends who would call on you to discuss their everyday experiences?	.77	[.67, .84]	4.32***
Do you have a best friend with whom you share your thoughts and feelings?	.74	[.63, .82]	3.85***
Do you have friends who would call on you in a crisis?	.69	[.55, .79]	3.31***
Do you have someone (family/friends) you can chat to about daily activities, feelings, or events?	.47	[.24, .63]	1.88***
Do you drop in to a neighbour's house or chat with them (at least weekly)?	.83	[.76, .88]	5.83***
How often do you catch up with a friend for dinner or a movie or some other social activity?	.72	[.60, .81]	3.63***
How often do you have a meal with someone else?	.85	[.78, .89]	6.43***

How often do you share everyday activities with others such as watching television together?	.76	[.65, .83]	4.06***
How often do you talk to a family member or friend on the telephone?	.79	[.71, .86]	4.90***
How often do you connect with someone via SMS text message or social media?	.87	[.81, .91]	8.07***
I don't enjoy social activities due to fear, anxiety, not having the right people to share them with	.74	[.63, .82]	3.98***
I often feel unwelcome, like I don't belong	.69	[.55, .78]	3.22***
I don't have very good self-confidence or self-esteem (I'm shy, find it hard to meet people etc.)	.78	[.69, .85]	4.61***
I don't have a group of friends to call on to do anything with socially	.85	[.78, .89]	6.49***
I feel excluded or not part of the group when taking part in new activities or joining new groups	.63	[.47, .74]	2.76***
I haven't participated in any social or community activities for a long time, I don't know where to start	.52	[.31, .66]	2.13***
There aren't any social activities that I know of that I'm interested in taking part in	.66	[.52, .77]	2.99***
I don't know what I need to do to improve my circumstances	.68	[.54, .78]	3.13***
I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things	.67	[.53, .77]	3.03***
I don't have the time to do what I think I should do. I need more time in the day	.62	[.46, .74]	2.68***
Does your emotional health interfere in your ability to achieve all you would like in your life?	.74	[.62, .82]	3.75***
Are the retail services in your local neighbourhood or community of a good standard?	.60	[.42, .72]	2.51***
Are the general community services in your local neighbourhood or community of a good standard?	.61	[.44, .73]	2.55***

Are the health services in your local neighbourhood or community of a good standard?	.58	[.39, .71]	2.36***
Are the public internet services in your local neighbourhood or community of a good standard?	.58	[.40, .71]	2.38***
Are the local sports/youth/hobby groups in your neighbourhood or community of a good standard?	.46	[.22, .63]	1.84***
Have you assisted in planning, organising or running a community event (e.g. a local street party)?	.87	[.81, .91]	7.44***
I belong to a number of minority groups	.62	[.46, .74]	2.66***
I experience either stigma or discrimination on a regular basis	.54	[.34, .68]	2.19***
I feel like I am bullied by others	.51	[.30, .66]	2.04***
I've had so many bad things happen to me, why should I expect that anything would improve?	.77	[.66, .84]	4.27***
Do you feel that you earn considerably less than others in your community?	.82	[.74, .88]	5.54***
Is your income so low that you suffer from financial strain?	.63	[.47, .74]	2.69***
Do you currently receive an income from work or study (e.g. scholarship)?	.87	[.81, .91]	7.52***
Are you currently working for payment other than monetary?	.72	[.60, .81]	3.60***
Are you currently unemployed with no activity?	.64	[.48, .75]	2.81***
How many of the past 12 months did you work or study for?	.84	[.77, .89]	6.33***
Do you have an illness that is likely to disrupt employment (e.g. having time off due to illness)?	.30	[.01, .51]	1.44*
How often would you currently take part in physical exercise?	.86	[.80, .90]	7.06***

How many alcoholic beverages (e.g., glass/cup, small bottle, or can) do you drink per week?	.93	[.89, .95]	13.53***
Do you have physical ailments that prevent you from accessing services to help improve your life?	.55	[.35, .69]	2.19***

Note. Wording of items is abbreviated for the sake of brevity. ICC (3,2) = Intraclass Coefficient model 3 and type 2. Method of ICC was ‘absolute agreement.’ 95%CI = 95% confidence interval for ICC (3,2)

*= $p < .05$; ** = $p < .01$; *** = $p < .001$

Construct Validity of F-SIM Components/Dimensions

Table 5 shows r_s correlations between F-SIM component/dimension scores and other variables. Dimension 1 (*Interpersonal Connections*) scores had a weak-to-moderate positive correlation with hours spent on social/leisure activities ($r_s=.26$, $p=.001$). They had a moderate negative correlation with K10 score ($r_s=-.38$, $p<.001$), and moderate positive correlations with AQoL-8D subscales independent living ($r_s=.38$, $p<.001$), coping ($r_s=.38$, $p<.001$), and mental health ($r_s=.41$, $p<.001$). They had moderate-to-strong positive correlations with the self-worth ($r_s=.48$, $p<.001$) and happiness ($r_s=.49$, $p<.001$) subscales of the AQoL-8D. Dimension 1 (*Interpersonal Connections*) scores had a strong positive correlation with SIS total score ($r_s=.52$, $p<.001$), AQoL-8D total score ($r_s=.55$, $p<.001$), and AQoL-8D relationships subscale score ($r_s=.59$, $p<.001$). They had a strong negative correlation with UCLA Loneliness Scale score ($r_s=-.59$, $p<.001$).

Dimension 2 (*Community Integration*) scores had a weak positive correlation with AQoL-8D total score ($r_s=.18$, $p=.03$). They had a weak-to-moderate negative correlation with K10 score ($r_s=-.24$, $p=.003$). Dimension 2 (*Community Integration*) scores had a weak-to-moderate positive correlation with SIS total score ($r_s=.27$, $p=.001$). They had a moderate positive correlation with hours worked ($r_s=.33$, $p<.001$), and a moderate negative correlation with UCLA Loneliness score ($r_s=-.31$, $p<.001$).

Table 5

Spearman's r_s correlations among scores on two dimensions of the F-SIM and established measures of related constructs (social functioning, loneliness, QoL, social inclusion, and psychological distress) for N=152 young adults aged 18–25 from the general community

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. <i>Interpersonal Connections</i> scores	1	.14	-.38**	.52**	.08	-.19*	.26**	-.59**	.55**	.38**	.49**	.41**	.38**	.59**	.48**	.04	.28**
2. <i>Community Integration</i> scores		1	-.24**	.27**	.33**	.10	.04	-.31**	.18*	.18*	.11	.13	.15	.14	.18*	.09	.15
3. K10			1	-.40**	-.07	.01	-.02	.50**	-.71**	-.29**	-.55**	-.74**	-.58**	-.57**	-.63**	-.25**	-.13
4. SIS Total				1	.13	-.02	.32**	-.67**	.55**	.30**	.52**	.39**	.52**	.59**	.47**	.06	.23**
5. Hours worked last week					1	-.29**	-.01	-.09	.04	.07	.05	.09	.11	.04	.04	-.04	-.12

6. Hours per week education	1	.04	.03	-.03	-.05	-.14	.03	-.15	-.03	-.03	.06	.06
7. Hours last week social activities	1	-.27**	.25**	.12	.28**	.13	.16*	.30**	.20*	.08	.22**	
8. UCLA Loneliness			1	-.72**	-.40**	-.70**	-.55**	-.54**	-.77**	-.59**	-.17*	-.31**
9. AQoL-8D Total				1	.53**	.81**	.89**	.77**	.82**	.83**	.35**	.43**
10. AQoL-8D independent living					1	.42**	.34**	.35**	.41**	.39**	.33**	.31**
11. AQoL-8D Happiness						1	.65**	.76**	.67**	.68**	.14	.25**
12. AQoL-8D Mental Health							1	.65**	.64**	.71**	.31**	.27**

13. AQoL-8D	1	.55**	.65**	.20*	.19*
Coping					
14. AQoL-8D		1	.63**	.16*	.38**
Relationships					
15. AQoL-8D			1	.25**	.34**
Self Worth					
subscale					
16. AQoL-8D				1	.16*
Pain					
17. AQoL-8D					1
Senses					

Note. K10 = Kessler-10 Psychological Distress Scale; SIS=Social inclusion Scale; AQoL-8D=Australian Quality of Life Instrument, 8 Dimension Version

*= $p < .05$; ** = $p < .01$; *** = $p < .001$

Acceptability and Face Validity of the F-SIM

The average self-reported completion time of the F-SIM was 19.89 minutes ($SD=9.64$). In response to the question *Do you think the F-SIM took too long to complete?* 74.00% ($n=112$) of participants selected *No*, 19.00% ($n=29$) selected *Maybe a little*, and 7.00% ($n=11$) selected *Yes*. In response to the question *How well do you think that the F-SIM actually measures social inclusion?* 31% ($n=47$) said *Very Well*, 62% ($n=94$) selected *Somewhat*, and 6% ($n=10$) selected *Not very well*. In response to the question *Did you find the F-SIM difficult to complete in anyway?* 94% ($n=141$) selected *No* and 6% ($n=9$) selected *Yes*. Those who specified ($n=6$) reported perceived ambiguity, and vagueness/inapplicability of questions.

Discussion

This is the first study to examine psychometric properties of the F-SIM among young adults from the general community. The key finding was that the instrument captures two dimensions of social inclusion (*Interpersonal Connections*, and *Community Integration*) in this population. This suggests similarities and differences to the three F-SIM dimensions (*Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*) found in a study of young adults with SMI (Gardner et al., 2019). This implies some overlap but also some distinctions in terms of what it means to be socially included in each of these two populations.

Comparison to Previous Research

The relatively low mean level of psychological distress reported here falls midway between estimates from young adults in the general population and those

from a university student sample (Bore et al., 2016). The mean total SIS scale score reported here (50.92, $SD=7.20$) could not be compared to results from Berry and Greenwood (2018), who used a 16-item version in their community sample of young adults but did not report SIS total scale score. It was significantly lower than the mean SIS total score in a sample of university students ($M=60.27$, $SD=7.92$ [C. Wilson, personal communication, August 6, 2018]). However, Wilson and Secker (2015) used a 19-item version of the SIS and their sample was older (mean age-in-years=31.37, $SD=13.04$, range=18 to 66). The mean level of loneliness reported here was comparable to normative data for young adults (Knight et al., 1988). The mean level of overall QoL was also comparable to normative data for young adults (Maxwell et al., 2016).

As noted, there are virtually no studies examining the psychometric properties of social inclusion measures specifically among young adults aged 18–25 years from the general community. This makes it difficult to compare these findings regarding internal consistency, stability of measurement, construct validity, and face validity to those from other studies in this population. However, Berry and Greenwood (2018) studied the facilitators of social inclusion in a sample of 387 young people aged 14- to 36-years-old with no current mental health problems in the United Kingdom and the Republic of Ireland. They used the Social Relationships Scale (McFarlane et al., 1981) to measure objective social network size, and the SIS to measure subjective perceptions of social and occupational participation. Their two-dimensional model suggested that social inclusion involved *Social Activity* (i.e., social network size, reciprocity within relationships, frequency of contact) and *Community Belonging* (i.e., meaningful occupation, cultural and political inclusion) for young people. These are

similar to the two dimensions of social inclusion underlying the F-SIM (*Interpersonal Connections*, and *Community Integration*) reported in this study. Although Berry and Greenwood sampled a much wider age range, this suggests that these may be key dimensions of social inclusion for young adults in the general community.

In terms of psychometric properties of the F-SIM, estimates of internal consistency, stability of measurement, and convergent validity reported here are comparable to those reported in a sample of young adults with SMI (Gardner et al., 2019). There were important differences across studies, though. In the SMI study, $n=72$ items had component/dimension loadings $\geq .32$. In the present study, $n=47$ items had loadings $\geq .32$. This suggests that fewer F-SIM items shared $>10\%$ of overlapping variance with other items loading on their respective dimensions in this study than was the case in the SMI study (Costello & Osborne, 2005). That is, overlapping variance among items within F-SIM dimensions appears to be more widespread for young adults with SMI than those in the general community. It is unclear why this is the case. As noted in the introduction, the literature is inherently and singularly focused on groups who are socially excluded (Rawal, 2008). Perhaps F-SIM items, which were based on a broad search of this literature, capture more aspects of social inclusion for young adults with SMI than for those in the general community (e.g., *Have you been unable to get a job or keep one because of discrimination due to having a mental illness?*). There was some evidence to support this. In the SMI study, 44.00% ($n=70$) said that the F-SIM measured social inclusion very well, compared to 31.00% ($n=47$) in the present study. This significant difference, $\chi^2(1, n=311)=5.68$, $p=.02$, occurred despite the fact that general community members participated in consensus agreement on which items should be included in the F-SIM (Filia et al.,

2019a). Perhaps we are conditioned to consider social inclusion in terms of marginalised groups, even if we do not belong to such groups ourselves and such terms do not capture our own experiences.

Implications

The *Interpersonal Connections* dimension reported here was also found in the SMI sample of the previous study (Gardner et al., 2019), suggesting that regular positive contact with friends and family is crucial for social inclusion across these young adult populations. However, the somewhat broad *Community Integration* dimension reported here was not found in the SMI study, where more specific *Vocational & Financial Security* and *Healthy Independent Lifestyle* dimensions emerged. Perhaps there are illness-related factors associated with the emergence of these specific dimensions of social inclusion for young adults with SMI. At any rate, if these dimensional similarities and differences are replicable then they raise questions with significant implications. Specifically, how do we examine differences in social inclusion between these two groups? Perhaps a set of core nomothetic indicators (i.e., items shown to be relevant and generalisable to social inclusion in both populations) can be identified and used to examine group differences. However, potential idiographic effects of social milieu (i.e., unique aspects of distinct social environments experienced by particular populations) may need to be considered. It is important for measures of social inclusion to be able to model the variation in social milieu from one population to another (Berry & Greenwood, 2018).

Strengths & Limitations

In the literature, it is implicitly assumed that dimensions of social inclusion are fixed across SMI and community populations (e.g., Huxley et al., 2012). Comparing our previous work in an SMI sample (Gardner et al., 2019) to findings from the present study, the validity of that assumption may need to be questioned (at least as it applies to young adult populations). This is a strength of the study. The findings of excellent internal consistency, good stability of measurement, and good convergent validity for the F-SIM are also strengths. There were also limitations. This was a preliminary exploratory study from which causality cannot be inferred, and the findings of which must be replicated. It has been suggested that ≥ 10 cases per variable may be required in dimension reduction analyses (Pearson & Mundform, 2010). This was not possible in the present study for pragmatic reasons (i.e., insufficient resources to recruit a larger sample). Arguably, this increases the chance that the dimensional structure reported here is unstable (because of a low ratio of items to cases). However, many items loaded on each dimension, with multiple loadings $\geq .60$. These have been posited as sufficient conditions for a stable dimensional structure with sample sizes as low as $n=50$ (Guadagnoli & Velicer, 1988). Females and people with lower weekly incomes were more likely to complete surveys at T2, which calls into question the representativeness of test-retest data.

Future Directions

This study presents preliminary data identifying relevant F-SIM dimensions and indicators for young adults in the general community. It supports theoretical assumptions regarding associations between the F-SIM and measures of social inclusion, social functioning, QoL, loneliness, and psychological distress. However,

further development of the F-SIM is required. A shortened version of the measure must be created and validated for use among young adults. It may then be appropriate to reassess whether the two-dimensional structure identified here, and seemingly supported by Berry and Greenwood (2018), is replicable. In the social inclusion literature more broadly, future studies should consider whether dimensions of social inclusion are invariant across populations, and how to manage the methodological implications if they are not.

Conclusion

Social inclusion has been almost entirely conceptualised in terms of excluded groups, such as people with SMI. Levels of social inclusion in the general population are not well understood, meaning that the putative exclusion of marginalised groups relative to general community members is unclear. Young adults are a particularly important population to focus on, given the developmental implications of social inclusion during this life stage. We previously reported psychometric properties of a preliminary version of the F-SIM among young adults with SMI (Gardner et al., 2019). In the present study, we explored the psychometric properties of a preliminary version of the F-SIM among young adults from the general community. Internal consistency, test-retest reliability, and convergent validity were good-to-excellent in this cohort. Similarities and differences were discussed regarding the dimensional structure of the F-SIM identified in each population across the two studies. This preliminary exploration of psychometric properties of the F-SIM among young adults from the general community may inform future efforts to shorten and validate the instrument in this population.

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Appendix

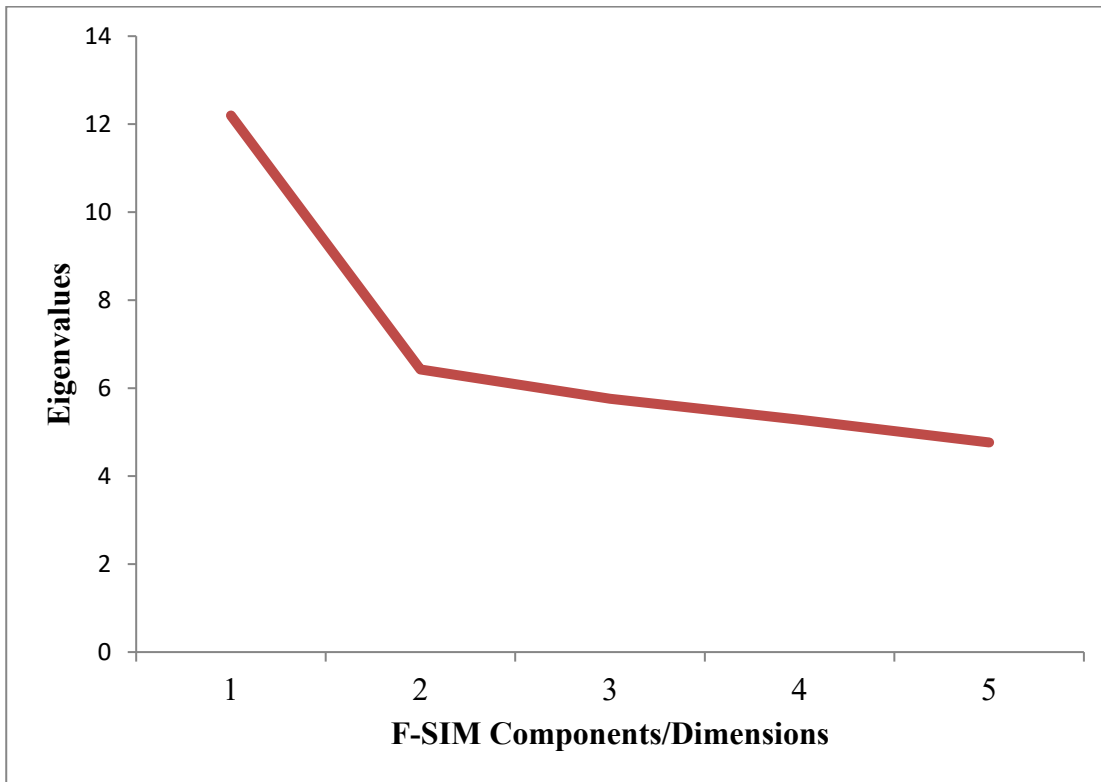


Figure 1. Scree plot of five components/dimensions of the Filia Social Inclusion Measure (F-SIM) among young adults aged 18–25 years from the general community on the x-axis, and the corresponding eigenvalue for each component/dimension on the y-axis.

CHAPTER SIX: MEASURING SOCIAL INCLUSION AMONG YOUNG ADULTS IN THE GENERAL COMMUNITY

Overview of Results

The paper presented in this chapter entailed an exploration of psychometric properties of a preliminary version of the F-SIM among young adults aged 18–25 years from the general community. This included an examination of the F-SIM's dimensional structure, internal consistency of its dimensions, test-retest reliability of its items over two weeks, its validity with respect to measures of theoretically related constructs, and its user acceptability/face validity. Being methodologically identical to the paper presented in Chapter Five, this permitted a discussion of similarities and differences between psychometric properties of the F-SIM among young adults with SMI and those in the general community.

In contrast to the SMI sample where three dimensions emerged, results suggested two dimensions underlying the F-SIM (*Interpersonal Connections*, and *Community Integration*) among young adults in the general community. Internal consistency of these dimensions was excellent, and test-retest reliability of F-SIM items was good. Each dimension exhibited convergent validity with measures of social inclusion, social functioning, QoL, psychological distress, and loneliness. Similarities (e.g., interpersonal factors) and differences (e.g., greater differentiation of community integration for young adults with SMI) in F-SIM dimensions between populations were observed. This has significant theoretical and practical implications, which will be addressed in Chapter Eight: Discussion.

The generation of F-SIM data in the SMI sample of Chapter Five, and comparative community data in this chapter, enables an exploration of differences in social inclusion between these two groups in the next chapter.

CHAPTER SEVEN: GROUP DIFFERENCES IN SOCIAL INCLUSION BETWEEN YOUNG ADULTS WITH SERIOUS MENTAL ILLNESS AND THOSE FROM THE GENERAL COMMUNITY

Preamble

The previous two studies examined preliminary psychometric properties of the F-SIM among (i) young adults with SMI (Chapter Five); and, (ii) young adults in the general community (Chapter Six). Relevant F-SIM dimensions and indicators varied across these studies (e.g., three dimensions in the SMI sample compared to two dimensions in the community sample). The broad implications of such differences are discussed at length in the general discussion (Chapter Eight). However, these differences had direct practical implications for the paper presented in this chapter, an aim of which was to examine group differences on the F-SIM. Young adults with SMI were the primary population of interest in this research program. Hence the F-SIM dimensions and indicators identified as relevant in that population (Chapter Five) were used in this chapter to examine group differences. Potential issues stemming from this approach are addressed in the general discussion of Chapter Eight.

To the author's knowledge, this is the first study to examine differences between young adults with SMI and peers from the general community on a psychometric measure of social inclusion. In so doing, it provides a more granular level of detail regarding discrepancies between groups than has previously been available. It also provides clinically useful information for early intervention services offering treatment to young adults with SMI. The paper presented in this chapter was accepted for publication in the *International Journal of Social Psychiatry* in July 2019.

A brief overview of results from the study is presented at the end of this chapter.

Group differences in social inclusion between young adults aged 18 to 25 with serious mental illness and same-aged peers from the general community

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Abstract

Aims: Young adults with serious mental illness (SMI) are thought to be socially excluded. However, psychometric measures of social inclusion have not been employed to examine group differences relative to peers from the general community. The aim of this study was to employ such a measure to determine differences in social inclusion between young adults with SMI and peers from the general community.

Methods: A cross-sectional hierarchical logistic regression was conducted to identify which dimensions and individual indicators from the Filia Social Inclusion Measure (F-SIM) discriminated between $n = 152$ young adults aged 18–25 from the general community ($M = 21.36$, $SD = 2.16$) and $n = 159$ young adults aged 18–25 with SMI ($M = 21.13$, $SD = 2.21$).

Results: Group membership was accounted for by *Interpersonal Connections* (Nagelkerke $R^2 = .32$), *Vocational & Financial Security* (Nagelkerke $R^2 = .32$) and *Healthy Independent Lifestyle* (Nagelkerke $R^2 = .08$) dimensions of the F-SIM. Relative to young adults from the general community, those with SMI were five times less likely to feel they had friends who would call on them in a crisis, odds ratio (OR) = .19 (95%CI = .04, .53), $p = .04$, almost five times more likely to live with their parents, OR = 4.79 (95%CI = 1.98, 11.15), $p = .004$, almost four times less likely to have worked/studied any time over the past 12 months, OR = .27 (95%CI = .11, .64), $p < .001$, and three-and-a-half times more likely to report unstable accommodation, OR = 3.58 (95%CI = 1.14, 11.15), $p = .03$.

Conclusion: Young adults with SMI are socially excluded relative to peers from the general community in terms of interpersonal connections, vocational engagement, autonomy/independence and housing stability. In addition to the well-established focus on vocational engagement, interventions to improve social inclusion in this population must promote reciprocity within social relationships and healthy autonomy/independence (including stable housing).

Keywords

Social inclusion, social exclusion, young adult, group difference, mental illness

Hallmark characteristics of social inclusion, for example, high-quality interpersonal relationships, are robustly associated with better health (Holt-Lunstad, Robles, & Sbarra, 2017). There is no unanimously agreed definition of social inclusion, but it is broadly considered to comprise objective and subjective factors (Berry & Greenwood, 2018). It has been defined as a sense of belongingness/acceptance in relation to opportunities to participate in valued social roles (Gardner, Filia, Killackey, & Cotton, 2019). Social inclusion initially emerged in antithesis to the established social exclusion construct (Spandler, 2007), which may be defined as a sense of loneliness/isolation in relation to dissatisfaction with opportunities to participate in such roles. This typically involves active processes of exclusion by society, for example, enforced lack of participation (Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007). Social inclusion and

exclusion are widely considered to be dimensional opposites (Baumgartner & Burns, 2014). They are also widely agreed to be multidimensional (Huxley, Evans, & Munroe, 2006). Commonly cited dimensions include the following: social relationships, employment/education, leisure activities,

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housing and accommodation, financial situation and health (Filia, Jackson, Cotton, Gardner, & Killackey, 2018; Huxley et al., 2012). The particular roles that are valued across these dimensions likely differ throughout the lifespan. Focusing on subgroups defined by developmental stage may therefore be helpful – particularly during key transitions such as young adulthood (Hayes, Gray, & Edwards, 2008).

The terms youth and young adulthood have been applied somewhat interchangeably to the transition from childhood to adulthood for people in their late-teens to mid-20s (UNESCO, 2017). It is important to examine social inclusion during this stage because it appears to be a sensitive period for related processes, for example, peer group acceptance (Blakemore & Mills, 2014). Mental illness onset typically occurs during this stage and may complicate such processes (McGorry et al., 2013). Serious mental illness (SMI) is often defined by diagnosis (e.g. schizophrenia) but may be defined as any mental illness that makes it difficult for a person to complete everyday activities without assistance (Australian Bureau of Statistics, 2015).

Young adults with SMI are considered socially excluded (Social Exclusion Unit, 2005). This is largely based on evidence from objective indicators, for example, lower vocational engagement relative to peers from the general community (Iyer et al., 2018). However, subjective indicators are under-researched in this population (Sündermann, Onwumere, Bebbington, & Kuipers, 2013), where loneliness remains poorly understood (Lim, Gleeson, Alvarez-Jimenez, & Penn, 2018). Psychometric measures of social inclusion combine objective and subjective indicators (Shepherd & Parsonage, 2011). Such measures have not been used to examine group differences in social inclusion between young adults with SMI and peers from the general community: there is a lack of research targeting young adults in the social inclusion literature (Evans-Lacko et al., 2014). This makes it difficult to adequately assess group differences between young adults from the general community and those with SMI. That is, to move beyond gross discrepancies in for example, vocational engagement toward a more granular understanding that incorporates subjective perceptions of social opportunities. It is at this granular level where individual interventions may be most effective (Australian Mental Health Outcomes Classification Network, 2016).

The primary aim of this study was to examine group differences between young adults aged 18–25 with SMI and those from the general community on a newly developed measure of social inclusion. The secondary aim was to identify particular dimensions and individual indicators of social inclusion that discriminated between groups.

Method

This cross-sectional study involved analysis of baseline data from studies exploring the psychometric properties of a social inclusion measure among 18–25 year olds with

SMI (Gardner, Cotton, O'Donoghue, et al., 2019) and from the general community (Gardner, Cotton, Killackey, et al., 2019). This age range was selected for reasons explained above (i.e. it appears to be a sensitive period for social inclusion).

Setting and Sample

Clinical sample. Participants were recruited from (a) Orygen Youth Health, a public mental health service for people aged 15–25 in the northwest of Melbourne, Australia; and (b) Mind Australia, youth psychosocial rehabilitation services for people aged 16–25 across Melbourne, Australia. Both services support young adults with diverse manifestations of SMI. This study employed a transdiagnostic conceptualization (Hartmann et al., 2019), reflecting the diagnostic instability endemic of early-stage SMI (Menezes & Milovan, 2000). Diagnoses of mental illness were recorded via self-report, a method used in genome-wide studies of depression (Hyde et al., 2016). Participants were approached in consultation with clinical staff from these services. Exclusion criteria were clinician-assessed symptom severity precluding informed consent (e.g. florid psychosis) and lack of fluency in English (due to pragmatic reasons).

General community sample. Participants were living in Melbourne, Australia and were recruited from a range of settings (e.g. universities, restaurants/café, public housing, shopping centers). Recruitment techniques included advertisement (e.g. social media, flyers/posters) and snowballing. Exclusion criteria were lack of sufficient fluency in English, and diagnosis of SMI. As this was a general community sample (not 'healthy controls'), a diagnosis of mental illness per se did not necessarily exclude participants. Anxiety and depression are highly prevalent among the general population of young adults (Gustavson et al., 2018). General community participants reporting a lifetime mental illness diagnosis were asked followup questions to help determine whether this ought to be considered SMI. For example, they were asked whether the illness made it difficult for them to manage everyday tasks by themselves and whether they had ever accessed psychiatric services.

Measures

The Filia Social Inclusion Measure (F-SIM) is a 72-item self-report measure of social inclusion over the past month. Item creation was based on a thematic analysis identifying indicators of social inclusion (Filia et al., 2018) and a Delphi study seeking consensus on which indicators to include in the measure (Filia, Jackson, Cotton, & Killackey, 2019). The F-SIM employs dichotomous-, ordinal-, nominal- and ratio-level items to assess objective (e.g. *How many of the past 12 months did you work/study for?*) and subjective (e.g. *I often feel unwelcome, like I don't belong*)

aspects of social inclusion. Like other social inclusion measures (Coombs, Reed, & Rosen, 2016), frequencies/percentages can be used to examine responses to individual items. This maximizes clinical utility by targeting specific areas of social inclusion (Australian Mental Health Outcomes Classification Network, 2016). Items are grouped into three dimensions: *Interpersonal Connections* (Cronbach's $\alpha = .94$), *Vocational and Financial Security* (Cronbach's $\alpha = .87$) and *Healthy Independent Lifestyle* (Cronbach's $\alpha = .82$). The F-SIM is one of the only measures to demonstrate reliability and validity specifically among young adults aged 18–25 with SMI (Gardner, Cotton, O'Donoghue, et al., 2019). Demographic information and self-reported lifetime mental disorder diagnosis were obtained via the F-SIM. Participants were asked whether they had ever received a diagnosis from the following *DSM-5* categories: depressive disorders, anxiety disorders, schizophrenia spectrum & other psychotic disorders, bipolar and related disorders, eating disorders, obsessive-compulsive and related disorders, trauma-related disorders, substance-related and addictive disorders or personality disorders. Participants who indicated that they had been diagnosed with a mental disorder at some point in their lives were asked a series of follow-up questions (e.g. history of accessing psychiatric services and/or psychiatric hospital admissions).

Ethics

This study received ethical approval from the Melbourne Health Human Research and Ethics Committee (HREC/16/MH/325) and was endorsed by the Mind Australia Research and Evaluation Committee. The Youth Research Council at Orygen, the National Centre of Excellence in Youth Mental Health, provided consumer perspective and feedback on the study plan and design. Data were collected via online surveys. Informed consent was implied by survey submission, which was explained via the participant information form. Participants received a retail voucher for their participation.

Data analyses

Analyses were conducted using IBM® SPSS® Statistics Version 25. Little's Missing Completely at Random (MCAR) test was used to assess missing data. Descriptive statistics were inspected for accuracy of input and compared between groups. Such comparisons were conducted via bivariate logistic regressions, with group membership as the outcome variable. This method was selected so as to produce the same type of test statistic (i.e. Wald) and effect size (i.e. odds ratios) reported in the primary analysis of interest outlined below.

A four-block hierarchical logistic regression was conducted to predict membership to one of two groups: young

adults aged 18–25 from the general community and young adults aged 18–25 with SMI. Logistic regression was chosen because many variables were non-continuous. There should be ≥ 10 cases for each predictor variable in a logistic regression model (Vittinghoff & McCulloch, 2007). With $N = 311$, this afforded the inclusion of ≤ 31 predictor variables. To avoid over-fitting of the model, 22 predictor variables were included. Therefore, not all F-SIM items ($n = 72$) could be included in the analysis. A rationale for the selection of F-SIM items is provided below.

Age and gender were entered into the first block to control for the potentially confounding effect of these variables. The dimensional structure of the F-SIM has been reported in a study examining its psychometric properties among young adults aged 18–25 with SMI (Gardner, Cotton, O'Donoghue, et al., 2019). This dimensional structure was used as a rationale for the hierarchy of the final three blocks in the model. The seven best-performing items (i.e. those with the highest dimension loadings) from the *Interpersonal Connections* dimension were entered as predictors in Block 2 (dimension loading range = .64–.80). The seven best-performing items from the *Vocational and Financial Security* dimension (loading range = .48–.80) were entered as predictors in Block 3. Finally, the seven best-performing items from the *Healthy Independent Lifestyle* dimension (loading range = .46–.70) were entered as predictors in Block 4. Figure 1 depicts the four blocks of the hierarchical logistic regression and details the individual F-SIM items included within each block.

From the logistic regression model, we were able to determine how each block contributed to the explanation of group differences. Omnibus tests of model coefficients were examined to determine chi-square change between blocks (χ^2_{Δ}). Chi-square (χ^2) and Hosmer–Lemeshow tests were conducted to assess the overall goodness-of-fit of each of the steps of the model, as well as the final model. Nagelkerke R^2 values were generated to indicate the amount of variation in group membership explained by the cumulated blocks of variables. Classification tables were generated to examine the ability of each of the steps in the model to accurately identify group membership. The relative contribution of individual predictors in the models was tested with the Wald statistic. Odds ratios (OR) and their 95% confidence intervals [95%CI] were calculated to assess the effect size of individual predictors. Effect sizes were interpreted as small (OR = 1.5), medium, (OR = 2.0) or large (OR = 3 (Sullivan & Feinn, 2012)).

Results

Cohort characteristics

Between April 2017 and August 2018, $N = 311$ participants (general community $n = 152$; SMI $n = 159$) completed surveys. Table 1 describes the two samples. In the SMI group,



Figure 1. F-SIM dimensions that comprise each block, and the individual F-SIM item indicators within each dimension, for the hierarchical logistic regression with group membership (general community=0, serious mental illness=1) as the outcome variable. F-SIM: Filia Social Inclusion Measure.

seven people identified as transgender and seven did not identify as female, male or transgender. In the general community group, one individual identified as transgender. There were no significant differences in age or binary gender (male/female) between groups. Young adults with SMI were six times less likely to have access to the Internet at home (OR=0.16, 95%CI [0.04, 0.74], $p=.02$) and two-and-a-half times less likely to have a current drivers license, (OR=0.38, 95%CI [0.23, 0.62], $p<.001$). Young adults with SMI were three times less likely to receive

income from work/study (OR=0.34, 95%CI [0.22, 0.55], $p<.001$), six-and-a-half times more likely to receive government payments (OR=6.54, 95%CI [3.92, 10.87], $p<.001$) and almost four times less likely to receive money from family members (OR=0.27, 95%CI [0.15, 0.46], $p<.001$). The most commonly self-reported diagnostic categories in the SMI group were depression (53%, $n=84$), anxiety (43%, $n=69$) and schizophrenia spectrum disorders (30%, $n=48$). Comorbidity was common: 64% ($n=103$) in the SMI group reported more than one

Table 1. Demographic and other characteristics of (a) a sample of young people aged 18–25 from the general community (GC) and (b) a sample of young people aged 18–25 with serious mental illness (SMI).

Characteristic		GC (n = 152)	SMI (n = 159)	Wald test of group difference	OR [95%CI]
Gender					
Female	% (n)	51.3 (78)	48.40 (77)		
Male	% (n)	48.0 (73)	42.80 (68)		
Transgender	% (n)	.70 (1)	4.40 (7)	0.06	0.94 [0.60, 1.49]
I do not identify as female, male or transgender		–	4.40 (7)	–	–
Age in years	M (SD)	21.36 (2.16)	21.13 (2.21)	0.86	0.95 [0.86, 1.06]
How many dollars (AUD) per week do you personally spend on rent or mortgage payments?	M (SD)	121.32 (130.42)	96.28 (122.78)	2.99	1.00 [0.99, 1.01]
Do you have access to the Internet at home? (% Yes)	Median	109.50	60.00		
Do you have a current drivers license (% Yes)	% (n)	98.7 (150)	92.50 (147)	5.50*	0.16 [0.04, 0.74]
Nett weekly income in dollars (AUD)	% (n)	77.00 (117)	56.00 (89)	14.92***	0.38 [0.23, 0.62]
	M (SD)	420.06 (322.45)	317.87 (239.23)	9.45**	0.99 [0.98, 1.00]
	Median	310.00	280.00		
Where do you currently receive an income from?					
Payment from work or study (e.g. scholarship) (% Yes)	% (n)	58.60 (89)	32.70 (52)	20.45***	0.34 [0.22, 0.55]
Government payment (e.g. youth allowance, newstart allowance, single parent payment, disability support pension) (% Yes)	% (n)	19.70 (30)	61.60 (98)	51.71***	6.54 [3.92, 10.87]
Spouse or other family member provides money (% Yes)	% (n)	40.10 (61)	15.10 (24)	23.04***	0.27 [0.15, 0.46]
I don't receive an income – I have no money (% Yes)	% (n)	7.90 (12)	11.30 (18)	1.04	0.67 [0.31, 1.45]
Have you ever received a diagnosis of a mental illness from a health professional? (% Yes)	% (n)	4.60 (7)	96.20 (153)	–	–
DSM-V category:					
Depressive Disorders	% (n)	1.32 (2)	52.83 (84)	–	–
Anxiety Disorders	% (n)	2.63 (4)	43.40 (69)	–	–
Schizophrenia Spectrum and Other Psychotic Disorders	% (n)	–	30.20 (48)	–	–
Personality Disorders	% (n)	–	25.79 (41)	–	–
Bipolar and Related Disorders	% (n)	–	18.87 (30)	–	–
Trauma-related Disorders	% (n)	0.66 (1)	17.61 (28)	–	–
Eating Disorders	% (n)	1.32 (2)	10.06 (16)	–	–
Obsessive-Compulsive and Related Disorders	% (n)	0.66 (1)	6.29 (10)	–	–
Substance-Related and Addictive Disorders	% (n)	–	4.40 (7)	–	–

M: mean; SD: standard deviation; n: number of participants; OR: odds ratio; 95%CI: 95% confidence interval; AUD: Australian Dollars; TAFE: Technical and Further Education; DSM-V: Diagnostic and Statistical Manual of Mental Disorders, 5th Edition.

* $p < .05$; ** $p < .01$; *** $p < .001$.

diagnosis of mental illness. In the general community group, $n=7$ reported the following lifetime diagnoses: anxiety disorders (2.63%, $n=4$), depressive disorders (1.32%, $n=2$), eating disorders (1.32%, $n=2$), trauma-related disorders (0.66%, $n=1$) and obsessive-compulsive-related disorders (0.66%, $n=1$). None of these seven participants reported that the illness made it difficult for them to complete everyday tasks by themselves or that they had ever accessed psychiatric services. Hence they were retained in the general community sample.

Logistic regression to predict group membership

Statistical assumptions require ≥ 5 observations in 80% of cells for χ^2 analyses (McHugh, 2013). Hence two logistic regressions were performed: one without $n=15$ participants who did not identify as male or female and one including these participants but dropping the gender variable from the analysis. Binary gender did not predict group membership. The two analyses produced near identical results (e.g. statistically significant individual predictors of group membership were exactly the same). In the spirit of inclusion, results of the logistic regression that excluded the gender variable and included all participants are reported here.

Age was entered in Block 1 of the hierarchical logistic regression, explaining $<1\%$ of variance in group membership, over and above that which was explained by the constant in Block 0. Seven items from the *Interpersonal Connections* dimension of the F-SIM were entered in Block 2. After controlling for age, this block explained a statistically significant additional 32% of variance in group membership, Nagelkerke $R^2=.32$, χ^2_{Δ} ($df=7$)=84.65, $p<.001$. The model was statistically significant, χ^2 ($df=8$)=85.51, $p<.001$, and demonstrated goodness-of-fit, Hosmer–Lemeshow χ^2 ($df=8$)=11.28, $p=.19$. Seven items from the *Vocational and Financial Security* dimension of the F-SIM were entered in Block 3. After controlling for variables included in previous blocks, this block explained a statistically significant additional 32% of variance in group membership, Nagelkerke $R^2=.64$, χ^2_{Δ} ($df=7$)=119.53, $p<.001$. The model was statistically significant, χ^2 ($df=15$)=205.04, $p<.001$, and demonstrated goodness-of-fit, Hosmer–Lemeshow χ^2 ($df=8$)=5.48, $p=.71$. Finally, seven items from the *Healthy Independent Lifestyle* dimension of the F-SIM were entered in Block 4. After controlling for variables included in previous blocks, this block explained a statistically significant additional 8% of variance in group membership, χ^2_{Δ} ($df=7$)=36.37, $p<.001$. The final model with 22 predictor variables was statistically significant and explained 72% of variance in group membership, Nagelkerke $R^2=.72$, χ^2 ($df=22$)=241.41, $p<.001$. It demonstrated goodness-of-fit, Hosmer–Lemeshow χ^2 ($df=8$)=7.20, $p=.52$. The final model correctly classified 90% of general community cases, 85% of SMI cases and 87% of overall cases.

Table 2 provides a summary including individual variables that made a unique statistically significant contribution to the final model. Given group membership coding (general community=0, SMI=1), an OR between 0 and 1 denotes reduced likelihood for the SMI group whereas an OR >1 denotes increased likelihood for the SMI group. Young adults with SMI were five times less likely to feel they had friends who would call on them in a crisis (OR=0.19, 95%CI [0.04, 0.52], $p=.04$) and almost five times more likely to live with their parents (OR=4.79, 95%CI [1.98, 11.15], $p<.001$). They were almost four times less likely to have worked/studied at any time in the past 12 months (OR=0.27, 95%CI [0.11, 0.64], $p<.001$) and three-and-a-half times more likely to report unstable accommodation (OR=3.58, 95%CI [1.14, 11.15], $p=.04$). Young adults with SMI were more than two times less likely to be currently studying at a formal institution (OR=0.44, 95%CI [0.30, 0.64], $p<.001$). For every month worked/studied over the past 12 months, SMI group membership was 33% less likely than general community group membership (OR=0.67, 95%CI [0.56, 0.81], $p<.001$). For every glass/cup, small bottle or can of alcoholic beverage consumed per week, SMI group membership was 1.18 times more likely (OR=1.18, 95%CI [1.02, 1.37], $p=.02$).

Discussion

To our knowledge, this is the first study to use a psychometric measure of social inclusion to examine group differences between young adults aged 18–25 with SMI and those from the general community. This contributes to the much-needed establishment of normative and clinical data regarding social inclusion among young adult populations (Evans-Lacko et al., 2014). It also deepens understanding of gross objective discrepancies (e.g. smaller social networks) by elucidating nuances of the social exclusion experienced by young adults with SMI. In so doing, these findings suggest the need for novel approaches to improving social inclusion in this population.

Summary of findings

The F-SIM dimensions of *Interpersonal Connections*, *Vocational and Financial Security* and *Healthy Independent Lifestyle* significantly discriminated between groups and accounted for a large amount of variation in group membership. Individual indicators suggested that young adults with SMI were socially excluded relative to peers from the general community in a number of areas. Those with SMI were significantly less likely to feel they had friends who would call on them in a crisis, to have been vocationally engaged in the past year, and to be currently studying at a formal institution. They were significantly more likely to live with their parents and to report unstable accommodation. This logistic regression model demonstrated a high

Table 2. Summary of the hierarchical logistic regression with group membership of $N=311$ young adults aged 18–25 years ($GC=0$, $SMI=1$) as the outcome variable and age entered in Block 1, F-SIM Interpersonal Connections dimension items entered in Block 2, F-SIM Vocational and Financial Security dimension items entered in Block 3 and F-SIM Healthy Independent Lifestyle dimension items entered in Block 4 as predictor variables.

Regression block	Individual predictor variables	B	SE	Wald χ^2 (df=1)	OR	95% CI for OR
Block 1: Age						
Nagelkerke $R^2 = .01$	Age in years	–0.01	0.10	0.01	1.00	0.82, 1.20
Cases correctly classified = 52%						
Block 2: F-SIM Interpersonal Connections dimension						
Nagelkerke $R^2 = .32$	How satisfied are you with your social life?	–0.31	0.35	0.82	0.73	0.37, 1.44
Cases correctly classified = 71%	How satisfied are you with your social activities?	–0.41	0.39	1.12	0.67	0.31, 1.42
	I don't have a group of friends to do anything with socially	0.24	0.34	0.51	1.28	0.65, 2.50
	How often do you catch up with a friend for social activity?	–0.33	0.27	1.53	0.72	0.42, 1.22
	Do you have friends who would call on you in a crisis?	–1.66	0.84	3.93*	0.19	0.04, 0.53
	Do you have good friends you see or speak to regularly?	–1.07	0.62	2.98	0.34	0.10, 1.16
	Do you have friends who would call on you to discuss everyday experiences?	–0.21	0.78	0.07	0.81	0.18, 3.73
Block 3: F-SIM Vocational and Financial Security dimension						
Nagelkerke $R^2 = .64$	Are you currently unemployed?	0.38	0.72	0.27	1.45	0.36, 5.90
Cases correctly classified = 81%	Are you currently working for pay?	–0.07	0.24	0.09	0.93	0.58, 1.49
	How many of the past 12 months did you work or study for?	–0.40	0.10	17.44***	0.67	0.56, 0.81
	Over the past 12 months did you work or study at any time?	–4.61	1.17	15.58***	0.27	0.11, 0.64
	Have you been enrolled in any formal studies in the past 12 months?	–0.32	0.57	0.30	0.73	0.24, 2.22
	Are you currently studying at a formal institution?	–0.82	0.19	18.80***	0.44	0.30, 0.64
	Are all household members ≥ 18 years old currently employed or attending formal education?	–0.97	0.50	3.76	0.38	0.14, 1.01

(Continued)

Table 2. (Continued)

Regression block	Individual predictor variables	B	SE	Wald χ^2 (df=1)	OR	95% CI for OR
Block 4: F-SIM Healthy Independent Lifestyle dimension						
Nagelkerke $R^2 = .72$ Cases correctly classified = 87%	Do you currently live with your parents?	1.57	0.46	11.91**	4.79	1.98, 11.15
	Are health services in your local community of a good standard?	0.06	0.43	0.02	1.06	0.46, 2.46
	I don't have the time to do what I think I should do. I need more time in the day	0.47	0.30	2.48	1.60	0.89, 2.88
	Is your accommodation unstable (e.g. Are you worried about being evicted)?	1.27	0.58	4.74*	3.58	1.14, 11.15
	How many alcoholic beverages (e.g. glass/cup, small bottle or can) do you drink per week?	.17	.07	5.20*	1.18	1.02, 1.37
	Are you living in a location other than where you would like?	0.21	0.57	0.14	1.24	0.41, 3.70
	Do you currently use illegal substances?	1.24	0.90	1.91	3.70	0.60, 20.00

SE: standard error; OR: odds ratio; GC: General Community; SMI: Serious Mental Illness; F-SIM: Filia Social Inclusion Measure; Nagelkerke R^2 : estimated % of variance in group membership explained cumulatively by blocks in the logistic regression model.

* $p < .05$; ** $p < .01$; *** $p < .001$.

level of accuracy in group classification. Alongside evidence that young people at risk of developing SMI are socially excluded (Robustelli, Newberry, Whisman, & Mittal, 2017), these findings suggest that models of social inclusion may have a part to play in the early identification of SMI.

Comparison to previous literature

Comparisons to previous literature are complicated by the lack of studies using psychometric measures of social inclusion to examine group differences between young adults from the general community and those with SMI. Nonetheless, these findings are consistent with evidence that young adults with SMI have smaller social networks (Gayer-Anderson & Morgan, 2013), are less vocationally engaged (Iyer et al., 2018), experience lower levels of independence (Breitborde, Woolverton, Frost, & Kiewel, 2014) and higher levels of housing instability (Narendorf, Cross, Santa Maria, Swank, & Bordnick, 2017) than those from the general community.

The findings support evidence that vocational engagement contributes to social inclusion for young adults with SMI (Gardner, Cotton, Allott, et al., 2019). They also suggest subtle differences in historical versus current vocational engagement and in employment-specific versus education-specific factors. Unspecified historical vocational engagement (i.e. *Did you work or study at any time over the past year?*) significantly discriminated between groups. The education-specific indicator of enrolment in formal studies over the past year did not discriminate between groups. This raises the question as to whether observed differences in vocational engagement over the past year were driven by employment-specific factors. Young adults with SMI may have been less likely to have worked, but not necessarily less likely to have studied, than their peers from the general community over the past year. This remains speculative, because no indicators exclusively assessing work history over the past year were included in the analysis. It is also important to distinguish enrolment in formal studies from attendance at such studies. Although young adults with SMI were not significantly less likely to be enrolled in formal education over the past year, they were significantly less likely to be currently attending an educational institution. This is consistent with evidence that young adults with SMI are less likely to be engaged in postsecondary education than peers from the general community (Roy, Rousseau, Fortier, & Mottard, 2016). It also suggests that there may be some utility in examining discrepancies between rates of enrolment and rates of attendance in educational settings for young adults with SMI. Such discrepancies may provide a useful index of the disruption that SMI can engender for affected young people.

In this study, indicators of current unemployment did not significantly discriminate between groups. This is

inconsistent with evidence of a higher unemployment rate among young adults with SMI relative to peers from the general community (Ramsay, Stewart, & Compton, 2012). Methodological differences may have contributed to this inconsistency. Ramsay and colleagues included a wider age range for participants (18–40 years-of-age) and found that age was independently associated with unemployment. That is, younger age predicted higher unemployment. A relatively restricted age range in this study (i.e. 18–25) may have precluded us from detecting such an effect. Periods of unemployment, though likely detrimental to wellbeing, are commonly experienced by people in this age group (Lee et al., 2019). This may partly obscure the effects of illness-related employment difficulties for young adults with SMI, with such effects emerging from early to middle adulthood.

Clinical implications

Increased social inclusion (e.g. improved social relationships and vocational engagement) is a common treatment goal among young adults with SMI (Cotton et al., 2011; Iyer, Mangala, Anitha, Thara, & Malla, 2011; Ramsay et al., 2011). Individual Placement and Support (IPS) is an intervention that has demonstrated efficacy in terms of increasing vocational engagement for young adults with SMI (Killackey et al., 2019). However, perceptions of social exclusion in terms of interpersonal relationships are an important and under-researched treatment area in this population (Lim & Gleeson, 2014). The findings of the present study suggest that interventions to improve social inclusion should target such perceptions in addition to increasing vocational engagement. Young adults with SMI were significantly more likely to perceive that they had no friends who would call on them in a crisis, with a large effect size. The smaller social networks observed in this population likely reduce opportunities for young adults with SMI to receive interpersonal support. However, they may also reduce opportunities for young adults with SMI to demonstrate their ability to *provide* support to others – a crucial element of the reciprocity involved in satisfying interpersonal relationships. An implication of this finding is that interventions to improve social inclusion in this population need to address peer attitudes, beliefs and behaviors toward young adults with SMI. That is, a whole-of-community approach may be most effective (Saavedra, Pérez, Crawford, & Arias, 2017).

Relative to those from the general community, young adults with SMI were more likely to live with their parents, with a large effect size. Although it may be argued that this provides necessary social support for some individuals, there is evidence that living with parents is negatively associated with social inclusion for young adults with SMI (Gardner, Cotton, O'Donoghue, et al., 2019). Social inclusion interventions may therefore need to help empower

young adults with SMI to establish an optimal level of autonomy/independence while ensuring access to support. Young adults with SMI were also more likely to report unstable accommodation, with a large effect size. This suggests a role for housing support services in any interventions aimed at promoting adaptive autonomy/independence in this population.

These findings have several implications regarding how early intervention services may best respond to the psychosocial needs of their clients. It may be helpful for clinicians to ask whether young adults with SMI feel they have opportunities to demonstrate their capacity to be a source of support *to* others. This may be an overlooked element of social inclusion compared to the more common enquiries about available support *from* others. Related to this are notions of autonomy and independence. It may be helpful for clinicians to assess how satisfied young adults with SMI are with their level of independence (particularly as it relates to living situation), while being sensitive to individual support needs. Such approaches may be combined with evidence-based vocational programs (e.g. IPS) to improve social inclusion for young adults with SMI.

Strengths and limitations

It is plausible that mental illness causes social exclusion (the 'social drift' hypothesis), and plausible that social exclusion causes mental illness (the 'social causation' hypothesis (O'Donoghue, Roche, & Lane, 2016)). A limitation of this study is that causality cannot be inferred from these cross-sectional, correlational findings. Given that the F-SIM is administered entirely via self-report, none of its items can be considered strictly objective. This is a further limitation. However, the F-SIM has been developed through consultation with experts, carers and consumers (Filia et al., 2019). Also, its psychometric properties have been examined specifically among young adults with SMI (Gardner, Cotton, O'Donoghue, et al., 2019). These are strengths of the study. Another strength is the item-level examination of social inclusion variables, which afforded a sufficiently granular level of detail so as to be clinically informative. The novelty of the finding that young adults with SMI were less likely to experience reciprocity in interpersonal relationships is another strength. It is important to note that the 95%CI around the OR for this effect was relatively wide, and its lower bound estimate was approaching zero. This highlights the need for replication of the effect, and is a potential limitation.

Future research directions

It will be helpful for future research to further examine actual and perceived reciprocity in interpersonal relationships (e.g. do members of the wider peer group around young adults with SMI note the proposed discrepancy in

reciprocity?). Exploring additional methods for measuring reciprocity may help increase the precision of the proposed effect. There is no 'gold standard' measure of social inclusion – existing tools require ongoing development (Cordier, Milbourn, Martin, Buchanan, & Chung, 2017). This includes the F-SIM, which is one of the first measures to examine social inclusion specifically among young adults with SMI (Gardner, Cotton, O'Donoghue, et al., 2019). Although it has demonstrated reliability and validity in this population, the F-SIM requires further refinement to become clinically useful (e.g. the production of a shortened version). It would also be helpful to examine potential mediators of the relationship between group membership (general community vs SMI) and social inclusion among young adults. There is evidence that self-stigma predicts reduced social inclusion for young adults with SMI (Berry & Greenwood, 2018). Further examination of such potentially mediating variables may enable the development of more effectively targeted interventions.

Conclusion

Young adults with SMI are considered socially excluded relative to peers from the general community, but this has not been examined via psychometric measures of social inclusion. We undertook such an examination and found evidence of social exclusion in terms of interpersonal connections, vocational engagement and independence. Improving the social inclusion of young adults with SMI may involve addressing peer attitudes and maximizing independence, in addition to the more established vocational interventions.

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CHAPTER SEVEN: GROUP DIFFERENCES IN SOCIAL INCLUSION BETWEEN YOUNG ADULTS WITH SERIOUS MENTAL ILLNESS AND THOSE FROM THE GENERAL COMMUNITY

Overview of Results

The paper presented in this chapter examined group differences in social inclusion between young adults aged 18–25 years with SMI and same-aged peers from the general community. This involved a four-block hierarchical binary logistic regression, with group membership as the outcome variable and demographic as well as individual F-SIM items entered as predictor variables. So as to avoid over-fitting, only 23 predictor variables were entered into the model. Age and gender were entered as predictors in block one. The seven strongest loading items from each of the three F-SIM dimensions identified in the SMI sample of Chapter Five (*Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*) were entered as predictor variables in the subsequent three blocks.

The results suggested that the three F-SIM dimensions accurately discriminated between groups, and explained significant amounts of variation in group membership. Significant group differences on individual indicators suggested that young adults with SMI were socially excluded relative to peers from the general community in each of these dimensions. Young adults with SMI were significantly less likely to feel they had friends who would call on them in a crisis, and to have been vocationally engaged at any time in the past 12 months. They were significantly more likely to live with their parents, and to report unstable accommodation.

The relevant theoretical and clinical implications of these findings will be addressed in the following Discussion chapter.

CHAPTER EIGHT: GENERAL DISCUSSION

The overarching purposes of this research program were to clarify dimensions and indicators of social inclusion among young adults with SMI, and to better understand the putative social exclusion of this cohort. Accordingly, the literature on social inclusion in this population was reviewed. Observational research was presented exploring the psychometric properties of a novel measure of social inclusion (the F-SIM) among young adults both with and without SMI. Differences between these two cohorts in terms of social inclusion were also delineated. The research program involved more than 150 participants from various segments of the general community, as well as over 150 participants with SMI who were attending different mental health services across Melbourne, Australia. Much of the research is novel, and the results have implications for assessment and intervention to increase social inclusion among young adults with SMI, and for the social inclusion literature more broadly. The main findings of the research program are summarised in this chapter, which will also discuss implications of the findings, consider the strengths and limitations of the thesis, and identify areas for future research.

Summary of Research Findings

The literature review presented in Chapter Two identified significant gaps in the social inclusion literature. Specifically, a lack of operationalisation (i.e., few studies offering formal definitions of social inclusion) was noted. This was particularly evident among young adult populations, who appeared to be underrepresented in the emergent social inclusion literature. Young adults with SMI were putatively socially excluded, but this had not been empirically examined in an integrative, multi-dimensional way. Evidence for their social exclusion relative to same-aged peers from the general community came from objective indicators in independent areas of research (e.g., higher unemployment rates). The review found a lack of psychometric tools, which combine objective and subjective indicators across dimensions, to measure social inclusion specifically

among young adults – with or without SMI. This was noted as impeding a comprehensive understanding of the social exclusion experienced by young adults with SMI relative to same-aged peers from the general community.

The empirical paper presented in Chapter Five reported on psychometric properties of a preliminary version of the F-SIM among young adults with SMI. Findings regarding the reliability and validity of the F-SIM were promising. Three dimensions emerged, suggesting that social inclusion involves *Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle* in this population. These dimensions were only partially replicated in the methodologically similar examination of a preliminary version of the F-SIM among young adults from the general community (Chapter Six). Two dimensions emerged in that study (*Interpersonal Connections*, and *Community Integration*). Estimates of reliability and validity were promising in that population, although the F-SIM explained less variation than in the SMI population.

The empirical paper presented in Chapter Seven reported group differences between young adults with SMI and same-aged peers from the general community on F-SIM indicators. As noted above, similarities and differences in terms of relevant dimensions and indicators of the instrument were identified in each population. Given the overarching purposes of the research program, the relevant F-SIM dimensions and indicators identified among young adults with SMI (Chapter Five) were used in this study. The F-SIM was highly accurate at predicting, and explained a large amount of variation in, group membership. Relative to young adults from the general community, those with SMI were socially excluded according to individual indicators in all three F-SIM dimensions (*Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*).

These findings raise several questions, which have significant theoretical and practical implications.

Do Dimensions of Social Inclusion Differ Between Populations?

Common theoretical assumptions are that social inclusion is multidimensional (Baumgartner & Burns, 2014; Morgan et al., 2007), and that dimensions are consistent across populations (Cordier et al., 2017). If it is derived from a fundamental human need to belong (Baumeister & Leary, 1995), one would expect some universality in dimensions of social inclusion. Another common assumption is that social inclusion is process-like, dynamic, and relative to place and time (Huxley et al., 2006), allowing the possibility that dimensions may differ depending on population-specific factors. The findings of this research program support the notion that social inclusion is multidimensional, that there may be a universal interpersonal dimension, and that further dimensions may vary between populations (at least regarding young adults with SMI and those in the community). This has not been considered in the literature, where an implicit assumption seems to be that dimensions of social inclusion are fixed across community and SMI samples (e.g., Huxley et al., 2012). It is important to note that these findings are preliminary, and do not provide critical evidence that dimensions of social inclusion necessarily differ between populations. They do, however, encourage a questioning of the assumption that dimensions of social inclusion are fixed across populations. We will now consider possible explanations for why a different dimensional structure emerged in each of the two populations that were sampled in this research program.

What Does the Emergence of Different F-SIM Dimensions Signify?

Figure 3 offers a schematic representation of similarities and differences in dimensions of social inclusion suggested by results of the principal components analyses of the F-SIM.

Interpersonal Connections emerged as the cardinal dimension of social inclusion for young adults with and without SMI. Similar dimensions have been posited in many social inclusion studies examining key components of the construct in various populations (e.g., Berry & Greenwood, 2018; Huxley et al., 2012; Mezey et al., 2013; Secker et al., 2009). This is consistent with an evolutionary

account where affiliative bonds are required to satisfy a universal need to belong (Baumeister & Leary, 1995). Simply put, it appears that spending time with good friends and supportive family is likely the most significant aspect of social inclusion for all of us. Evolutionary accounts may also help explain the differences in F-SIM dimensions that emerged between groups. Social Rank Theory suggests that young adults with SMI may perceive their social status to be lower than that of their peers in the community, based on difficulties reaching developmentally appropriate milestones relative to such peers (Birchwood et al., 2006). Social roles identified with achieving such milestones (e.g., employment/education, independence from parents) may become especially valued by young adults with SMI, as a means of attaining parity with peers. Though still important for young adults in the community, such roles may be somewhat taken for granted and remain equally weighted with other aspects of the normative transition to adulthood in this population. This may help explain the somewhat broad and heterogeneous specification of community integration in the community sample, relative to the more differentiated *Vocational & Financial Security* and *Healthy Independent Lifestyle* dimensions among those with SMI. The former dimension is well established as a salient aspect of recovery for young people with SMI (Killackey et al., 2006). There is evidence that the latter is positively associated with social functioning and QoL among young adults with SMI (Breitborde et al., 2014), but it is novel as a dimension of social inclusion. As reported in Chapter Five, living with parents was a negative indicator of social inclusion for young adults with SMI. It was unrelated to social inclusion in the general community sample, for whom living with parents is likely a transitory arrangement with no direct bearing on social inclusion. For a variety of reasons, living with parents may not be a brief, transitory arrangement for young adults with SMI. An independent lifestyle may become highly valued in this cohort as a marker of capacity to ‘keep up’ with peers from the general community who are launching themselves into adulthood. Such theoretical accounts may help inform future research on similarities and differences between dimensions of social inclusion across these two populations. However, they do not address the more proximal issue of how to further develop the F-SIM for use in these populations.

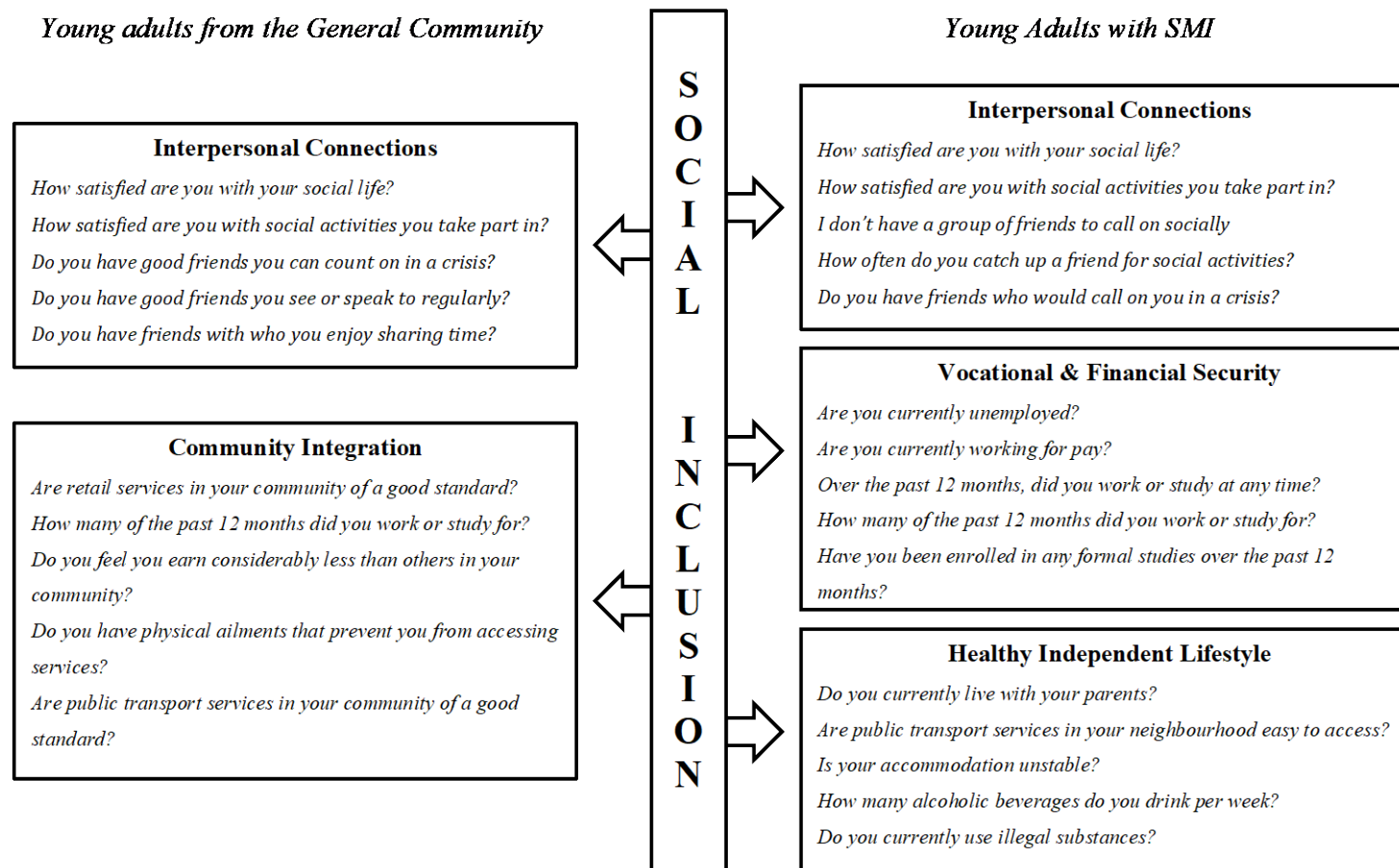


Figure 2. Schematic representation of similarities and differences in dimensions of social inclusion suggested by results of the principal components analyses of the Filia Social Inclusion Measure (F-SIM) within each group. Text boxes represent dimensions of the F-SIM, and italicised text within the text boxes represents individual F-SIM items that are characteristic of the relevant dimension.

How do We Further Develop the F-SIM?

Assuming results of the psychometric evaluations of the F-SIM among young adults with SMI (Chapter Five) and in the general community (Chapter Six) are replicable, then subtly different versions of the measure may be indicated in each population. This is, of course, common practice. For example, the Strengths and Difficulties Questionnaire was originally developed for use among 3–16 year olds displaying emotional and/or behavioural disturbances (Goodman, 1997). Subsequent versions with different items and/or scales have been developed specifically for adolescents (Goodman et al., 1998), general population samples (Goodman et al., 2010), and adults with Down syndrome (Glenn et al., 2013). With appropriate development, the F-SIM may become a useful tool for assessing the efficacy of early intervention services in terms of increasing social inclusion for young adults with SMI, and also for screening for social exclusion among young adults in primary healthcare settings, where such tools are needed (O'Donnell et al., 2018). However, careful consideration must be given as to how a version of the F-SIM with norms and cut-off scores (i.e., that can compare social inclusion/exclusion across populations) ought to be developed.

Implications for Between-Group Comparisons

The concept of 'healthy normativity,' which is ubiquitous in the health and social sciences (Sripada & Stich, 2006), may be complicated to assess with social inclusion measures. That concept may apply to the social determinants of health, i.e., the material conditions in which people live (Marmot, 2005). The findings of the present thesis suggest that social determinants of health (e.g., objective neighbourhood factors) contribute to social inclusion in each of the young adult populations that were sampled. The hallmark characteristic of social inclusion – one which differentiates it from related constructs – is subjective perception (Berry & Greenwood, 2018), e.g., of material conditions. In this research program, some subjective indicators on the F-SIM (e.g., perceived dangerousness of neighbourhood) loaded on dimensions of social inclusion among young

adults with SMI, but not those in the general community. This is perhaps emblematic of broader difficulties applying norm-based models to subjective aspects of social inclusion. For example, the specific opportunities that are valued, and levels of belongingness need, vary significantly in young adulthood (Verhagen et al., 2018). It is unclear how to satisfactorily accommodate idiographic factors in general measures designed to compare differences in social inclusion across groups. In this research program, the F-SIM dimensions and indicators identified among young adults with SMI (Chapter Five) were used to examine differences between that group and young adults in the general community (Chapter Seven). This may be theoretically justifiable in terms of addressing the overarching purposes of the research program. Indeed, the high levels of accuracy, and large percentage of variation explained, in predicting group membership by those dimensions supports this approach. However, it is methodologically problematic, because it may violate the statistical assumption of metric invariance (Schnabel et al. 2015). This challenge is not unique to social inclusion research. Similarities and differences in the factor structure of social cognition measures between people with psychosis and controls have been reported (Buck et al., 2016). The optimal approach to examining group differences on complex constructs that demonstrate dimensional similarities and differences across populations is unclear. With respect to measures of social inclusion, it may be necessary to integrate the seemingly universal interpersonal dimension, relevant nomothetic indicators (e.g., social determinants of health), and idiographic aspects.

One idiographic aspect of social inclusion at the group level that seems to be under-emphasised in the literature is the effect of social milieu (i.e., unique aspects of particular social environments). When developing the Social Inclusion Scale in adult psychiatric samples, Secker et al. (2009) included a number of items assessing the extent to which participants' social lives were limited to activities within mental health services. Although this potentially raises issues of stigma, it seems an ecologically valid aspect of social inclusion for adults with SMI, given evidence that their socialising largely occurs in treatment contexts (Moll & Saeki, 2009). When adapting the

Social Inclusion Scale to a population situated within a different social milieu, i.e., university students (Wilson & Secker, 2015), such items were appropriately omitted. The same issue was encountered when using the Social Inclusion Scale to examine construct validity of the F-SIM in this research program. In the SMI sample (Chapter Five), the mental health service use items were retained. In the community sample (Chapter Six), those items were removed. If group comparisons between these two samples on the Social Inclusion Scale were to be conducted, which version ought to be used? Berry and Greenwood (2018b) took a novel approach to accommodating the idiographic effects of social milieu. They adapted the above-mentioned Social Inclusion Scale items from the psychiatric version so that participants were free to insert relevant information about their social milieu (e.g., the groups that they felt most strongly defined them). A version of the F-SIM designed to examine group differences between young adults with and without SMI might benefit from applying such an approach to group- and individual-level (e.g., social roles that they feel most strongly define them) idiographic factors. This would require subsequent development of the instrument to involve a stronger emphasis on mixed quantitative-qualitative methods.

In this section, we have discussed the challenges of comparing young adults with and without SMI on measures of social inclusion, and acknowledged limitations of the approach to doing so that was taken in this thesis. Next we will discuss findings of social exclusion among young adults with SMI relative to peers in the community, speculate as to potential mechanisms of exclusion, and consider relevant interventions to improve social inclusion in this population.

How do we Explain and Address Social Exclusion among Young Adults with SMI?

The research presented in this research program offers a combination of replication and novel insight in terms of the putative social exclusion experienced by young adults with SMI. In line with previous research, young adults with SMI reported less vocational engagement (Iyer et al., 2018), lower income (Burns & Esterhuizen, 2008), and more unstable accommodation (Doré-

Gauthier et al., 2019) than same-aged peers from the general community. As discussed in the literature review in Chapter Two, such disparities in social determinants of health between these two populations are well established. The finding that living with parents was negatively related to social inclusion for young adults with SMI, and was more likely than for peers from the community, is a novel aspect of social exclusion. Likewise, the finding that young adults with SMI were less likely to feel they had friends to whom they could *provide* support (as opposed to having friends from whom they may *receive* support) is a novel contribution. These observational findings pertaining to the social exclusion of young adults with SMI afford no inference of causality. However, they may inform a speculative discussion of potential mechanisms of social exclusion and interventions to address it in this population.

Potential Mechanisms of Social Exclusion.

It is plausible that mechanisms of social exclusion operate at the ‘within-person’ (i.e., biological, psychological) and ‘within-community’ (i.e., social) levels. Social cognition, defined as the perception, interpretation, and processing of social information (Penn et al., 1997), represents a potential within-person mechanism. Social cognitive skills are important for enabling successful group membership (Frith, 2008). Young adults with SMI demonstrate deficits in social cognition relative to same-aged peers without SMI, particularly in terms of emotion recognition (Healey et al., 2016). Difficulties accurately identifying emotions (e.g., misperceiving neutral or happy facial expressions as hostile [Catalan et al., 2016]) might mean that young adults with SMI are more likely to feel excluded during innocuous interactions with others. Social cognition may also constitute a ‘within-community’ mechanism. Young adults in the community may avoid those who have SMI, due to discomfort stemming from an inability to rely on implicit social cognitive assumptions that govern normative interactions. Both of these pathways might plausibly explain the social exclusion of young adults with SMI evident in the above thesis findings (especially a perceived lack of reciprocity in social relationships). However, there is preliminary evidence that social cognition and

social inclusion may not be significantly related among young adults with SMI (Gardner et al., 2019a). As with social inclusion, further development of social cognition measures is needed (Pinkham et al., 2015). As their measurement improves, it will be important for future research to examine the potential relationships between these two constructs.

Stigma, which also operates on within-community and within-person levels, is another plausible mechanism for explaining the social exclusion experienced by young adults with SMI. Public stigma is the process whereby general community members label people with SMI as ‘different’ (i.e., othering) based on negative perceptions, e.g., that they are distasteful or fearsome (Penn et al., 1994). Up to 76% of young adults with SMI report being stigmatised, the most troubling aspects of which were reported to be general public shunning, difficulties making and keeping friends, and being stigmatised by family members (Kinson et al., 2018). This suggests that for young adults with SMI, public stigma contributes to a global sense of exclusion from the community, and a specific sense of exclusion from the peer and family groups. Community attitudes and public stigma are not typically measured in social inclusion studies, and were not included as variables in this research program. Future research examining the social exclusion of young adults with SMI must take these factors into account, in order to determine the extent to which community-level interventions may be indicated.

Self-stigma is the process whereby negative community perceptions are internalised by people with SMI (Corrigan & Watson, 2002). It has been suggested that self-stigma contributes to social withdrawal for people with SMI via psychological pathways, e.g., reduced hopefulness and self-esteem (Yanos et al., 2010). Berry and Greenwood (2018a) found that self-stigma predicted reduced social inclusion, and that hopefulness mediated that relationship, within a sample of young adults with SMI. They also found evidence that the negative association between self-stigma and social inclusion strengthened with age. Coupled with evidence that self-stigma is less prevalent

among younger relative to older people with SMI (Thabrew, 2014), this suggests that such potentially modifiable psychological factors may be targets of interventions to reduce social exclusion. However, it is unclear what effect self-stigma and hopefulness in this population may have on group differences in social inclusion between young adults with SMI and those from the community. It will be helpful for future research to explore the potential mediating role of these variables in group comparison studies.

The prodromal phase of SMI may play a crucial role in the social exclusion of affected young people. There is evidence that young adults at high risk of developing SMI are more likely to live with parents and be vocationally disengaged than those from the general population (Fusar-Poli et al., 2010). Within such high-risk samples, baseline indicators of social disability (e.g., difficulties in making and keeping friends, and in joining community activities) predict transition to SMI at 18-month follow-up (Velthorst et al., 2010). Hence, social exclusion may predate, and potentially be an aetiological factor in, the onset of SMI (i.e., the social causation hypothesis [Kohn, 1972]). Yet social withdrawal is a hallmark characteristic of some forms of SMI, e.g., the negative symptoms of psychosis (American Psychiatric Association, 2013), suggesting that psychopathology may initiate or exacerbate social exclusion (i.e., the social selection hypothesis [Muntaner et al., 2004]). Both hypotheses have received empirical support, and the debate over which is more applicable has continued over many years across many countries (Saraceno et al., 2005). Meanwhile, there is evidence that social exclusion persists longitudinally after symptomatic remission for young adults with SMI (Alvarez-Jimenez et al., 2012; Revier et al., 2015). This perhaps supports the hypothesis that adolescence and early adulthood constitute a sensitive period for social inclusion. The prodromal phase of SMI may engender a psychosocial gap between affected young people and their peers from the general community, which is maintained or widened during the onset and course of the illness. Those who make a symptomatic recovery, which seems more common than previously thought (Revier et al., 2015), may nonetheless find it difficult to bridge the psychosocial gap due to

the ‘scarring’ effect of time away from peers and vocational pursuits (Killackey et al., 2013). If this is the case, then the age range considered in this thesis (18–25 years old) may be inadequate in terms of implementing effective early intervention strategies to prevent social exclusion among young people with SMI. Screening for indicators of social exclusion among young people less than 15 years of age may be required, given that approximately half of all lifetime mental disorders have their onset in the mid-teens (Kessler et al., 2008). Prospective research focusing on the trajectories of social inclusion among young people (i.e., those in the community, those at risk of developing SMI, and those who develop SMI) is needed to help clarify these issues.

Candidate Interventions to Improve Social Inclusion.

The findings of this research program indicate the need to combine existing interventions in established areas (e.g., vocational disengagement) with developing interventions to address novel aspects of social exclusion (e.g., lack of reciprocity in social relationships) for young adults with SMI. With respect to reduced vocational engagement, Individual Placement and Support (IPS) is an evidence-based intervention with demonstrated efficacy in improving employment outcomes for this population (Bond, Drake & Campbell, 2016). The findings of this thesis suggest that educational disengagement may be a more significant vocational contributor to social exclusion for young adults with SMI. There is some evidence that IPS is efficacious in terms of improving educational engagement for young people with SMI (Killackey et al., 2017; Robson et al., 2010). However, a systematic review found no difference in educational enrolment rates between young people attending early intervention services who received IPS and those who did not (Bond, Drake & Luciano, 2015). In this research program, being enrolled in formal studies at any stage in the past 12 months was not a significant predictor of group membership. However, young adults with SMI were significantly less likely to be actively *participating* in education (i.e., currently attending a formal institution) than same-aged peers in the general community. Support in maintaining (e.g.,

overcoming barriers towards) active participation in education after enrolment may be an especially important aspect of IPS in terms of improving social inclusion for young adults with SMI.

The IPS model has been successfully applied among young people with SMI who are homeless (Ferguson, Xie & Glynn, 2012). Given the thesis finding of increased housing instability in this population, and the well-established link between employment and housing outcomes, such indirect interventions to address homelessness (i.e., ‘employment first’ [Finn, 2003]) may help increase social inclusion for young adults with SMI. Clinical services have not historically been efficacious in terms of directly addressing homelessness (Odell & Commander, 2000). However, emerging evidence suggests that a ‘housing first’ approach combined with clinical case management can be efficacious in terms of improving housing outcomes for homeless youth with SMI (Kozloff et al., 2016). In order to increase social inclusion among young adults with SMI, early intervention services must have such housing interventions at their disposal.

The perceived lack of reciprocity in friendships for young adults with SMI (i.e., that others do not call on them for support) suggests the need for within-person and within-community interventions. Addressing unhelpful cognitions about existing social networks may be useful in terms of improving current relationships in this population (Lim & Gleeson, 2014). Social skills training, which may help improve existing relationships and provide tools to expand social networks, has demonstrated efficacy among young adults with SMI (Bartholomeusz et al., 2013; Penn et al., 2011). It is important to note that perceived lack of reciprocity in social relationships is often entirely realistic for young adults with SMI (due to stigma, ‘othering’ by peers etc.). The concept of early intervention as it relates to social inclusion may therefore need to be broadened. Comprehensive assessment of at-risk mental states among young people has become part of evidence-based care in early intervention services (Yung et al., 2005). It may similarly be useful to screen young people in the general population for beliefs and attitudes that signify increased risk of

stigmatising others. There is evidence that prejudicial attitudes towards people with SMI are predicted by authoritarian distancing (i.e., the inability to take the perspective of stigmatised others, or to empathise with the emotional pain they may be experiencing [Levin et al., 2016]). Screening for such risk factors at the community level (e.g., in schools) may help identify young people who would benefit from interventions to reduce stigmatising attitudes/behaviour. The Jigsaw Classroom (Aronson, 1978) is a well-established intervention designed to cultivate interdependence among small groups comprised of students with diverse backgrounds and abilities. A simple ten-step procedure makes it easy for educators to implement, and it has demonstrated efficacy in reducing prejudice, increasing peer acceptance, and improving academic performance (Walker & Crogan, 1998). Increased psychological flexibility in the general public (e.g., learning to manage the discomfort of awkward social interactions with others who are unlike oneself) has also shown efficacy in reducing stigma (Krafft et al., 2018). The particular dimensions and unique developmental aspects of mental illness stigma among young people in the community need to be better understood (De Luca, 2019). Nonetheless, the above interventions may help prevent or reduce the social exclusion of young adults with SMI, and augment existing awareness raising and mental health literacy campaigns.

The results of this research program suggest that living with parents may inhibit social inclusion for young adults with SMI. They also suggest that this living arrangement is much more likely in this cohort than among same-aged peers from the general community. More research is needed to better understand the relationship between living with parents and social inclusion among young adults with SMI. High expressed emotion (i.e., negative intrafamilial emotional expressions about/towards the family member with SMI) is highly prevalent among family systems in this population (Raune et al., 2004). Expressed emotion was not considered here, yet may impact the relationship between living with parents and social inclusion. We have argued that this living arrangement may inhibit social inclusion for young adults with SMI by diminishing their

independence. If this is the case, then increasing independence in this cohort should be a treatment target for early intervention services. Clinical services may need to provide psychoeducation to families and friends about the importance of autonomy and independence in terms of social inclusion for young adults with SMI. Simple strategies such as encouraging the young person to navigate their own way to and from appointments, when appropriate, may be useful. Some parents/family members may feel understandably protective of the young person, and find it challenging to accept increased independence as a treatment target. Family therapy and/or individual sessions wherein parents/carers can receive appropriate support may be indicated in such cases. Also in the context of family systems, it is important to note that there may be intergenerational factors contributing to the social exclusion of young adults with SMI. For example, there is evidence that familial history of dependence on income support is strongly related to not being in education, employment, or training (NEET) in this population (Ryan & Sartbayeva, 2011). This NEET status may in turn be a practical barrier to independent living (e.g., moving out of the parental home) for young adults with SMI, perhaps mediated by attendant financial difficulties. This highlights the need for clinicians to be sensitive to the complex interrelationships between various aspects of social exclusion at the level of the family unit.

Given the variety and complexity of social inclusion, a broad therapeutic framework within which specific interventions can be enacted may be needed. Social recovery therapy (Fowler et al., 2013) is a cognitive behavioural approach designed to address the social disability often experienced by young people with SMI. It focuses on practical/behavioural strategies while building positive beliefs about the self and others (as opposed to only challenging negative beliefs). Crucially, the intervention emphasises an individually tailored approach focusing on the identification of meaningful values and goals. Participation in valued social roles (e.g., employment/education) is integral to social inclusion, but role specifics will be unique to the individual (e.g., working in a particular industry, enrolling in a specific course). Given its

idiographic emphasis, social recovery therapy seems promising as a therapeutic framework for social inclusion interventions. There is emerging evidence that social recovery therapy increases engagement in structured social activity and improves hopelessness and positive self-beliefs for young adults with SMI (Fowler, Hodgekins & French, 2019). This is encouraging, given that there are no established interventions for self-stigma in early SMI (Thabrew, 2014).

Future Research

Suggestions for future research have been made at various points throughout the above discussion, and will not be repeated here. This section will briefly outline direct extensions of the research program in terms of developing the F-SIM, as well as broader issues for future research within the social inclusion literature.

Direct extensions of the research.

This research program has provided preliminary data regarding which dimensions and indicators of the F-SIM may be relevant for young adults with and without SMI. It has also supported assumptions about the associations between the F-SIM and measures of related constructs, and suggested the psychometric suitability of the measure in these populations. Assuming they are replicable, these preliminary findings may help inform the development of a shortened and validated version of the F-SIM. This may be done either individually within each population, or with a view to creating a single measure that is capable of assessing deviation from the norm/s of social inclusion. Both approaches have advantages and disadvantages.

A version of the F-SIM designed specifically for young adults with SMI could be developed through confirmatory techniques imposing the three-dimensional structure reported here on a fresh and ideally larger sample. The 61 F-SIM items with component loadings $\geq .32$ and test-retest reliability ($ICC_{3,2}$) $\geq .70$ that were identified in Chapter Five could be used as a starting point for

further item reduction (to make the instrument shorter and more usable in busy early intervention services). A more thorough examination of construct validity, combining a replication of findings of convergent validity reported here with an exploration of discriminant validity, would be required. Assuming the psychometric suitability of the F-SIM continues to be supported in subsequent research, some thought must be given to scoring guidelines. In its present form, the F-SIM does not provide subscale scores based on individual dimensions, nor total scale scores. This is partly a function of the mixed-measurement approach that the F-SIM adopts. For example, the *Interpersonal Connections* dimension contains items that are scored on five-point and three-point ordinal Likert scales, as well as items that are scored on dichotomous *yes/no* scales. Items may need to be adapted so that they are all scored *yes/no* (enabling summary scores to be calculated via frequencies and percentages), or all scored on the same ordinal Likert scale (allowing summary scores to be calculated by summing items). Reverse scoring would need to be explored in the latter scenario: strictly speaking, a number of F-SIM items measure social exclusion (at least, as they are presently worded). Such modifications may permit the development of scoring guidelines, and enable future research to establish relevant cut-off scores, which would facilitate the implementation of the F-SIM in both clinical and research settings. Ongoing service-user input will be important throughout the above process, to maximise user acceptability and uptake of the measure.

A version of the F-SIM specifically for young adults from the general community could be developed through similar methodology (i.e., seeking to replicate and extend the findings of this research program, and incorporating further input from young adults). These separate measures may be useful in terms of cross-sectional assessment and longitudinal monitoring of social inclusion within each population. As such, they would provide important information about within-subjects change (e.g., intra-individual improvements in social inclusion for young adults with SMI). An advantage of such an approach is that it would capture unique aspects of social inclusion that may be idiographic to each group. However, as was encountered in this research program, their

applicability in between-subjects designs is questionable (depending upon the study aims and population of interest). Such measures are incompatible with approaches seeking to characterise the extent to which levels of social inclusion among young adults with SMI deviate from the norms of young adulthood.

A single version may be developed by identifying a core set of F-SIM dimensions and indicators that are relevant to social inclusion for young adults with and without SMI. This could be achieved by conducting exploratory and then confirmatory factor analyses across consecutive studies using large, combined samples of young adults with and without SMI. However, the dimensions and indicators would need to demonstrate metric invariance, i.e., that the same construct/s are being measured across groups (Schnabel et al., 2015). Assuming metric invariance, a similar but more thorough psychometric evaluation to those conducted in this research program (e.g., assessing discriminant as well as convergent validity) could be conducted. Such an approach would have the advantage of producing an instrument that offers more readily comparable results (e.g., normed cut-off scores). However, information about unique aspects of social inclusion that is idiographic to each group may be lost.

Either of the above approaches may be appropriate, depending on the particular research questions and aims that are relevant to future studies. In any case, future research seeking to develop the F-SIM will need to consider the fundamental challenges of adequately modelling nomothetic and idiographic indicators of social inclusion.

Broader issues to be covered in future work.

It will be important for future research to examine how generalisable the findings of this thesis are vis-à-vis differing dimensions of social inclusion across populations. This will help determine whether these findings are anomalous, apply narrowly to the populations considered in

this research program, or reflect a fundamental aspect of the social inclusion construct more broadly. Longitudinal research examining how stable social inclusion is across time for young adults with SMI will also be helpful. This may elucidate whether there are qualitative changes in social inclusion across illness phases (e.g., do instruments developed in the community more adequately measure social inclusion for people in recovery than do instruments developed in SMI samples?).

Strengths of the Research

Input from young adults both with and without lived experience of mental illness was sought prior to and throughout the research program. Data were collected from more than 300 young adults across the two samples. With respect to the general community sample, recruitment was conducted across various sectors of the community and not solely through universities (which is the case in many studies). Regarding young adults with SMI, recruitment was conducted across various mental health services in different metropolitan regions of Melbourne, Australia. The conceptualisation of SMI was broad enough to accommodate the diagnostic instability that is common to early stages of SMI. These methods helped maximise the ecological validity of the findings. This thesis represents the latest iteration of an ongoing empirical process of measurement development that began with a thematic analysis (Filia et al., 2018, see Appendix 2), a Delphi study (Filia et al., 2019a, see Appendix 3), and pilot-testing of the F-SIM (Filia et al., 2019b, see Appendix 4). The thematic analysis and Delphi study informed an evidence-based approach to item creation for the F-SIM. Items were not simply taken from existing measures of similar constructs, which is a common practice in the literature. A priori assumptions about the number and type of dimensions underlying the F-SIM were empirically tested within each sample: it was not assumed that the dimensions would necessarily be the same across populations. These aspects demonstrate the rigour of the research undertaken in this thesis. To the author's knowledge, these are the first preliminary examinations of the psychometric properties of a measure of social inclusion to be

conducted exclusively among young adults aged 18–25 with SMI and their peers from the general community. The research also represents, to the author’s knowledge, the first examination of differences in social inclusion between these two groups using a psychometric measure. This demonstrates the novelty of the findings contained within the research program, and highlights their clinical relevance.

Limitations of the Research

Perhaps the most significant limitation is that these are exploratory and correlational findings from which causality cannot be inferred. The findings regarding psychometric properties of the F-SIM reported in Chapters Five and Six are preliminary, and have not produced versions of the F-SIM that are suitable for use in clinical settings. As with any novel findings, the results of this research program require replication. Currently there is no ‘gold standard’ measure of social inclusion (Cordier et al., 2017; Wilson & Secker, 2015), which means that the criterion validity of the F-SIM could not be established. Some (but not all) F-SIM items asked responders explicitly to consider their current (i.e., over the past month) social inclusion, whereas other items were worded in a manner that implied a different timeframe (either shorter or longer). These are limitations with respect to the two-week test-retest interval, which was adopted primarily for consistency with previous social inclusion measurement studies (e.g., Huxley et al., 2012). Subsequent versions of the F-SIM may specify a uniform timeframe for all items on the measure, and future studies may tailor the test-retest interval accordingly. Discriminant validity, which is an important aspect of construct validity, was also not examined. Methodological heterogeneity makes it difficult to compare findings across studies in the relatively small literature on psychometric measures of social inclusion. For example, different studies use measures of different constructs to establish convergent validity. The measures selected to examine the construct validity of the F-SIM in this research program were chosen based on their conceptual overlap with social inclusion. While this may be theoretically justifiable, it impacts the generalisability of the relevant findings. Another

issue limiting generalisability is that the studies were conducted in Australia and the majority of measures selected to explore the validity of the F-SIM were validated in that country. It is therefore unclear whether and how the measure, or indeed the construct, may generalise cross-culturally (although see Chan et al. [2016] for cross-cultural validation of a social inclusion measure). The reliance on self-report measures may be viewed as a limitation, although subjective experience is integral to social inclusion. Social cognition was not measured in this thesis, although, as mentioned, there is tentative evidence that social cognition and social inclusion may not be significantly related among young adults with SMI (Gardner et al., 2019a). The absence of measures examining community attitudes (e.g., stigma) towards young adults with SMI is a limitation, given that social inclusion is a whole-of-community phenomenon. Ethnocultural data were also not collected, which is a limitation given that such data may be relevant to social inclusion (particularly within SMI populations in urban settings). No diagnostic interviews were conducted to compliment self-reported mental illness, although as noted above, diagnoses are unstable in early stages of SMI. Further, service-entry criteria at the recruitment sites afforded a reasonable level of confidence that participants were experiencing SMI.

Conclusion

The broad aims of this research program were to clarify dimensions and indicators of social inclusion among young adults with SMI, and to better understand the putative social exclusion of this cohort. The research within the thesis addressed several gaps in the literature, thus making a substantial and original contribution to the knowledge-base. A preliminary exploration of psychometric properties of a measure of social inclusion among young adults aged 18–25 years with SMI was conducted. This addresses the absence of such measures for use in clinical research and early intervention settings. A preliminary exploration of psychometric properties of a measure of social inclusion was also conducted among young adults aged 18–25 years in the general community. This addresses the lack of community data from psychometric measures of social

inclusion within young adult populations. Group differences between young adults with SMI and their peers from the general community were examined via a psychometric measure of social inclusion. Findings suggested that young adults with SMI were socially excluded relative to peers from the general community across dimensions of *Interpersonal Connections*, *Vocational & Financial Security*, and *Healthy Independent Lifestyle*. These findings replicated previous research and added novel insights regarding the putative social exclusion of young adults with SMI. They also enabled speculation regarding potential mechanisms of social exclusion in this cohort, and appropriate interventions to address this. More broadly, the thesis makes important contributions regarding theoretical and methodological issues in the social inclusion literature. The implicit assumption that dimensions of social inclusion are fixed across populations may need to be questioned. Approaches to measurement that can more readily accommodate the inherent complexity of the construct (e.g., combining nomothetic and idiographic indicators) may be required. This thesis offers a solid platform upon which to base more refined measurement of social inclusion among young adults with SMI. It also allows future research to deepen understanding of the social exclusion they experience, and create evidence-based interventions to improve the social inclusion of this potentially vulnerable group.

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APPENDIX 1

Preliminary version of the Filia Social Inclusion Measure (F-SIM)

The Filia Social Inclusion Measure (F-SIM)

Interviewer to complete:

Participant Initials: _____

Study Code: _____

1. How do you describe your gender? Please circle one:

Female / Male / Transgender / I do not identify as female, male, or transgender

2. What is your age in years? _____

Rater Instructions

For all questions regarding 'currently' – please refer to the past month as an average

Italics represent further information/explanations to make an assessment on a question

If more than one answer is given, always go with the higher answer

HOUSING, NEIGHBOURHOOD & SERVICES
--

3. Who do you currently live with? (Please mark all that apply)

Parents	
Siblings	
Partner	
Children	
Other family member/s (please specify): _____	
Friend	
Flatmate	
Other residents	
Self and pets	
Self alone	

4. Where are you currently living?

Homeless, living on the streets (no roof over your head)	
Homeless shelter, transitional housing or hostel	
Public housing	
Nursing home or supported accommodation	
Private rental	
Own home (paying off mortgage or own outright)	
Family home (with your parents or other family members)	

5. How much money per week (in dollars) do you personally spend on rent or mortgage payments?

6. Of the household members over the age of 18, are all currently employed or attending formal education? YES / NO

7. Is there anyone under the age of 18 living in your household? YES / NO

8. If there is someone under the age of 18 living in your household, are they considered your dependent? YES / NO

(A dependent is a child under the age of 18 that is in your primary custody and is reliant upon you financially).

9. Thinking about your accommodation, your neighbourhood and the community in which you live, please choose yes or no for the following questions

	YES	NO
Is your accommodation unstable? <i>Eg. Are you unsure how long you have left on your tenancy? Are you worried about being evicted or having to move from your accommodation in the near future?</i>		
Is your housing lacking in any way that makes it difficult to live in? <i>Eg. Does it lack important things such as heating, ventilation, is it dirty in ways that is outside of your control, do you have rising damp, does it lack security? Are there not enough rooms for the number of people living there?</i>		
Are you living in a location other than where you would like? <i>Eg. Were you placed in a different area to where you would like or are you living away from family support, etc. due to financial constraints?</i>		
Do you find your neighbourhood lacking in some way? <i>Eg. Is your neighbourhood poor or disadvantaged?</i>		
Have you experienced any neighbourhood crime and/or violence in your time in the area?		
Do you find that you don't venture out as much because of fear of crime or personal attack in your neighbourhood?		

10. Thinking about the people and the groups in your neighbourhood or community, please answer yes or no to these questions

In the past 12 months I have:

	YES	NO
Had opportunities for regular contact (at least weekly), with people in the local community <i>Eg. Chatting to staff in shops or cafés</i>		
Dropped in to a neighbour's house or chatted with them (at least weekly)		
Belonged to a neighbourhood group of some sort, a community association or local organisation <i>Eg. A sporting club, youth group, church group, political party</i>		
Taken part either by attending meetings, protests or some other action to either improve or protect the local neighbourhood in some way <i>Eg. Housing developments, development of new clubs or groups, initiatives to keep the neighbourhood clean</i>		
Assisted in planning, organising or running a community event <i>Eg. A local fete, street party, or something else</i>		

11. Thinking about the services that are available to you in your local neighbourhood or community, please note the following features of each of these (please mark all features that apply for each service listed)

	Of a good standard	Easy to access	I don't know, I don't use them	Not of a good standard	Not easy to access
General community services, such as local post office, banking and library					
Retail services, such as supermarkets, pharmacy, local trinket or clothing store					
Health services, GPs, physio, dentist, etc.					
Public transport					
Local services club, or other local organisations, including a sporting club, youth group, or hobby groups					
Support services, such as drop in centres, support groups, community assistance programs, youth services					
Public internet services					

12. The Internet

a) Do you have access to the internet at your home address? YES / NO

b) Do you use the internet for social purposes? YES / NO

Eg. Twitter, Facebook, chat rooms, blogs, support groups

c) Does the internet fill a need for you socially that you aren't getting elsewhere? *That is, if the internet wasn't available would you feel lonely? Does it help you to make friends and talk to people when you may not usually?* YES / NO

13. Do you have a current drivers licence? YES / NO

14. If YES, do you have access to or can you use a car whenever you need one?

YES / NO

RELATIONSHIPS, ACTIVITIES & SETBACKS

15. How satisfied are you with your social life? Please mark one of the following:

Very satisfied	Mostly satisfied	It could do with some improvement but generally satisfied	Mostly dissatisfied	Very dissatisfied
----------------	------------------	---	---------------------	-------------------

16. Thinking about the people in your life, do you feel that you have:

	YES	NO
Someone, whether it be family member or friend, that you can chat to about your day to day activities, feelings, or events		
Good friends who you see or speak to regularly. A group of friends who you share experiences, thoughts and feelings with		
Friends with whom you share common interests and values		
Friends with whom you enjoy sharing time and look forward to seeing		
Good friends who you can count on to talk through stuff and be there for you in a crisis		
A best friend with whom you share your thoughts and feelings		
Friends who would call <u>on you</u> to discuss their everyday experiences		
Friends who would call <u>on you</u> in a crisis		

17. Thinking about the different social activities people take part in, how often do you do each of these on average

	At least daily	At least once or twice a week	At least once or twice a month	At least once or twice a year	Rarely or Never
Share everyday activities with others such as watching television together					
Have a meal with someone else					
Talk to a family member or friend on the telephone					
Catch up with a friend for dinner or a movie or some other social activity					
Connect with someone via SMS text message or social media (<i>e.g., Twitter, Facebook, Instagram</i>)					

18. How satisfied are you with the social activities that you take part in? Please mark one of the following:

Very satisfied	Mostly satisfied	They could do with some improvement but generally satisfied	Mostly dissatisfied	Very dissatisfied
----------------	------------------	---	---------------------	-------------------

19. Following is a list of limitations that some people experience when trying to do the things they'd like to socially. Have any of these things stopped you from doing the things you'd like to do socially in the last month?

	Not at all	A little bit	Very much so
There aren't any social activities that I know of that I'm interested in taking part in			
I find I don't really enjoy social activities <i>Eg. because of fear, anxiety, not having the right people to share them with</i>			
I don't have very good self-confidence or self-esteem <i>Eg. I'm a bit shy and find it hard to meet people or make conversation, etc.</i>			
I often feel unwelcome, like I don't belong			
I feel like I am bullied by others			
I haven't participated in any social or community activities for a long time, I don't know where to start			
I feel excluded or not part of the group when taking part in new activities or joining new groups			
I don't have a group of friends to call on to do anything with socially			
I experience either stigma or discrimination on a regular basis			
I belong to a number of minority groups and feel like it all adds up against me <i>Eg. having mental health issues and belonging to an ethnic minority group</i>			

20. Sometimes it can be difficult to make the changes we know we should to improve things in our lives. Here is a list of reasons that can make it difficult. Please read over them and note whether you have felt like you have experienced these difficulties in the past month

	Not at all	A little bit	Very much so
I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things			
I don't know what I need to do to improve my circumstances			
I just don't have the time to do what I think I should do. I have other things I have to do. I need more time in the day			
I've had so many bad things happen to me, why should I expect that anything would improve			

21. Illegal Activity

a) Have you used violence against a person or property in the past month?

YES / NO

Eg. Gotten into a fight, hit someone during an argument, been in a situation of domestic violence? Broken furniture during a time of anger, punched a hole in a wall, thrown something in anger?

b) Have you ever been charged with a criminal offence (e.g., drug use, theft, violence or other crime)?

YES / NO

c) Do you currently use, manufacture or deal illegal substances?

YES / NO

EMPLOYMENT AND EDUCATION

22. Over the past 12 months, did you work or study at any time? YES / NO

If NO, please move to question 26.

23. If YES, did you or do you:

	YES	NO
Work/study in mainstream employment/education <i>E.g. Alongside people with or without disabilities</i>		
Work/study in a chosen area of employment <i>E.g. Employed in a role that you're interested in and are suitably qualified for</i>		
Work/study in a friendly environment		
Work/study under good conditions <i>Eg. pay appropriate to your role, receive your leave entitlements, work/study without bullying or harassment</i>		
Work/study more hours a week than you would like		
Work/study less hours than you would like		
Feel that your job/education interferes in your ability to take part in social activities <i>Eg. because of a lack of time, rostering at odd times, so far away can't get home in time to do anything fun</i>		

24. Are you currently: *(Please mark for each line)*

	Yes, Full Time	Yes, Part Time	Yes, Casual	No
Working for pay?				
Working for payment other than monetary?				
Working in a voluntary capacity?				
Studying at a formal institution, leading to a qualification <i>(i.e. Tafe or University)</i>				
Unemployed with no activity				
Other <i>(please specify)</i> : _____				

25. How many of the past 12 months did you work or study for?

26. Have any of the reasons below limited you in your current employment situation?

	Definitely limited	Limited a bit	Not at all
Poor employment opportunities <i>Eg. a lack of suitable roles available</i>			
Being unable to get a job or keep one because of discrimination due to having a mental illness			
Having an illness that is likely to impair your ability to either perform your occupational role or disrupt employment <i>Eg. not being able to concentrate properly, or having to have time off work due to illness</i>			
Having an illness that has previously impaired your ability to obtain skills or qualifications necessary for employment <i>Eg. not being able to concentrate properly, or having to have time off studying or withdraw from courses due to illness</i>			
Not having skills or qualifications that are required for employment			

27. What is the highest year of primary or secondary schooling that you have completed?

28. Did you complete the highest year of secondary school education?

YES / NO

29. Have you completed any additional qualifications since leaving primary or secondary school? (Please mark all that apply):

Certificate III	
Certificate IV	
Trade or Apprenticeship	
Diploma	
Degree	
Postgraduate Degree	
Other (please specify): _____	
No, I have not completed any additional qualifications since leaving primary or secondary school	

30. Have you been enrolled in any formal studies in the past 12 months? (E.g., at a university or TAFE, leading towards a qualification – Certificate III or above, Diploma or Degree)

YES / NO

FINANCES

31. Where do you currently receive an income from? (please mark all that apply)

Payment from work or study (e.g. scholarship)	
Centrelink/Government payment (e.g. youth allowance, newstart allowance, single parent payment, disability support pension)	
Spouse or other family member provides you with money <i>Incl. Child support or maintenance payments</i>	
Don't receive an income (I have no money)	

32. How much nett income do you receive each week, prior to any deductions?

(For example, if you receive Centrelink/Government payments but have a set amount reduced for rent, bills, etc. please put the amount of the full Centrelink/Government payment, not what you receive in hand after such deductions come out)

33. Thinking about your current financial situation, please answer the following questions:

	YES	NO
Do you receive enough income to cover your basic everyday costs		
Is your income is so low that you suffer from financial strain		
Do you feel that you earn considerably less or suffer more financial strain than others in your community		
Have you experienced long-term poverty <i>Experienced financial hardship for longer than 5 years</i>		
Would you be able to raise money from family or friends in case of an emergency		
Would you be able to raise money from sources other than family or friends in case of an emergency		

34. Considering the income that you receive, have you experienced the following financial hardships in recent times? (Over the past 12 months)

	YES	NO	Not applicable
Unable to keep up with paying the bills			
Having pawned belongings in the past 12 months to get by			
Finding it difficult to provide for family (including children)			
Unable to afford basic household or personal goods necessary for wellbeing <i>Eg. washing machine, fridge, microwave, bedding; warm clothes, soap, toothpaste</i>			
Unable to afford health insurance			
Unable to afford healthcare (doctors' appointments, medications, specialists)			
Unable to afford a variety of healthy food			
Unable to participate in social activities with friends due to a lack of funds			
Unable to attend important events such as weddings, funerals, birthday celebrations due to a lack of funds			
Unable to take up a hobby or leisure activity of choice			
No holiday in past 5 years			
Unable to afford a car			
Unable to afford insurance for house, contents, car			
Lack of savings for use in an emergency			

HEALTH AND WELLBEING

35. In the past several months, do you feel that you have focused *less* on your physical wellbeing than your mental wellbeing? YES / NO

36. In the past 12 months have you received regular check-ups for things such as dental care, cholesterol checks, skin checks and/or other preventative health measures? YES / NO

37. Do you have any ongoing physical ailments that prevent you from:
a) Achieving all you would like in your life? YES / NO

- b) Accessing services that would help to improve your life or circumstances?
Eg. health services, public transport, internet YES / NO

38. Do you feel that your emotional health interferes in your ability to:

- a) Achieve all you would like in your life? YES / NO
 b) Access services that would help to improve your life or circumstances?
Eg. health services, public transport, internet YES / NO

39. Have you ever received a diagnosis of a mental illness from a health professional? YES / NO

If NO, please move to question 46.

40. If YES, do you recall what the exact diagnosis or diagnoses is? Please choose either YES or NO below:

YES, my diagnosis (or diagnoses) is: _____

NO, I can't recall what the exact diagnosis (or diagnoses) is

40a. If you cannot remember the specific diagnosis/diagnoses, please tick any and all of the following broad categories that apply:

☐ Depressive Disorders	☐ Anxiety Disorders	☐ Schizophrenia Spectrum & Other Psychotic Disorders
☐ Bipolar and Related Disorders	☐ Eating Disorders	☐ Obsessive-Compulsive and Related Disorders
☐ Trauma-Related Disorders (e.g., Post Traumatic Stress Disorder)	☐ Substance-Related and Addictive Disorders	☐ Personality Disorders
☐ I'm not quite sure, but you can contact me to discuss		

41. Does your mental illness make it difficult for you to manage everyday tasks (e.g., paying bills, keeping appointments) by yourself?

YES / NO

42. Have you ever been admitted to a mental health facility? YES / NO

If NO, please move to question 46.

43. If YES, how many admissions to a mental health facility have you had over your lifetime? _____

44. How many admissions to a mental health facility have you had over the past 12 months? _____

45. How long, on average, would each admission have lasted for?

DAYS / WEEKS / MONTHS

46. Have any of your close family members ever received a diagnosis of mental illness? (e.g., a parent, sibling, spouse, child, or any other close relative) OR Have you been a carer for a person with mental illness?

YES / NO

If NO, please move to question 49.

47. If YES, please indicate your relationship with that person. Are they your:

Please mark all that apply:

Mother	
Father	
Brother	
Sister	
Husband	
Wife	
Partner	
Son	
Daughter	
Other (<i>please specify</i>): _____	

48. Can you recall what the exact diagnosis (or diagnoses) of your family member or person you cared for is? Please choose either YES or NO below

YES, their diagnosis (or diagnoses) is:

NO, I can't recall what their exact diagnosis (or diagnoses) is

48a. If you cannot remember the specific diagnosis/diagnoses, please tick any and all of the following broad categories that apply:

☐ Depressive Disorders	☐ Anxiety Disorders	☐ Schizophrenia Spectrum & Other Psychotic Disorders
☐ Bipolar and Related Disorders	☐ Eating Disorders	☐ Obsessive-Compulsive and Related Disorders
☐ Trauma-Related Disorders (e.g., Post Traumatic Stress Disorder)	☐ Substance-Related and Addictive Disorders	☐ Personality Disorders
☐ I'm not quite sure, but you can contact me to discuss		

49. How much do you currently weigh? (without shoes) _____ kgs

50. How tall are you? (without shoes)

_____ cm or _____ feet/inches

Body Mass Index:

(Interviewer to complete: $\text{Weight}/\text{Height}^2$ in m)

51. How many meals a week would you buy fast food or takeaway food on average? Including all three meals, breakfast, lunch and dinner

52. How often would you currently take part in physical exercise? *That is, how often do you perform some physical activity that increases your heart rate for at least 30 minutes at a time? Please mark one of the following:*

At least daily	At least once or twice a week	At least once or twice a month	At least once or twice a year	Rarely or Never
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53. How many times per week do you eat a balanced meal for your main meal of the day that either you or someone else has prepared at home? *A balanced meal includes portions of vegetables and protein (Examples of protein include chicken, beef or lamb, or a vegetarian alternative such as tofu, nuts or eggs)*

54. How many days per week do you eat breakfast?

55. How many full sugar soft drinks, cordials, or juices (e.g., glass/cup, small bottle, or can) do you drink per week?

56. How many alcoholic beverages (e.g., glass/cup, small bottle, or can) do you drink per week?

57. Do you currently consume tobacco (e.g., smoke cigarettes, chew tobacco)?

YES / NO

58. If YES, how often do you consume tobacco? *Please mark one of the following:*

Rarely (a few times a year)	Occasionally (a few times a month)	Regularly (a few times a week)	Every day
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That was the end of the Filia Social Inclusion Measure (F-SIM). Thank you for completing it.

By answering the next few questions, we'll get to understand what it was like for you to complete it, and if there are some ways that we can make it a little easier and more user-friendly.

59. How long in minutes did it take you to complete the questionnaire?

60. Do you think that the questionnaire took too long to complete? Please circle one: YES / NO / Maybe a little

61. How well do you think this questionnaire actually measures social inclusion? Please mark one of the following:

Very well	Somewhat	Not very well	Doesn't seem to measure social inclusion at all
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62. Did you find the questionnaire difficult to complete in any way? YES / NO
If NO, please move to the next page.

63. If YES, in what ways was it difficult? Please mark all that apply:

The way the questions were worded made it difficult to understand	
The type of questions asked were a bit sensitive	
Another reason (please specify below):	

Thank you for taking the time to complete this questionnaire!

APPENDIX 2

What is Social Inclusion? A Thematic Analysis of Professional Opinion

What Is Social Inclusion? A Thematic Analysis of Professional Opinion

Kate M. Filia

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Objective: Social inclusion is increasingly recognized as an important contributor to positive mental health outcomes, particularly for people with mental illness. There is a lack of consensus regarding what it means to be socially included and what the key contributors to social inclusion may be. The aim of this investigation was to determine such key contributors, as identified by those with professional experience. **Method:** A thematic analysis of literature regarding social inclusion was conducted to obtain the opinions of professionals regarding key contributors of social inclusion. Seventy-one pieces of literature were reviewed: peer-reviewed literature (academic literature regarding social inclusion in general [$n = 25$] and social inclusion and mental illness [$n = 26$]), and gray literature (organizational reports [$n = 20$]). Within- and between-groups analyses were performed to determine group differences and increase understanding of which contributors were deemed important consistently across groups. **Results:** A comprehensive list of 90 contributors to social inclusion and exclusion was compiled, categorized into 13 domains based on commonalities. Contributors related to employment and education, housing and neighborhood, and social activities and support were highly cited. Differences were observed between-groups regarding specificity of contributors, with organizational reports reporting more detailed contributors. **Conclusions and Implications for Practice:** A comprehensive and specific understanding of social inclusion was obtained. This improved understanding will allow for better measurement of social inclusion which will assist in evaluating programs and interventions, identifying areas of greatest need, and in planning services, policy and strategies to target specific contributors proven to improve social inclusion and subsequent mental health outcomes.

Keywords: social inclusion, social exclusion, thematic analysis, definition

Social inclusion has important and beneficial implications for health, well-being, and quality of life (Floyd et al., 2017; Levitas et al., 2007). Socially excluded individuals place a significant

burden on society, with socioeconomic consequences for government, community, and familial supports. Improved social inclusion can reduce this burden (Boushey, Fremstad, Gragg, & Waller, 2007).

People with severe mental illness are among the most vulnerable to poor social inclusion (Baumgartner & Burns, 2014; Huxley & Thornicroft, 2003). Improvements in areas of social inclusion (e.g., employment, social supports) result in significant reductions in illness and relapse rates for people with severe mental illness (Psychiatric Disability Services of Victoria, 2008). Therefore, the identification of modifiable contributors to social inclusion will assist in improving social inclusion, and subsequent mental health outcomes for this disadvantaged group.

Definitions of social inclusion are varied as seen in Table 1. Unfortunately, issues concerning the definition of social inclusion exist (Boushey et al., 2007; Huxley et al., 2012; Vinson, 2009). Definitions differ in the amount of detail, with some quite brief (e.g., Dunn, 1999), others specific (e.g., Levitas et al., 2007) and then very broad, generalized statements (e.g., Boushey et al., 2007).

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Table 1

Definitions of Social Inclusion or Social Exclusion

Author	Definition
Atkinson & Kintrea (2001)	An <i>inclusive society</i> is over and above nonspatial explanatory social categories, such as gender and class, and specific disadvantages, such as unemployment or ill-health.
Boushey, Fremstad, Gragg, & Waller (2007)	At its core, <i>social inclusion</i> involves including everyone in social institutions and relations in ways that matter for well-being.
Burchardt, Le Grand, & Piachaud (2002)	An individual is <i>socially excluded</i> if he or she does not participate in key activities of the society in which he or she lives . . . the individual is not participating for reasons beyond his/her control, and he or she would like to participate
Dunn (1999)	<i>Social inclusion</i> must come down to somewhere to live, something to do, and someone to love.
European Commission (2004)	<i>Social exclusion</i> is a process whereby certain individuals are pushed to the edge of society and prevented from participating fully by virtue of their poverty, lack of basic competencies and lifelong learning opportunities, or as a result of discrimination. This distances them from job, income, and education opportunities as well as social and community networks and activities. They have little access to power and decision-making bodies and thus often feeling powerless and unable to take control over the decisions that affect their day to day lives.
	<i>Social inclusion</i> is a process that ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social, and cultural life and to enjoy a standard of living and well-being that is considered normal in the society in which they live. It ensures that they have greater participation in decision making that affects their lives and access to their fundamental rights.
Harrison et al. (2008)	<i>Social exclusion</i> is defined as a person having limited opportunities for participation in education, work, and leisure.
Levitas et al. (2007)	<i>Social exclusion</i> is a complex process operating across several dimensions or domains. 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. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.
Marino-Francis et al. (2010)	<i>Social inclusion</i> is about each person taking part in society and having control over their own resources. It is also about a community that cares for its members, makes them feel welcome and is willing to adjust to fit their various needs.
Poggi (2003)	We define <i>social inclusion</i> as the impossibility to achieve some relevant functioning. Because the impossibility to reach functioning leads to a state of deprivation, the "state" of social exclusion can be defined as a combination of some relevant deprivations.
Repper et al. (2001)	<i>Social inclusion</i> , at its most basic definition, requires equality of opportunity to access and participation in the rudimentary and fundamental functions of society.
Sayce (2001)	We can conceptualize <i>social exclusion</i> in relation to mental health service users specifically as the interlocking and mutually compounding problems of impairment, discrimination, diminished social role, lack of economic and social participation, and disability. Among the factors at play are lack of status, joblessness, lack of opportunities to establish family, small or nonexistent social networks, compounding race and other discriminators, repeated rejection and consequent restrictions of hope and expectation.
	<i>Inclusion</i> may be defined in terms of a virtuous cycle of improved rights of access to the social and economic world, new opportunities, recovery of status and meaning, and reduced impact of disability. Key issues will be availability of a range of opportunities that users can choose to pursue, with support and adjustment where necessary.
Social Exclusion Unit (1998)	<i>Social exclusion</i> is a shorthand label for what can happen when individuals or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health, and family breakdown.
Australian Government Social Inclusion Unit (now defunct website)	To be <i>socially included</i> , a person must be given the opportunity to secure a job; access services; connect with family, friends, work, personal interests, and local community; deal with personal crises; and have their voice heard.
Stain et al. (2012)	<i>Social inclusion</i> refers to the participation of a person in society and is evidenced by an individual having the opportunities, resources, and abilities to build and maintain relationships, engage in education and employment, and participate in community events and organizations.
Todd et al. (2004)	<i>Social exclusion</i> is defined by this study as being homeless, unemployed, having a lower educational level, and isolated, (e.g., living alone).
United Nations (2010)	<i>Social exclusion</i> is defined here as the involuntary exclusion of individuals and groups from society's political, economic, and societal processes, which prevents their full participation in the society in which they live.
World Bank (2013)	<i>Social inclusion</i> is defined in the following two ways: (1) the process of improving the terms for individuals and groups to take part in society and (2) the process of improving the ability, opportunity, and dignity of those disadvantaged on the basis of their identity to take part in society.

The more precise definitions help identify and contextualize factors contributing to social inclusion. The range of contributors can assist in identifying those vulnerable to social exclusion. Conversely, the broader definitions are appealing in their simplicity, allowing a more generalized understanding and widespread application; however, may lend themselves to broad subjective interpretation.

These definitional inconsistencies contribute to uncertainty about how to best address issues of social exclusion, without a clear delineation of contributing factors (Boushey et al., 2007; Shepherd & Parsonage, 2011). It is also difficult to accurately measure and assess social inclusion with precision (United Nations, 2010).

The need for psychometrically robust measures of social inclusion is crucial to the evaluation of the worth and efficacy of attempts to improve it (Huxley et al., 2012; Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007; Vinson, 2009). Measurement is necessary to conduct methodologically sound research (e.g., Bertram & Stickley, 2005; Hacking, Secker, Spandler, Kent, & Shenton, 2008), evaluate policy implementation and determine whether particular individuals or groups are at risk of exclusion.

Despite these definitional issues, some common themes and contributors to poor social inclusion exist. These include the following: the negative impact of poor social capital and a lack of social participation (Morgan et al., 2007; Vinson, Brown, Graham, & Stanley, 2009; Webber & Huxley, 2004), a lack of education and unemployment (Evans-Lacko et al., 2014; Hayes, Gray, & Edwards, 2008), and poor housing in disadvantaged neighborhoods (Craig & Timms, 2000; Duff, Jacobs, Loo, & Murray, 2013; Vinson et al., 2009).

Themes and contributors vary across disciplines and groups, with differences related to the work different groups conduct (e.g., research vs. health care vs. policy vs. support services) and the diversity of the populations with which they work. Identifying common themes and contributors, as well as variance within and across groups, allows for a more well-rounded and informed understanding of the concept.

A focused review and thematic analysis was undertaken to determine key contributors to social inclusion as identified by professionals working in the field and to explore how contributors differ in the number and type identified by three different groups: (1) academics working in the field of social inclusion, (2) academics working specifically with social inclusion in mental illness, and (3) organizations working to improve social inclusion.

Following a preliminary review of the literature, it was hypothesized that (1) the most commonly identified contributors to social inclusion would fall under the domains of social support and participation in social activities, labor force participation and geographical disadvantage; (2) each group would consistently identify contributors related to these domains, while identifying different individual contributors; and (3) a higher number of contributors to social inclusion would be cited in the organizational reports than in the academic literature, with these contributors containing more specific and individual level detail.

Method

Literature Selection

Literature search. The initial literature selection and analysis was completed in 2010. In May 2017, an updated search was completed, using the original methodology.

A number of new and different authors and organizations were identified in the updated search; with a selection of literature (selected as per following methodology) reviewed (details available on request). Findings reflected those of the original search, with no new contributors identified, and the majority of articles referring to definitions or contributors identified in earlier literature, or synthesizing old data to create new perspectives. Similar numbers of contributors were identified across groups as in the original selection, with the same themes again noted within and across groups. With such prominent saturation, the results presented are based on the original literature and analyses.

Academic literature. Searches using different search engines and databases, including Academic OneFile, Humanities and Social Sciences Collection, InfoNation, Ovid and Social Sciences Citation Index (SSCI), were trialed. Scopus was chosen for several reasons: its comprehensive scope (social sciences, in addition to science, technology, medicine, and arts and humanities)—a major benefit in identifying academic literature regarding social inclusion in general, not just with specific reference to mental illness; the number of journals included (over 7,000 in the social sciences area and 20,000 overall); and the detailed information provided from each search, enabling searches to be carried out with greater precision. Scopus provided not only articles for review, but also the number of articles published by each author regarding social inclusion/social exclusion, and number of citations for each article. By downloading these into a citation tracker, it was possible to identify those publishing most frequently in the field in addition to the most influential works based on the number of citations received.

The terms *social inclusion* and *social exclusion* were entered into Scopus. No limit was applied in terms of years searched. At the time of the first search in 2010, the 3,738 articles had an *h* factor of 51, the top 51 articles had been cited at least 51 times since publication. Initially a list of the most common authors was to be propagated from the 51 most-cited articles, with their articles then included in the thematic analysis. A selection of literature on social inclusion in general and social inclusion and mental illness was expected. The methodology required some slight modification with several issues arising, in part due to the lack of clarity surrounding the term's definition.

Although highly cited, most of the 51 most-cited articles were not actually about social inclusion. Most had simply used the term without employing a clear definition, or mentioned the term only once, it not actually the focus of the article. These articles were well-cited due to the topic of their research. The more relevant articles were recent publications and weren't featured as highly in the top 51. A scaling measure of numbers of citations was required.

The ISI Web of Knowledge provides tables for different fields of study indicating percentiles based on citation numbers and year of publication. The table relating to "All Fields" was used in this study (Essential Science Indicators, 2010). The 3,738 articles were sorted into percentile rank using this information.

The following steps were then taken to determine the most appropriate articles for review (see Figure 1). From Scopus, the top 20 authors who had published most frequently about social inclusion/exclusion were chosen in an attempt to identify those consistently working in the field, not cited due to other subject matter or indiscriminate use of the term.

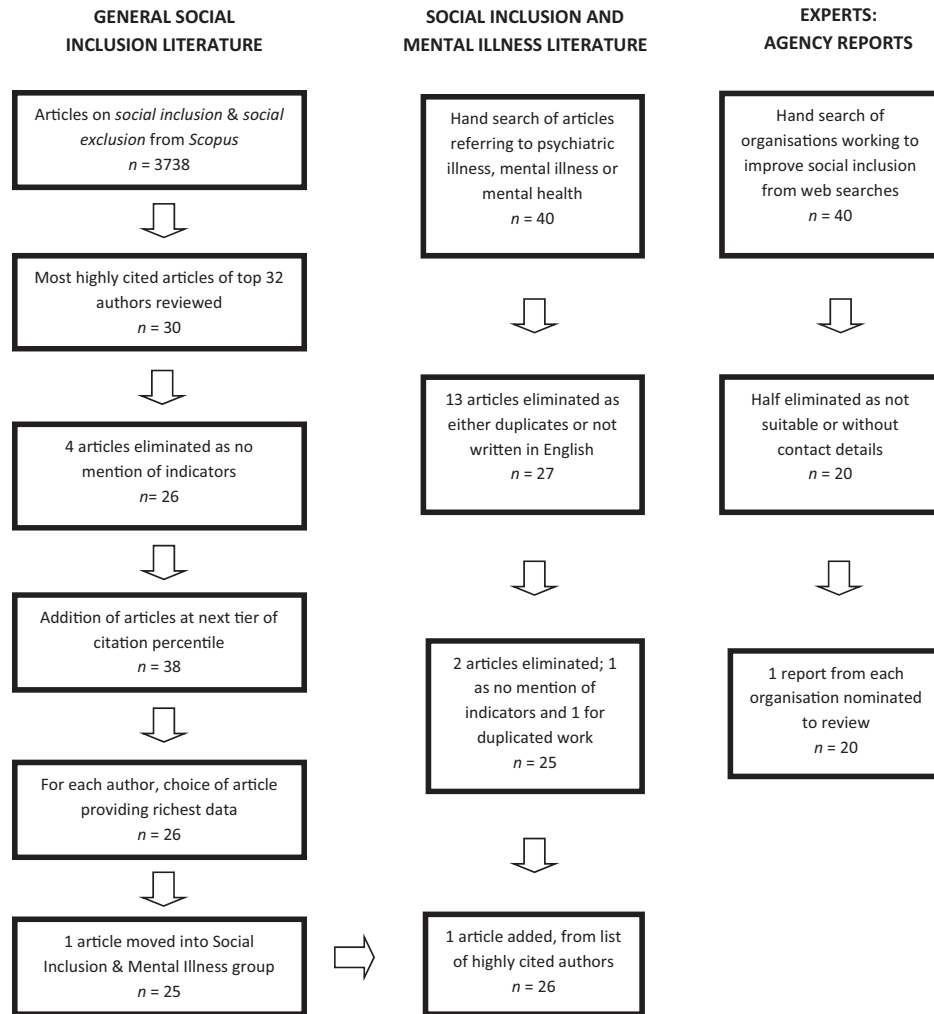


Figure 1. Selection process of literature to review.

The twentieth-ranked author had written five articles on social inclusion, as had the next 12. These top 32 authors were included for review. The most highly cited reference(s) of each author was reviewed ($n = 30$) with some overlap between authors, providing compromise between frequency of publication and more highly regarded articles (details of literature selected, citations and percentile publications available upon request).

Of the 30 articles, four were discarded as they did not mention *social inclusion* or *social exclusion*. Additional articles were subsequently reviewed from the next tier of citation percentiles for each associated author ($n = 12$). Finally, of authors with several articles within the highest percentiles of citation, the article containing the most contributors to social inclusion/exclusion was included in the final tally of 26 articles. All but one of the most highly cited authors wrote about social inclusion in general, with no specific reference to mental illness.

Therefore, the following steps were taken to identify appropriate works to review on social inclusion and mental illness. A search within the results for the term *mental illness* did not provide as comprehensive a list as desired. A hand-search of the 3,738 ref-

erences was carried out, with article and journal titles searched for reference to “psychiatric illness,” “mental illness,” or “mental health.” Forty articles were identified. Duplicates and articles not in English were eliminated, with 27 articles remaining for review. Two articles were discarded following review, one with no reference to what the terms social inclusion/exclusion meant, another a duplication of work by an already reviewed author, providing less information regarding social inclusion. The final tally of articles in this group was 26, including the one written by one of the highly cited authors (Secker, 2009). (Details of literature available on request.)

Experts: Agencies. The search engine Google was initially used to find the top 20 agencies worldwide working on *social inclusion* or *social exclusion*. The resulting number of responses was 481,000. Items such as scholarly articles, books, conference proceedings, and unreferenced sources were filtered out. Of the top 20 results, 15 were actual organizations.

A hand-search of the Google results was conducted, similar to those of reference lists in academic literature. Prominent organizations were chosen. The website of the now defunct Australian

Government Social Inclusion Unit provided a compendium of national and international organizations working to improve social inclusion. This was used alongside other searches to populate a list of organizations.

The final list included 40 organizations. Each agency was considered and webpages viewed. Of the 40, half were unsuitable as were conference presentations, outdated, or pages with little information and no further contact details.

Most organizations had comprehensive reports regarding social inclusion/exclusion available. Where reports were not readily available, members were contacted and asked to provide, or endorse one from another organization that represented what their organization believed social inclusion to mean. Each report was read with results added to the list of identified contributors.

As per the earlier literature selection, one report from each organization was included in the final tally, the report that best reflected the organization's view on social inclusion and provided the most data. Where there was overlap between endorsed reports and organizational reports, an additional one was sourced and reviewed. (Details of organizations and reports reviewed available on request).

Thematic Analysis

Following the identification of appropriate literature, a thematic analysis was conducted to identify key contributors to social inclusion. Braun and Clarke (2006) provide a six-step procedure for conducting thematic analysis, along with checklist criteria for good thematic analysis. Phases of thematic analysis include the following: (1) familiarizing oneself with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, (6) coding themes, and (7) producing a report. The instructions by Braun and Clarke were followed closely here.

Qualitative techniques including coding and category construction were undertaken to provide a comprehensive list of contributors and domains of social inclusion/exclusion identified in the literature. Each piece was initially read carefully. During a second reading, explicit references to the terms *social inclusion/exclusion* were considered. Definitions of, or references to the concept, were used to code data, demonstrating what each author or organization considered the term to mean. A list of contributors was populated, each categorized under appropriate domains also populated as the list expanded. To enable quantitative analyses, numbers of articles or reports that referenced each contributor to social inclusion/exclusion were noted. Due to limitations of time and resources, the coding and category construction tasks were undertaken by the first author, with regular consultation and supervision provided by two other authors.

The contributors identified included those that may play a role in being socially included or excluded, were actual causes of social exclusion, increased social inclusion or social exclusion, or impaired an individual's ability to improve their social inclusion. These contributors were identified either by the authors or their endorsements of previously proposed definitions. As it was common for authors to rely on previously proposed definitions, some repetition was seen; however, it remains indicative of the authors' choice or understanding of the term.

Statistical Analysis

Normality testing was conducted for relevant variables (overall number of contributors and each domain). Descriptive statistics, parametric and nonparametric analyses, where appropriate, were conducted to test the hypotheses. Specific tests included the following: multivariate analyses of variance to determine group differences, with Pillai's trace statistic and a more conservative alpha level of .01; one-way analyses of variance with planned comparisons such as Tukey's honest significant difference tests to determine extent of differences between groups and partial eta squared (η^2 ; the measure of effect), with Cohen's criteria for interpretation (Cohen, 1988); Kruskal-Wallis tests where the assumption of normality was violated, with Mann-Whitney *U* tests performed to identify which groups differed; and chi-square analyses with adjusted residuals where sufficient numbers to do so existed (>5 in each group). Where appropriate, Bonferroni adjustments were applied. All analyses were conducted using statistical package IBM SPSS Version 22.0. (IBM Corp., Released 2013)..

Results

Literature Reviewed

Seventy-one pieces of literature were reviewed: 26 regarding social inclusion and mental illness (MISI literature), 25 regarding social inclusion in general (GSI literature), and 20 organizational reports. The GSI literature was sourced from the fields of sociology ($n = 8$), psychology ($n = 6$), public policy ($n = 3$), urban studies ($n = 2$), transport ($n = 2$), geography ($n = 2$), substance use ($n = 1$), and learning disabilities ($n = 1$). The 20 organizational reports were from government agencies ($n = 5$), psychiatric disability rehabilitation and support services ($n = 5$), public health and disability support initiatives ($n = 3$), poverty support services ($n = 4$), universities ($n = 2$), and a collaborative organization of researchers and public policymakers ($n = 1$).

Overall Review Results

Ninety contributors were identified for their influence on *social inclusion/social exclusion*, in either a positive or negative fashion (see Table 2). The inclusion of both terms does not suggest that the presence of one indicates the absence of another, but that contributors to either are of importance and relevance here. Contributors were categorized into 13 domains based on commonalities.

Table 2 includes the number of reports citing each contributor to social inclusion, in total and by each group: Domains are presented in order of highest to lowest number of citations in each.

Of the 90 contributors, each was cited on average 9.79 times, with a range of 1 to 52. Twelve contributors were cited by only one piece of literature. Across all domains and including all reports, the 90 items were touted as contributors to social inclusion in 881 instances.

Normality Testing

Normality testing was performed, informing the type of analyses for each variable. Outliers were identified (literature with a greater number of contributors cited), but the effects were small, with only

Table 2

Number of Reports Citing Each Indicator (Including Percentage of Each Group)

Contributors to social inclusion or social exclusion	GSI % (n)	MISI % (n)	Organizational reports % (n)	Total citations % (n)
Employment or education				
Unemployment, irregular, or underemployment	52.0 (13)	76.9 (20)	95.0 (19)	73.2 (52)
Poor skills and lack of or limited opportunities for education or training	44.0 (11)	61.5 (16)	95.0 (19)	64.8 (46)
Poor employment opportunities	8.0 (2)	11.5 (3)	25.0 (5)	14.1 (10)
Jobless household			40.0 (8)	11.3 (8)
Long-term unemployment			25.0 (5)	7.0 (5)
Labor market disadvantage			10.0 (2)	2.8 (2)
Open employment		3.9 (1)		1.4 (1)
Total for domain	14.9 (26)	22.0 (40)	41.4 (58)	24.9 (124)
Social activities/social support				
Ostracism (exclusion or rejection from social activities or networks, lack of participation in social activities)	44.0 (11)	61.5 (16)	65.0 (13)	56.3 (40)
Poor social networks (reciprocal and productive processes, a good resource), poor social capital, poor social support	40.0 (10)	50.0 (13)	80.0 (16)	54.9 (39)
Family breakdown or lack of opportunity to establish family. Poor contact with family or poor family support	28.0 (7)	34.6 (9)	40.0 (8)	33.8 (24)
Having support in a crisis			15.0 (3)	4.2 (3)
Having friendships			10.0 (2)	2.8 (2)
Living alone		7.7 (2)		2.8 (2)
Looking after a family as a contributor to social inclusion	4.0 (1)			1.4 (1)
Total for domain	16.6 (29)	22.0 (40)	30.0 (42)	22.3 (111)
Housing and neighborhood				
Poor housing or homelessness	36.0 (9)	53.8 (14)	85.0 (17)	56.3 (40)
High crime environments or unsafe neighborhoods	32.0 (8)	19.2 (5)	50.0 (10)	32.3 (23)
Concentrations of poverty (living in poor or disadvantaged neighborhoods)	24.0 (6)	7.7 (2)	60.0 (12)	28.2 (20)
Rural or urban living			20.0 (4)	5.6 (4)
Public sector housing			20.0 (4)	5.6 (4)
No home ownership; renting	4.0 (1)	3.9 (1)	10.0 (2)	5.6 (4)
Poor quality of environment	4.0 (1)		10.0 (2)	4.2 (3)
Environmental pollution	8.0 (2)			2.8 (2)
Not living independently	4.0 (1)		5.0 (1)	2.8 (2)
Excluded from communities (geographically)		3.9 (1)		1.4 (1)
Total for domain	11.2 (28)	8.8 (23)	26.0 (52)	14.5 (103)
Limited access to services				
Poor transport options	32.0 (8)	7.7 (2)	55.0 (11)	29.6 (21)
Poor leisure facilities or lack of access to recreational activities; poor use of amenities	24.0 (6)	7.7 (2)	50.0 (10)	25.4 (18)
Poor community services or poor use of community services	4.0 (1)	7.7 (2)	45.0 (9)	16.9 (12)
No access to ICT	12.0 (3)	3.9 (1)	40.0 (8)	16.9 (12)
Unmet needs (discrepancy b/w levels of formal or informal help needed and those given)	4.0 (1)	11.5 (3)	25.0 (5)	12.7 (9)
Poor retail services or poor access to retail services	16.0 (4)		5.0 (1)	7.0 (5)
Total for domain	15.3 (23)	6.4 (10)	8.3 (44)	18.1 (77)
Poor health or disability				
Bad health or disability	28.0 (7)	42.3 (11)	85.0 (17)	49.3 (35)
Poor access to services (possibly due to mental health problems)	4.0 (1)	19.2 (5)	60.0 (12)	25.3 (18)
Impairment due to poor mental health		15.4 (4)	20.0 (4)	11.3 (8)
Lengthy and repeated admissions to psychiatric ward; contact with psychiatric services		7.7 (2)	10.0 (2)	5.6 (4)
Poor life expectancy at birth			15.0 (3)	4.2 (3)
Poor self-defined health status			15.0 (3)	4.2 (3)
Practitioner over-focus on symptoms of mental illness than assisting PT's to participate in local community		3.9 (1)	5.0 (1)	2.8 (2)
Risk of mental illness			5.0 (1)	1.4 (1)
Lack of regular exercise			5.0 (1)	1.4 (1)
Lack of leisure opportunities with people without mental illness		3.9 (1)		1.4 (1)
Total for domain	3.2 (8)	9.2 (24)	22.0 (44)	10.7 (76)
Minority groups and discrimination				
Stigma or discrimination (including bullying)	8.0 (2)	42.3 (11)	55.0 (11)	33.8 (24)
Membership in an ethnic minority group, ethnicity	8.0 (2)	23.1 (6)	35.0 (7)	21.1 (15)
Immigration and/or refugees		3.9 (1)	40.0 (8)	12.7 (9)
Identification with a cultural group or community (including religious groups) contributes to social inclusion	12.0 (3)	7.7 (2)	20.0 (4)	12.7 (9)

Table 2 (continued)

Contributors to social inclusion or social exclusion	GSI % (n)	MISI % (n)	Organizational reports % (n)	Total citations % (n)
Indigenous people			30.0 (6)	8.5 (6)
Having a non-English speaking background			20.0 (4)	5.6 (4)
Membership in a sexual minority group such as gay, lesbian, or transgender			10.0 (2)	2.8 (2)
Compounding issues of discrimination		3.9 (1)	5.0 (1)	2.8 (2)
Marginalization	4.0 (1)		5.0 (1)	2.8 (2)
Total for domain	3.6 (8)	9.0 (21)	24.4 (44)	11.4 (73)
Economic factor				
Low income, on welfare, or lack of earned income (low socioeconomic status)	48.0 (12)	57.7 (15)	75.0 (15)	59.2 (42)
Current lifestyle deprivation (due to economic strain)	4.0 (1)		40.0 (8)	12.7 (9)
Economic strain (irrespective of high or low income)	4.0 (1)		25.0 (5)	8.5 (6)
Poverty or at risk of poverty			30.0 (6)	8.5 (6)
No accumulation of savings	8.0 (2)		15.0 (3)	7.0 (5)
Relative poverty			10.0 (2)	2.8 (2)
Income inequality			5.0 (1)	1.4 (1)
Managing funds independently			5.0 (1)	1.4 (1)
Few, if any, sizeable assets (<50,000)			5.0 (1)	1.4 (1)
Total for domain	7.1 (16)	6.4 (15)	23.3 (42)	11.4 (73)
Poor life events/circumstances				
Disaffected youth (including school exclusions from suspensions, drop outs)	4.0 (1)	7.7 (2)	45.0 (9)	16.9 (12)
Poor life events such as repeated rejection; restrictions of hope and expectations		23.1 (6)	15.0 (3)	12.7 (9)
Child poverty	8.0 (2)		26.9 (7)	12.7 (9)
Continued and accumulated deprivation over time		3.9 (1)	26.9 (7)	11.3 (8)
Teenage pregnancy	4.0 (1)	3.9 (1)	20.0 (4)	8.5 (6)
Acting as a caregiver for another person	4.0 (1)		25.0 (5)	8.5 (6)
Lack of developmental opportunities			20.0 (4)	5.6 (4)
Poor life satisfaction or poor quality of life		7.7 (2)	5.0 (1)	4.2 (3)
Victim of domestic abuse			7.7 (2)	2.8 (2)
Poor or negative social norms	4.0 (1)		5.0 (1)	2.8 (2)
Social disorganization	8.0 (2)			2.8 (2)
Childless women			5.0 (1)	1.4 (1)
Total for domain	2.7 (8)	3.8 (12)	18.3 (44)	7.5 (64)
Limited opportunities for everyday life				
Limited opportunities for or lack of participation in everyday life. Lack of participation in social, economic, and political activity of society as a whole; denial of full rights of citizenship	20.0 (5)	38.5 (10)	75.0 (15)	42.3 (30)
Lack of ability to consume or access minimum level of services and goods normal in the society and to participate in social and cultural activities of wider society	16.0 (4)	19.2 (5)	50.0 (10)	26.8 (19)
Limited opportunities in life, poor freedom of choice. Lack of power	8.0 (2)	11.5 (3)	7.7 (2)	9.9 (7)
Total for domain	14.7 (11)	23.1 (18)	45.0 (27)	26.3 (56)
Demographic factor				
Age	12.0 (3)		26.9 (7)	14.1 (10)
Single parent; child of a single parent	12.0 (3)	3.9 (1)	25.0 (5)	12.7 (9)
Poor social class; lack of status	12.0 (3)	15.4 (4)	7.7 (2)	12.7 (9)
Gender	8.0 (2)		30.0 (6)	11.3 (8)
Elderly			30.0 (6)	8.5 (6)
Marital status		3.9 (1)		1.4 (1)
Total for domain	7.3 (11)	3.8 (6)	21.7 (26)	10.1 (43)
Civic/community participation				
Exclusion from community activities. Civic participation such as collective action processes; involvement in local or national decision making	8.0 (2)	38.5 (10)	75.0 (15)	38.0 (27)
Lack of interaction with neighbors	4.0 (1)		25.0 (5)	8.5 (6)
Community fragmentation	8.0 (2)		5.0 (1)	4.2 (3)
Newcomer to a community			5.0 (1)	1.4 (1)
Total for domain	5.0 (5)	9.6 (10)	27.5 (22)	13.0 (37)
Personal factor				
Poor motivation to improve circumstances	4.0 (1)	7.7 (2)	20.0 (4)	9.9 (7)
Self-exclusion or choosing not to participate	4.0 (1)	7.7 (2)	20.0 (4)	9.9 (7)
Poor sense of belonging		7.7 (2)	20.0 (4)	8.5 (6)
Time constraints	4.0 (1)		5.0 (1)	2.8 (2)
Total for domain	3.0 (3)	5.8 (6)	16.3 (13)	7.7 (22)

(table continues)

Table 2 (continued)

Contributors to social inclusion or social exclusion	GSI % (n)	MISI % (n)	Organizational reports % (n)	Total citations % (n)
Illegal activity				
Criminal history, history of violence	4.0 (1)	7.7 (2)	45.0 (9)	16.9 (12)
Drug misuse	4.0 (1)		30.0 (6)	9.9 (7)
Access to justice (for good social inclusion)			15.0 (3)	4.2 (3)
Total for domain	2.7 (2)	2.6 (2)	30.0 (18)	7.7 (22)
Total number of citations	7.9 (178)	9.7 (227)	26.4 (476)	13.8 (881)
Total number of citations per group	57.8 (52)	53.3 (48)	90.0 (81)	100.0 (90)

Note. GSI = general social inclusion literature; MISI = social inclusion and mental illness literature.

marginal differences seen upon a rerun of analyses. Thus, results presented here include data using untransformed variables.

Hypothesis Testing

Hypothesis 1: The three domains employment or education, housing and neighborhood, and social activities/social support contained the greatest number of cited contributors. The two most highly cited individual contributors were from the domain of employment or education: Unemployment, irregular, or underemployment was most highly cited overall and across all three groups (cited in 73.2% of reports), followed by poor skills, lack of, or limited opportunities for education or training (cited in 64.8% of reports). The six most highly cited contributors were from the three highest cited domains and were themselves cited overall in at least half of the reports, with consistent numbers across the three groups.

Hypothesis 2: Although the domains of employment or education, housing and neighborhood, and social activities/social support were among the three most highly cited domains overall, they were not consistently among the most highly cited domains in each of the three groups (see Table 3).

Of the three domains anticipated, employment or education was the only one noted among the top three most highly cited domains in each group. Housing and neighborhood was the second highest domain in the GSI Literature and the organizational reports, however was the fourth highest domain of the MISI Literature. The

domain social activities/social support was included among the most highly cited domains of the GSI and MISI literature, but it was only ranked seventh within organizational reports.

A statistically significant difference was found between groups for the domains social activities/social support and employment or education, $F(2, 67) = 7.80, p = .001$, (Pillai's trace = .37; partial $\eta^2 = .19$). Post hoc tests revealed significant differences (Bonferroni adjusted $\alpha = .025$) between the GSI literature and organizational reports for social activities/social support, $F(1, 68) = 7.80, p = .007$, and between the organizational reports and both the GSI literature, $F(1, 68) = 34.75, p = .001$, and the MISI literature, $F(1, 68) = 18.94, p = .001$, for employment or education. Greater numbers of contributors from these domains were consistently cited in organizational reports than in the academic literature.

A significant difference was also seen between groups regarding the domain of housing and neighborhood, $\chi^2(2, 71) = 13.23, p = .001$, with differences between the organizational reports and GSI literature ($U = 126.00, p = .004$) and the organizational reports and MISI literature ($U = 111.00, p = .001$). As per the previous domains, a greater number of contributors were cited in organizational reports than in the academic literature.

Hypothesis 3: A significant difference was seen between groups regarding the overall number of contributors identified in each piece of literature, $\chi^2(2, 71) = 26.45, p = .001$. Significant differences were noted between groups for the GSI literature and Organizational Reports ($U = 47.00, p = .001$) and the MISI literature and organizational reports ($U = 65.00,$

Table 3
Domains in Order of Number of Citations by Group

General social inclusion literature	Social inclusion and mental illness literature	Organizational reports
Social activities/social support (29)	Social activities/social support (40)	Employment or education (58)
Housing and neighborhood (28)	Employment or education (40)	Housing and neighborhood (52)
Employment or education (26)	Poor health or disability (24)	Limited access to services (44)
Limited access to services (23)	Housing and neighborhood (23)	Poor health or disability (44)
Economic factors (16)	Minority groups and discrimination (21)	Minority groups and discrimination (44)
Limited opportunities for everyday life (11)	Limited opportunities for everyday life (18)	Poor life events/circumstances (44)
Demographic factors (11)	Economic factors (15)	Social activities/social support (42)
Poor health or disability (8)	Poor life events/circumstances (12)	Economic factors (42)
Minority groups and discrimination (8)	Limited access to services (10)	Limited opportunities for everyday life (27)
Poor life events/circumstances (8)	Civic/community participation (10)	Demographic factors (26)
Civic/community participation (5)	Demographic factors (6)	Civic/community participation (22)
Poor personal factors (3)	Poor personal factors (6)	Illegal activity (18)
Illegal activity (2)	Illegal activity (2)	Poor personal factors (13)

Note. Numbers in parentheses represent number of citations per domain.

$p = .001$). Of the 90 contributors, 36.7% ($n = 33$) were cited by only one group; 25 citations by organizational reports, three by GSI literature, and five by MISI literature.

Differences between groups were seen for each domain; however, only the following reached statistical significance using a Bonferroni adjusted $\alpha = .006$: limited access to services, $\chi^2(2, 71) = 18.12, p = .001$; poor health or disability, $\chi^2(2, 71) = 26.54, p = .001$; minority groups and discrimination, $\chi^2(2, 71) = 17.67, p = .001$; economic factors, $\chi^2(2, 71) = 13.65, p = .001$; poor life events/circumstances, $\chi^2(2, 71) = 21.85, p = .001$; civic/community participation, $\chi^2(2, 71) = 22.60, p = .001$; and illegal activity, $\chi^2(2, 71) = 31.20, p = .001$. The domain limited opportunities for everyday life additionally showed differences between groups, $F(2, 68) = 8.10, p = .001$, with partial η^2 of 0.19. Post hoc tests indicated the mean score for organizational reports ($M = 1.35, SD = 0.81$) as significantly higher than either GSI literature ($M = 0.44, SD = 0.65$) or the MISI literature ($M = 0.69, SD = 0.84$).

Discussion

A comprehensive list of contributors to social inclusion/exclusion were identified, organized clearly into domains representing similar properties. Contributors either assisted a person by directly achieving social inclusion, directly impairing social inclusion or indirectly affecting either social inclusion/exclusion in some important way. Differences and similarities existed between groups in the numbers and types of contributors identified.

In terms of similarities across groups regarding overall contributors to social inclusion, as per Hypothesis 1, relative consistency was seen. As expected, the most commonly identified contributors to social inclusion overall were from the domains of social support and participation, employment or education, and housing and neighborhood. Within each domain, one or two stand-out contributors were well-cited across a number of articles.

The domains of employment or education and housing and neighborhood were consistently in the top four of each group. Social activities/social support was the seventh most highly ranked domain of the organizational reports, but the most highly rated domain within both groups of academic literature. The difference between groups in number of citations was fairly small, still indicating the importance of this domain. The two lowest cited domains were also consistent across groups: illegal activity and poor personal factors. The majority of citations for these groups came from organizational reports indicating that perhaps they were more a focus of organizations working with people with disadvantage.

The main contributors to social inclusion were not consistently identified across the three groups (Hypothesis 2). This was due to a consistently higher number of contributors identified in organizational reports than the academic literature.

Differences regarding the specificity of contributors were identified between the academic and organizational literature (Hypothesis 3). Examples include the contributor newcomers to a community from the domain civic/community participation, and the contributor childless women from the domain poor life events/circumstances. These vary from the broader and more often cited contributors of exclusion from community activities or disaffected youth from the respective domains.

The higher numbers of contributors cited in organizational reports are likely due to the reports from this group solely regarding social inclusion, whereas social inclusion may be a topic but not necessarily the focus of academic literature reviewed. The specificity provides insight into the particular problems and real-life challenges faced by the individuals who organizations work with. It is important to note though, that the identified contributors might be a clear delineation of the specific challenges or limitations encountered daily by them, or perhaps a representation of how the organizations would like to market themselves. That is, the identification of particular contributors to social inclusion may well be more aligned with how an organization would like to be perceived, and less aligned with actual practices endorsed and employed on a daily basis. Future research exploring the perceptions of service users and measuring the particular elements of social inclusion or exclusion experienced by service users will provide a greater understanding of what contributor organizations actually prioritize and endorse.

Differences were observed between the GSI and MISI literature with a greater focus on more individualized contributors relating to functioning and participation, health and well-being, and issues faced by minority groups such as stigma and discrimination noted in the MSI literature. Contributors at a population level and related to community-based involvement were identified in the GSI literature. These results were perhaps unsurprising given the different disciplines, roles and priorities explored in the literature. The organizational reports provided a combination of contributors, with perhaps a slightly greater emphasis on the individual level ones.

Variation in contributors to social inclusion appeared to depend on the area of interest or expertise of authors. For example, when considering age, some researchers and experts identified being elderly as a risk factor (Adams, 2009; Vinson et al., 2009), others identified youth (Stanley & Stanley, 2007; World Bank, 2007), and others either end of the age spectrum (Hayter, 2009; Taket et al., 2009; United Nations, 2010).

Overall, the findings support the view that social inclusion is multidimensional and that these dimensions are interrelated (Levitas et al., 2007; Stanley & Stanley, 2007; World Bank, 2007), dynamic and complex (Whelan & Maitre, 2005). The identified contributors demonstrate how they differ in their impact on social inclusion. Some contributors affect social inclusion immediately, such as whether a person currently participates in social activities. Some have greater long-term effects, such as lack of education or skills training. Different contributors may have either a direct or indirect effect (e.g., a direct contributor may be having a group of friends to spend time with); on the other hand, employment, although a commonly cited contributor to social inclusion, may also be considered an indirect contributor, providing an income to use on social activities as well as an increased social network.

Many of the contributors identified provide an objective picture of social inclusion, but not necessarily a subjective perspective. Contributors related to employment are a good example of this. Although it is seen as integral to social inclusion, employment may also negatively impact it under certain circumstances (e.g., long/inflexible hours, inconvenient shifts, unpleasant/unfair or isolative working conditions, poor remuneration and workplace bullying). Despite a person being perceived as socially included via employment (i.e., physically present at work), the subjective experience

may differ significantly. As noted by [Le Boutillier and Croucher's \(2010\)](#) conceptualization of social inclusion, the degree to which a person feels socially included may be of greater importance than how physically involved they are with others. Similarly, numerical information about a person's income may only provide part of a picture. Ascertaining a person's actual income provides objective data, but identifying their perceived minimally satisfactory income can provide more informative detail. Perhaps that individual lives with family, or has paid off their home and no longer has that expense, or perhaps has a large amount of debt and very little left to spend. This subjective experience is considered an important element, how people feel based on their personal expectations, the culture and local environments within which they live, and the shared perceptions that exist, all contribute to the experience of social exclusion ([Vinson, 2009](#)).

Additionally, interpretation of the key elements, or broad categories of social inclusion may, in a similar fashion to the term social inclusion itself, be subject themselves to personalized interpretations. A good example of this is employment. For individuals affected by mental illness, attainment of employment may be something they value for themselves; others may desire it as a social norm; some individuals might consider working in a part-time, a casual, or a volunteer capacity to be enough for them; others might consider full-time employment as a prized goal. These very subjective elements of an already contested term contribute to the difficulties in providing a clear definition of social inclusion and again speak to the need for some input from those most affected by social exclusion to delineate exactly what the categories might mean.

Finally, different conceptualizations of social inclusion were encountered during the viewing of analyzed and related literature. These include that of [Le Boutillier and Croucher \(2010\)](#), the quadrant approach of [Secker \(2009\)](#), the individualized American perspective outlined by [Silver \(1994\)](#) and the more collaborative perspective of the [European Union \(2012\)](#) which involves communication and joined-up approaches to improving social inclusion as a societal and governmental imperative. Unfortunately, a discussion of these conceptualizations was beyond the scope of this article.

Strengths and Limitations

A number of limitations were encountered during this study, some methodological and difficult to anticipate. These were easily rectified using step-by-step approaches as detailed in the Method section.

The most difficult limitation was that the majority of highly cited articles were so because of the topic of overall research rather than the concept of social inclusion. The more highly cited articles commonly did not identify many, if any, contributing factors to social inclusion. The use of citation rankings assisted in overcoming this minor complication, identifying the most influential articles by authors consistently publishing on social inclusion, not having been cited due to other subject matter. This point speaks clearly to the need for a study such as this; social inclusion has previously been treated as a self-evident concept in empirical research, allowing it to become a construct that is, problematically, "all things to all people."

Not all articles specifically about social inclusion/exclusion were as methodologically robust as those that covered it in less detail. With the purpose of this study to determine key contributors rather than evaluate the quality of studies, this minor limitation was simply noted.

Literature selection and the thematic analysis were largely completed by the first author due to pragmatic restrictions of resources available to the project. This must be noted as a limitation, with the potential for bias. However, the methodology required clear, explicit references to social inclusion be noted and included for quantitative analysis. In addition, regular supervision meetings were held with two of the authors, in consultation with another of the authors, who supervised the analysis. Therefore, though a bias may exist, it is not entirely specific to the first author.

Finally, the main analysis was completed in 2010. Since that time there has been a significant increase in articles related to social inclusion. A selection of these articles and reports were reviewed, selected using the original methodology. Since 2010, a number of reviews of the construct and its measurement have emerged (e.g., [Baumgartner & Burns, 2014](#); [Coombs, Nicholas, & Pirkis, 2013](#); [Evans-Lacko et al., 2014](#)), and some researchers have begun to examine cross-cultural factors in social inclusion (e.g., [Huxley et al., 2016](#)). Similar themes and continued acknowledgment of the construct's problems remain highlighted in this later work, with ambiguity around the concept continuing to exist. As expected, saturation had been reached in the previous search, with no new contributors to social inclusion identified.

A number of novel elements contributed to the strength of the study. The choice to include literature with and without specificity to mental illness was significant; as was the choice to include both academic and gray literature. The first point relates to the generalizability of findings. An emphasis was placed on identifying key contributors to social inclusion from a mental health perspective (the most vulnerable to and affected by social exclusion); however, significant efforts were made to include information related to other populations. This ensured the resulting information was broadly applicable, and though still relevant, not limited to issues pertinent to people with severe mental illness, but reflective of the concept of social inclusion as a whole.

The second novel component relates to the inclusion of both academic and gray literature. With much of the work related to social inclusion carried out by nonacademic groups such as charities, government organizations, welfare and advocacy groups, it is important that it is represented in any review regarding social inclusion.

Another novel aspect includes the focus on systematically, and thematically reviewing carefully selected, wide-ranging literature regarding social inclusion; with the additional aspect of providing a quantitative statistical analysis to provide some context to the findings.

Finally, we found support for the assumption that specific contributors are of significance, despite less frequent citations. The focus on greater specificity is a significant strength and novel aspect of the study, with others taking a broad overview of the concept, alluding to features rather than detailing specific contributors. This information additionally allows for a greater understanding of the particulars of causative factors related to poor outcomes also identified as contributors to social exclusion.

Implications and Conclusions

There are a number of positive implications of this investigation. First, the information provided allows for a more precise understanding of social inclusion as a concept. Second, the degree of specificity will allow for a greater understanding of the particular causative factors related to poor outcomes, themselves noted as contributors to social exclusion. Advancing our understanding of social inclusion will have significant translational implications for policy and service delivery. It will aid in identifying ways of addressing the extensive costs associated with poor social inclusion and mental illness (Shepherd & Parsonage, 2011) and reducing the personal and economic costs on individuals and those who support them. Moreover, advancing our understanding will assist in the identification of which interventions are most effective, determining at what stage of illness interventions would most benefit mental health outcomes, and allow for the provision of more targeted and personalized care, with greater ability to determine which areas of social inclusion require preserving, protecting or promoting in each individual.

The use of this information will assist in the development of further research, pointing us in the direction of which areas are most important or relevant to address. A next step of research within this group is to obtain the input of people with a lived experience of mental illness regarding the important contributors to social inclusion. This will remove any bias, and provide insight into what people most affected by social exclusion believe to be important contributors. It will additionally address the lack of peer literature regarding social inclusion, this itself potentially caused by the poor social inclusion of this group and the lack of platforms for them to voice their experience.

Finally, an improved understanding will allow for better measurement of the concept, pertinent to any attempts to understand and improve social inclusion in affected populations. The ability to monitor outcomes and team performance is important for service delivery and in ensuring that services are provided in an optimal manner (Brophy & Moeller-Saxone, 2012). In addition, the ability to incorporate information related to the success of attempts to improve social inclusion and provide some empirical information related to the extent and magnitude of social inclusion in various populations (geographical, diagnostically, with respect to age, gender, or various other characteristics) will assist in policy-making related to both social inclusion and to the mental health and well-being of people with mental illness.

It has been noted that a measure of social inclusion would be a welcome addition to the existing outcome measures in place in public mental health services within Australia (Brophy & Moeller-Saxone, 2012; Coombs et al., 2013). Currently implemented measures provide an overall impression of a person's social and occupational functioning within the context of symptom severity. These measures however, largely completed by mental health professionals, do not allow for the measurement of a range of items of interest, such as in which areas individuals feel that they may require more assistance and whether these areas are perceived to improve with input. Completing a measure of social inclusion at the outset of treatment would allow for the charting of progress across time. Completing a measure at routine time points and when symptoms may worsen

would allow for the ability to determine what correlations may exist for that particular individual with respect to risk factors and increases in symptomatology and, at the other end of the spectrum, the particular areas of social inclusion are of greatest benefit to that individual in keeping them well and on the path to recovery.

Our findings suggest that the most commonly identified contributors to social inclusion are simply the most basic requirements of life; activities that the majority of people participate in. As per our findings, social inclusion is multifaceted and complex, comprising of a range of key contributors related primarily to participation in social activities, good social networks with support available, stable and suitable housing in a safe and well-resourced neighborhood and involvement in employment or education (current and/or acquired education). Contributors related to health and well-being, service utilization and community involvement are also important. This consolidation of information from the many and varied sources reviewed here will assist us in furthering efforts to improve social inclusion in markedly disadvantaged and vulnerable populations.

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APPENDIX 3

Understanding what it means to be socially included for people with a lived experience of mental illness

Understanding what it means to be socially included for people with a lived experience of mental illness

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Abstract

Aims: Social inclusion is increasingly understood to have positive and beneficial implications for the mental health outcomes of people with severe mental illness. The concept is plagued by definitional inconsistencies and a lack of consensus regarding what it means to be socially included, in particular for groups most vulnerable to social exclusion, such as people with mental illness. The aim of this study was to obtain a consensus regarding the key contributors to social inclusion from the perspective of people with and without a lived experience of mental illness (consumers of mental health services, carers, and general community members).

Methods: Delphi methodology was employed to reach consensus agreement. The Delphi questionnaire was based on a previous review of the literature and consisted of 147 items categorized into 13 domains. It was presented to participants over three rounds. Participants ($N=104$) were recruited into three groups (32 consumers, 32 carers of people with a mental illness, and 40 members of the general community – neither consumers nor carers). Retention of participants from Round 1 to Round 3 was 79.8%.

Results: Similarities and differences were observed between the groups. A number of items were very strongly endorsed as key contributors to social inclusion, relating to social participation, social supports, housing, neighbourhood, community involvement, employment and education, health and well-being and service utilization.

Conclusion: Findings supported previous work, indicating the importance of having a strong sense of connection with others as well as the importance of safe and stable housing, support services and personal motivation and hope. We obtained a well-rounded perspective among groups regarding the key contributors to social inclusion, with a particular relevance to people living with mental illness. This perspective has significant clinical and research utility.

Keywords

social inclusion, social exclusion, Delphi methodology, consumer participation

Social inclusion entails a sense of connection to family and friends, the community, and possessing the means and opportunity to participate in social and civic activities. People with mental illness are among the most socially excluded (Dunn, 1999; Harrison & Sellers, 2008; Lloyd, Waghorn, Best, & Gemmell, 2008), commonly experiencing greater and multiple forms of disadvantage than others in the general community (Huxley & Thornicroft, 2003). This includes: higher rates of unemployment (>85%) (Evans & Repper, 2000; Shepherd & Parsonage, 2011); increased risks of homelessness (Craig & Timms, 2000; V. A. Morgan et al., 2011) and dependence on government assistance (85% for people with psychosis; V. A. Morgan et al., 2011).

The concept of social inclusion is plagued by definitional inconsistencies and a lack of consensus regarding what it means to be socially included (Huxley et al., 2012; C. Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007;

Vinson, 2009). An increased sense of optimism exists regarding the opportunity for improved outcomes for people with mental illness by enhancing social inclusion (Dunstan, Falconer, & Price, 2017; Fenton et al., 2017). Improvements in areas related to social inclusion are associated with better mental health outcomes. For example, social supports and structures have assisted those suffering from mental health

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conditions to significantly reduce both symptoms of illness and relapse rates (Psychiatric Disability Services of Victoria, 2008). Similarly, gainful employment has also resulted in increased social inclusion and quality of life (Psychiatric Disability Services of Victoria, 2008).

The ability to effectively improve social inclusion depends heavily on understanding clearly what social inclusion means, what factors contribute to social inclusion and what it means to be socially included. Previous research by Filia, Jackson, Cotton, Gardner, and Killackey (2018) involved a thematic analysis of social inclusion literature (peer-reviewed and grey) with an emphasis on mental illness. A list of specific contributors to social inclusion and social exclusion (in the sense of them being two ends of a fluid continuum) was developed based on professionals' perspectives, compiled to address the need for more specific data breakdowns for indicators (Social Inclusion Unit, Department of the Prime Minister and Cabinet, & Australian Social Inclusion Board, 2008). Social inclusion was found to be a multi-faceted and complex concept, with a range of inter-related and dynamic contributors. These contributors were strongly related to social relationships, participation in social and occupational activities, housing, and to a lesser but still important extent, health and well-being, access and utilization of services, and involvement in wider communities.

There is no agreement that these aspects capture the meaning of social inclusion for different populations. Most definitions of social inclusion imply a sense of relativity, stating that social inclusion involves participation in 'normal relationships and activities' (Levitas et al., 2007, p. 9) or in 'key activities of the society in which he or she lives' (Burchardt, Le Grand, & Piachaud, 2002, p. 30); or is about how a person may 'connect with family, friends' (Social Inclusion Unit, Department of the Prime Minister and Cabinet, & Australian Social Inclusion Board, 2008, p. 8), in 'ways that matter for well-being' (Boushey, Fremstad, Gragg, & Waller, 2007, p. 4).

Perception of individual circumstances is influenced by what a person sees around them and what they think of their own circumstances in relation to others (Vinson, 2009). The relativity of social inclusion is no more apparent than when considering the term as applied to marginalized groups. Such groups have reduced opportunities to engage or participate in social and civic life, often with additional circumstances further exacerbating their vulnerability to social exclusion. Therefore, when considering what social inclusion entails, relevance is required when applying it to specific groups because, as with individuals, the specific needs of each group, and what is perceived as important, necessary or able, for one group, may differ for another.

People with mental illness face additional challenges to achieve social inclusion. With a cyclical pattern of health issues and factors that contribute to social exclusion,

commonly prized elements of social inclusion may hold less value. For example, where employment is considered essential to social inclusion, part-time employment may be preferred over full-time; or more emphasis may be placed on any housing rather than preferred housing. Given the episodic nature of mental illness, perceptions of social inclusion and an individual's desire to be socially included may fluctuate with time and circumstances.

Perceptions of social inclusion may also vary between groups of individuals impacted by mental illness, such as people with mental illness themselves, their carers, family members, and friends. It would be of interest to identify similarities and differences regarding how social inclusion is perceived by these groups, as the information would be beneficial when working collaboratively.

The focus of this study was to develop a consensus regarding key features of social inclusion for people with a lived experience of mental illness. There were three specific aims: (1) to determine the face validity of an existing list of items pertaining to social inclusion compiled following thematic analysis of a wide range of literature (Filia et al., 2018); (2) to conduct a Delphi study to obtain consensus of the key features of social inclusion among broader stakeholders (consumers of mental health services, carers of people with mental health conditions, and community members); and (3) to compare perspectives of social inclusion in consumers, carers, and community members.

We anticipated that the results of the Delphi study would demonstrate differences between the three groups regarding items endorsed as important for social inclusion. For example, it was expected that community members might identify items such as full-time employment and earning an income as important contributors to social inclusion, whereas consumers and carers might not. Likewise, consumers and/or carers might identify items such as living in public housing or managing money independently as important contributors to good social inclusion, whereas community members may not identify the helpfulness or importance of these items.

Methods

Design

The Delphi method is a systematic technique used to establish consensus among groups of experts on a particular topic—expertise determined by specialized knowledge or lived experience (Jeffery, Ley, Brennan, & MacLaren, 2000; Mead & Moseley, 2001). It is a multi-stage approach; each stage builds on the results of the previous one, culminating in a final set of responses agreed upon by majority of participants in each group (McKenna, 1994).

A number of 'rounds' are completed in a Delphi study. During each round, items are presented to panel members, with each panel representing a group of experts in their

own right. Panel members are asked to rank or rate each item. With each round, items meet pre-determined criteria for 'endorsement', 're-rating' or 'neither'. As rounds progress, items decrease and opinions converge until consensus is reached (Murry & Hammons, 1995).

The Delphi method provides flexibility and the ability to achieve consensus while obtaining individual opinions through group data. It has been used to good effect in previous mental health research (Kelly, Jorm, & Kitchener, 2009; Kingston et al., 2009; National Public Health Partnership, 2000).

Participants

Participants were recruited into one of three groups: (1) consumers of mental health services; (2) carers of people with a mental illness; and (3) members of the general community (neither consumers nor carers). Strategies employed to recruit participants included presentations at area mental health services and psychiatric disability support services, phone calls to and advertisements at such services, and once the study was underway, referrals from existing participants.

Initially, consumers and carers were identified and recruited through their roles as paid or unpaid advocates at Area Mental Health Services and Psychiatric Disability Rehabilitation and Support Services within the state of Victoria, Australia. This was later extended to consumers and carers in general. These efforts were made (to recruit people specifically within the roles of consumer and carer advocates), as it was anticipated that they would provide well-rounded views, considering those of the people they advocate for.

Despite 10–15 participants per group considered ample for the Delphi technique (Hasson, Keeney, & McKenna, 2000; Hsu & Sandford, 2007), a minimum of 30 per group was sought due to high attrition rates seen in numerous studies (Hart, Jorm, Kanowski, Kelly, & Langlands, 2009; Jeffery et al., 2000; Kelly et al., 2009; Kingston et al., 2009; Langlands, Jorm, Kelly, & Kitchener, 2008; National Public Health Partnership, 2000). A priori power calculations also indicated that ≥ 30 participants in each group would provide sufficient power ($1-\beta=.80$) to reliably detect group differences between three groups, with a large effect size and $\alpha=.05$ (Cohen, 1992).

Delphi questionnaire

The initial Delphi questionnaire was based on the results of the thematic analysis detailed in Filia et al. (2018). It comprised 147 items categorized into 13 domains. Several iterations were reviewed by a group of advisors ($n=3$), and the questionnaire piloted on a small number of people ($n=5$), with feedback incorporated into a final version. The questionnaire was divided into 11 sections each including

multiple questions, with an explanation of its relevance to social inclusion. Participants were asked to rate whether they believed items were important to being socially included, contributed to good social inclusion, likely to contribute to or negatively impact upon a person's ability to be socially included, and whether they believed that certain items would limit a person's ability to be socially included. Additional questions were included to elicit more detailed information from participants, ensuring all possible contributors to social inclusion were identified.

Basic demographics were obtained: age, gender, diagnosis and length of time since diagnosis (of self, or person caring for); and for carers, age and relationship of the person caring for (e.g., son, spouse and sibling).

Procedure

Ethics approval was granted by Melbourne Health Human Research and Ethics Committee (HREC 2010.105). Participants were offered the option of completing the Delphi questionnaire via the mail, online using the survey platform surveymonkey.com, over the phone or face-to-face.

Three rounds of the Delphi questionnaire were completed. As per Delphi methodology (Jorm, 2015), participants received a copy of group results alongside individualized summary reports following each round. These included group responses to items due for re-rating alongside personal responses for Rounds 1 and 2, and a summary of results for each item following Round 3.

Data analysis

Participants were characterized at the initial round using descriptive statistics (means, standard deviations, percentages and counts). Comparisons between groups regarding demographic characteristics were conducted using chi-square (χ^2) analyses and one-way analyses of variance (ANOVA) with Tukey's honestly significant difference (HSD) test post hoc comparisons.

Delphi study data. Items on the Delphi questionnaire were assessed after each round to see whether they were to be 'Endorsed', 'Not Endorsed' or 'Re-Rated'. Overall domains of social inclusion were rated on a 4-point scale from $1 = \text{not important}$ to $4 = \text{essential}$. Remaining items were rated on 3-point scales, providing a mid-point for analysis; responses ranged from $1 = \text{not important}$ to $3 = \text{extremely important}$, $1 = \text{not likely}$ to $3 = \text{very likely}$ and for items that might limit a person's ability to achieve good social inclusion, $1 = \text{would not limit}$ to $3 = \text{definitely limit}$. Initially, it was anticipated that items would be assessed using the highest rating from each scale. However following analysis of findings after the first round, so very few items reached endorsement (4.8%, $n=7$) and only 14.3% met criteria for re-rating ($n=21$). At this time, it became apparent that our method of scoring

Table 1. Number of participants approached using each recruitment strategy.

Recruitment strategy	Consumers	Carers	Community members
Phone calls to AMHS and PDRSS	23	24	–
Presentations and advertisements	10	1	1
Emails and phone calls	–	–	18
Referrals from existing participants	9	11	22
Totals	42	36	41

AMHS: Area Mental Health Service; PDRSS: Psychiatric Disability.

items was flawed and that we had neglected to include a neutral mid-point. A decision was made to combine the two highest (or positive) responses to reflect a dichotomous rating system. Items were now essentially rated as ‘important/not important’, ‘essential/not essential’, ‘would not limit/would definitely limit’.

Endorsed items. An item was considered ‘endorsed’ when $\geq 80\%$ of participants in each group rated the item as particularly important, likely to contribute to, or limiting to being socially included.

Items for re-rating. Items that received ratings of $\geq 80\%$ of one group, or $\geq 70\%$ – 79% of two groups were included in subsequent rounds for re-rating.

Remaining items. Items that did not meet either criterion were not included in the subsequent round.

Chi-square (χ^2) tests for independence were conducted to identify differences between groups regarding Delphi data. The value for Fisher’s Exact Probability Test (FET) was used where $>80\%$ of cells had expected frequencies of <5 . Post hoc analyses focused on adjusted residuals (z) for each cell to determine which groups differed.

Statistical analyses were conducted using IBM® SPSS®, version 20.0.

Results

Participants

In total, 104 participants were recruited. Table 1 shows number of participants recruited using each approach. The Delphi questionnaire was provided to participants via surveymonkey.com ($n=102$) or in the mail ($n=2$).

Rehabilitation and support service. In Round 1, 32 consumers, 32 carers and 40 community members participated (see Table 2). In Round 2, 91 participants participated and in Round 3, 83 participants participated. Groups were made up of 30%–31% consumers, 30%–31% carers and 38%–40% community members in each round. Retention was high between Rounds 1 and 2 (87.5%); from Round 1 to Round 3 retention was 79.8%.

Group differences were noted with respect to age; carers were significantly older than community members ($p=.001$) and consumers ($p=.001$). Gender was evenly distributed across groups (see Table 2).

Most consumers reported a diagnosis of affective disorders (68.7%, $n=22$): Major Depressive Disorder, Bipolar Disorder and Schizoaffective Disorder. Carers were similarly more likely to care for those with affective disorders.

Carers reported caring mostly for their children (46.88%, $n=15$) or spouse (18.75%, $n=6$). They also reported caring for in-laws (9.4%, $n=3$), parents (6.25%, $n=2$) and other friends and relatives (18.75%, $n=6$).

Delphi results

The final outcome for each item is detailed in Table 3. Round-by-round details for each item are available upon request.

Round 1. Of the 147 items, 94 were endorsed in Round 1. A total of 15 received 100% endorsement and 54 were considered important contributors to social inclusion by $\geq 90\%$ participants in each group.

A total of 49 items were sent through to Round 2; 28 items for re-rating and 21 for re-rating following clarification of wording. Four items were not endorsed during Round 1 (2.7%), not fulfilling criteria for either endorsement or re-rating.

Round 2. A further 28 items were endorsed during Round 2. Seven items were considered by 100% of participants to play a likely role in a person’s ability to achieve social inclusion, 8 by $\geq 90\%$ in each group and another 13 by $\geq 80\%$ of participants in each group.

Only one item rated again after clarification of wording required re-rating in Round 3.

A total of 20 items were not endorsed as important contributors to social inclusion in Round 2 (40.8%). A greater number of items were not endorsed in this round due to the rules of Delphi methodology.

Round 3. The single item re-rated in Round 3 was not endorsed.

Table 2. Demographic characteristics of participants in Delphi study.

Variable	Consumers	Carers	Community	Test statistic	p-value
Total number of participants, % (n)					
Round 1 (Total n = 104)	30.8 (32)	30.8 (32)	38.5 (40)		
Round 2 (Total n = 91)	30.8 (28)	30.8 (28)	38.5 (35)	–	–
Round 3 (Total n = 83)	30.1 (25)	30.1 (25)	39.8 (33)		
Gender: % (n)	37.5% male (12); 62.5% female (20)	15.6% male (5); 84.4% female (27)	35.0% male (14); 65.0% female (26)	$\chi^2 = 4.50$	.106
Age, years: M (SD), Range	40.73 (11.60) (22–81)	53.66 (10.64) (33–79)	41.50 (14.52) (21–71)	F = 10.06	.001
Skewness (SE)	1.20 (.43)	.05 (.43)	.55 (.37)		
Kurtosis (SE)	3.90 (.83)	.16 (.85)	–1.01 (.73)		
Diagnosis (%) of consumers and those the carers care for					
Depression	10 (31.3)	5 (15.6)			
Bipolar disorder	7 (21.8)	7 (21.9)			
Schizoaffective disorder	5 (15.6)	3 (9.4)			
Schizophrenia	3 (9.4)	2 (6.3)			
Psychotic illness not otherwise specified	3 (9.4)	–			
First episode psychosis	–	1 (3.1)			
Personality disorder	–	1 (3.1)			
Anxiety disorder	–	1 (3.1)			
Autism spectrum disorder	–	2 (6.3)			
Dementia	–	2 (6.3)			
Anorexia nervosa	1 (3.1)	–			
Mental Illness due to Physical Conditions	–	3 (9.4)			
Unspecified	3 (9.4)	5 (15.6)	–	–	–

SD: standard deviation; SE: standard error.

Group differences. Significant between-group differences in the ratings of items were seen in six instances; five during Round 1 and one in Round 2 (see Table 4).

A smaller proportion of consumers endorsed the items ‘Working in a chosen area of employment’ and ‘Living in a household with others’. A greater proportion of carers endorsed the items ‘No secondary school qualification’ and ‘Earning an income’. Finally, a smaller proportion of community members endorsed the item ‘Living in a location other than where would choose’ and ‘Earning an income’.

Discussion

This research extends our work on social inclusion by furthering our understanding of key contributors to social inclusion beyond that of the work of academic and professionals. Findings from this novel and comprehensive study of consumers, carers and general community members’ perspectives of social inclusion are of significant clinical and research relevance.

Using a consensus technique, the core characteristics of social inclusion as identified by these three groups related to participation in social activities, social supports, housing and neighbourhoods, community involvement, employment and education, health and well-being, and service utilization.

There were some interesting findings – most items were either endorsed or not endorsed as important direct or indirect contributors to social inclusion by consumers, carers and community members alike. This indicated that people with a lived experience of mental illness (consumers and carers) and members of the general community share similar views regarding the importance of these contributors to social inclusion.

Items of particular interest were those who received 100% endorsement (seen in Table 3). These particular items highlight the importance of a solid support group, from which individuals can gain comfort and enjoyment, and the financial ability to participate in and celebrate activities and important life events. They also highlight the need to continue working towards reducing the stigma and discrimination experienced by people with mental health conditions (Hunting, Grace, & Hankivsky, 2015; Twardzicki, 2008) and to present opportunities wherever possible to encourage individuals who lack the motivation, or hope, to work towards improving their circumstances themselves.

Interestingly, disparity was seen between which contributors to social inclusion were considered important by professionals (as per Filia et al., 2018) and participants in the consensus study. A number of items endorsed by a very high proportion of the sample (>95% of each group) in the

Table 3. List of items included in Delphi study and final outcome for each.

Domain/item	Final result
Overall domains	
Taking part in social activities, having good social networks (friends and family)	Endorsed
Being employed or studying	Not endorsed
Living in stable, comfortable and affordable housing. Living in a safe neighbourhood	Endorsed
Having access to services such as shops, doctors, leisure facilities, transport and the Internet	Endorsed
Being in good health, with little impairment due to mental or physical health concerns	Not endorsed
Having an income, receiving enough money to afford life's basic necessities: gas, water, electricity, heating, clothes and phone	Endorsed
Living in circumstances where stigma or discrimination does not exist	Not endorsed
Having opportunities to take part in everyday life, that is, the normal social and cultural activities that are common to a person's community	Endorsed
Good individual circumstances such as motivation to improve own circumstances; having had a happy upbringing in a house free from poverty. Being surrounded by examples of good social norms	Not endorsed
Civic participation, taking part in activities that share your voice as part of a community. For example, voting, taking part in local community meetings, volunteering in local charities, events	Not endorsed
Leading a life free from illegal activity such as violence, drug use, theft or other crime	Not endorsed
Social resources	
Sharing everyday activities with others such as watching television together	Endorsed
Sharing meals with others	Endorsed
Talking to a family member or friend daily on the telephone	Endorsed
Running errands or doing chores with others	Not endorsed
Living in a household with others	Not endorsed
Having regular contact with neighbours and others in the community, for example, chatting with the person at the post office, bank, local shops or other community service	Endorsed
Providing advice or support to a family member or a friend	Endorsed
Having someone to chat to about your daily activities or daily events	Endorsed
Having a group of friends among whom you share experiences, thoughts and feelings	Endorsed
Having a best friend with whom you share your thoughts and feelings	Endorsed
Good friends who you see or speak to regularly and can count on in a crisis	Endorsed
Friends with whom you share common interests and values	Endorsed
Friends with whom you enjoy sharing time and look forward to seeing	Endorsed
Friends who would call on you to discuss their everyday experiences	Endorsed
Friends who would call on you in a crisis	Endorsed
Someone who would call you their best friend	Endorsed
Lack of self-confidence or self-esteem	Endorsed
Feeling unwelcome, like you do not belong	Endorsed
Not having participated in any social or community activities in the past 12 months	Endorsed
Feeling excluded or ostracized from activities because you have not taken part in them previously (e.g., when joining a new group or club)	Endorsed
Not having established social networks to draw upon for social participation (i.e. not having anyone to do social activities with)	Endorsed
Not enjoying social activities (for example, because of social anxiety, being shy, not finding anyone who shares common beliefs or interests)	Endorsed
Labour market and education	
Working full-time in paid employment	Not endorsed
Working part-time in paid employment	Endorsed
Doing voluntary work or work without pay	Endorsed
Being employed for 12 months or more	Not endorsed
Working in open employment (in mainstream employment alongside people with or without disabilities)	Endorsed
Being enrolled in education that will lead to a qualification	Endorsed
Working in a chosen area of employment (that is, being employed in a role that the employee is suitably qualified for and interested in)	Endorsed
Friendly working environment	Endorsed
Good working conditions (pay appropriate to the role, leave entitlements, free from bullying or harassment)	Endorsed

Table 3. (Continued)

Domain/item	Final result
Unemployment	Endorsed
Long-term unemployment	Endorsed
Irregular or under-employment (working less hours than would like to be)	Endorsed
Living in a jobless household (no adult member currently employed)	Endorsed
Being unable to get a job or keep one because of discrimination in the job market	Endorsed
Poor employment opportunities (for example, lack of availability and suitable roles)	Endorsed
Having a disability that is likely to impair ability to perform in occupational role or disrupt employment	Endorsed
Lacking skills or qualifications required for employment	Endorsed
No secondary school qualification	Endorsed
Did not complete primary school	Endorsed
No postsecondary qualifications	Not endorsed
Impairment or disability having caused disruption to educational achievement	Endorsed
Housing and neighbourhood	
Homelessness	Endorsed
Living in transitional housing or in hostels	Endorsed
Unstable or unsuitable accommodation	Endorsed
Living in accommodation lacking basic necessities (e.g. heating, ventilation, access to utilities and not well-maintained)	Endorsed
Living in a location other than where would choose	Endorsed
Living in a poor or disadvantaged neighbourhood	Endorsed
Experience of neighbourhood crime and/or violence	Endorsed
Confinement due to fear of crime or personal attack	Endorsed
Own home and paying off a mortgage	Endorsed
Own home outright	Endorsed
Living in private rental	Endorsed
Living in rent-free circumstances (e.g. with parents or other family members)	Endorsed
Living independently (not in supported accommodation)	Endorsed
Dependent on or living in public housing	Not endorsed
Cost of housing more than 25 of income	Endorsed
Living alone	Not endorsed
Health and well-being	
Being in poor health or having a disability (mental or physical)	Endorsed
Being unable to access services due to physical or mental health condition	Endorsed
Contact with psychiatric services	Not endorsed
Lengthy or repeated admissions to psychiatric services	Endorsed
Poor diet and lack of regular exercise	Endorsed
More focus on mental health to the detriment of physical health (perhaps inadvertently overlooking physical health concerns)	Endorsed
Not receiving regular check-ups for things such as dental care, skin checks or other preventive health measures	Endorsed
Economic	
Receiving a government pension	Endorsed
Earning an income	Not endorsed
Earning an income high enough to cover basic costs	Not endorsed
Able to raise money from family or friends in case of an emergency	Endorsed
Able to raise money from sources other than family or friends in case of an emergency	Endorsed
Managing money independently	Endorsed
Sharing expenses with others (rent, food and bills)	Not endorsed
Ability to live life as desired (for example being able to afford to choose the services would like to use, interests or hobbies to take part in, housing in location of choice)	Not endorsed
No income	Endorsed
Low-income earners	Endorsed
Financial strain due to low income	Endorsed

(Continued)

Table 3. (Continued)

Domain/item	Final result
Long-term poverty (having experienced financial hardship for longer than 5 years)	Endorsed
Poverty compared to others in community	Endorsed
Lack of savings for use in an emergency	Endorsed
Unable to keep up with paying the bills	Endorsed
Unable to afford insurance for house, contents and car	Endorsed
Unable to afford health insurance	Endorsed
Unable to afford a car	Endorsed
Having pawned belongings in the past 12 months to get by	Endorsed
Finding it difficult to provide for family (including children)	Endorsed
Unable to afford basic personal goods required for well-being (e.g. warm clothes, soap and toothpaste)	Not endorsed
Unable to afford basic household goods necessary for well-being (e.g. washing machine, fridge, microwave and bedding)	Not endorsed
Unable to afford health care (doctors' appointments, medications and specialists)	Endorsed
Unable to afford a variety of healthy food	Endorsed
Unable to attend important events such as weddings, funerals, birthday celebrations due to a lack of funds	Endorsed
Unable to participate in social activities with friends due to a lack of funds	Endorsed
Unable to take up a hobby or leisure activity of choice	Endorsed
No holiday in past 5 years	Endorsed
Service exclusion	
Access to the Internet	Not endorsed
Availability of transport (ownership of or access to a car and access to public transport)	Endorsed
Retail services and ease of access to retail services	Endorsed
Health services and ease of access to health services	Endorsed
Good community services such as local post office, banking and library	Endorsed
Good leisure facilities, including local hobby groups, classes, sporting clubs or other groups	Endorsed
Services that assist in meeting individuals' needs (e.g. community assistance programmes and support groups)	Endorsed
Stigma and discrimination	
Stigma or discrimination	Endorsed
Being bullied by others	Endorsed
Belonging to an ethnic minority group	Endorsed
Belonging to a sexual minority group (e.g., gay, lesbian, transsexual or transgender)	Endorsed
Having a disability, physical or mental	Endorsed
Coming from a non-English speaking background	Endorsed
Being an immigrant	Endorsed
Being an indigenous person	Endorsed
Belonging to a religious or other cultural group	Not endorsed
Belonging to a number of minority groups or having additional issues of discrimination (e.g. having a mental illness and belonging to an ethnic minority group)	Endorsed
Individual circumstances and negative life events	
A lack of desire or motivation to improve circumstances	Endorsed
A lack of time (due to other responsibilities) required to take part in activities to achieve good social inclusion	Endorsed
Self-exclusion due to a lack of interest in participating in such activities, fear or concerns about participating	Endorsed
A poor sense of belonging in general	Endorsed
Little understanding about social norms (perhaps from being surrounded by others who also do not understand or respect social norms)	Endorsed
Having to act as a carer for another person (therefore restricted opportunities)	Endorsed
Having experienced bad life events such as repeated rejections leading to a negative outlook on hope and expectations of life	Endorsed
Experiencing a number of negative circumstances for some time (e.g. a person with a disability, who has poor access to services and has been unemployed for a long time)	Endorsed

Table 3. (Continued)

Domain/item	Final result
Civic and community participation	
Voting in a local or federal election	Not endorsed
Attending council, community or local neighbourhood meetings	Endorsed
Taking part in a collective action designed to improve or protect the local social or physical environment	Endorsed
Belonging to a neighbourhood civic or community association	Endorsed
Belonging to a local services club or other local organization	Endorsed
Belonging to a local religious or cultural group	Endorsed
Talking to the local Member for Parliament	Not endorsed
Being a member of a political party	Not endorsed
Volunteering in a local charity	Endorsed
Assisting in the planning, organizing or running of a community event	Endorsed
Helping neighbours with odd jobs, lending tools or household items, looking after neighbours' pets or house while they are away	Endorsed
Dropping in to a neighbour's house or enquiring after them regularly	Endorsed
Illegal activity	
Have a history of violence	Endorsed
Have a criminal record	Endorsed
Be using illegal substances (drug use)	Endorsed
Being involved in the manufacturing or dealing of illegal substances	Endorsed

Table 4. Differences between groups in ratings of items in Delphi study.

Item Domain	Consumers %	Carers %	Community Members %	Chi square (χ^2) or FET statistic	Sig value ($p=$)
Working in a chosen area of employment <i>Labour Market and Education</i>	86.7 [†]	100.0	100.0	6.96*	.007
No secondary school qualification <i>Labour Market and Education</i>	80.0	100.0 [†]	84.6	7.77*	.015
Living in a location other than where would choose <i>Housing and Neighbourhood</i>	100.0	100.0	84.6 [†]	7.98	.004
Earning an income <i>Economic</i>	76.7	90.3 [†]	56.4 [†]	10.37	.006
Living in a household with others <i>Social Resources</i>	53.6 [†]	85.2	80.0	8.33	.016

FET: Fisher's Exact Probability Test.

*Fisher Exact Probability Test value.

[†]Cells with significant adjusted residuals ($z > 1.96$, $\alpha = .05$).

consensus study were only identified once or twice in 71 pieces of literature reviewed during the compilation of the list. These included items such as managing money independently, working in open employment, poverty compared to others in the community, a poor diet and lack of regular exercise, and a lack of time required to take part in activities to achieve good social inclusion.

Conversely, a number of items that appeared of significance in the literature failed to receive endorsement in the Delphi study. One example relates to civic participation, a theme seen repeatedly through the literature (Dorer, Harries, & Marston, 2009; Farrell & Bryant, 2009; Harrison

& Sellers, 2008; Lloyd et al., 2008; Nash, 2002; Schneider & Bramley, 2008; Webber & Huxley, 2004) and often relates back to ensuring that all people have a voice and are heard. Nash (2002) noted that voting may help people with mental illness feel less disenfranchised from many societal functions and may be one of the most fundamental aspects of societal inclusion. Participating in activities such as collective action processes, and involvement in local or national decision-making (presumably through voting) was cited in nearly 40% of the literature reviewed by Filia et al. (2018). However, when presented to participants in the Delphi study, neither item 'Civic participation, taking part

in activities that share your voice as part of a community' or 'Voting in a local or federal election' were endorsed. Nash (2002) did suggest that the paucity of literature regarding the right to vote for people with mental illness may be a consequence of its perceived lack of importance, which may also be evidenced here.

The item 'access to the Internet' similarly did not receive endorsement. This was despite the majority of participants completing the study online. The now almost ubiquitous nature of the Internet, with increased ease of access and decreased costs associated with accessing it, has perhaps contributed to its perceived value decreasing. Alternatively, there exists some reluctance to admit obtaining any social benefit from the Internet, with some stigma attached to reaching and identifying with others online without meeting offline. While there are demonstrated benefits of the Internet, enabling people to connect, find support and fill a need socially that may not be filled elsewhere (Brunette et al., 2017), these benefits were not recognized here.

Strengths, limitations and implications

There was some confusion with the wording of several questions in the Delphi questionnaire; however, this was resolved easily by clarifying and presenting the items again for rating in the next round. There were also some challenges during recruitment. Some consumer advocates expressed discontent at not being involved in the compilation of the initial list of items. This option had been explored initially but a stakeholder approach was identified as a more comprehensive technique, with the opinions of all involved parties sought to ensure richer information than that obtained from just one or two groups.

We had originally wanted to have professionals included in the Delphi study. For mostly pragmatic reasons, the opinions of professionals were obtained via their publications (Filia et al., 2018) and presented to participants here with the option for them to suggest any additional items or feedback. This list was intended to serve as a prompt to participants and to facilitate engagement in the survey. While feedback was given on existing items, no new items were suggested to be added to the list. This suggests that the list of items was appropriately comprehensive.

Discussions held with participants emphasized the importance of determining whether contributors were in fact considered important or relevant to people with a lived experience of mental illness. Frequent discontent was expressed during these discussions, regarding the construction of concepts and measures applied to people with mental illness by academics or professionals who may not have any lived experience of mental illness themselves. The obtainment of input from people with a lived experience of mental illness, both consumers and carers, was therefore considered a major strength of the study. This input, of experts in their own circumstances, provided a

different perspective regarding some of the key contributors to social inclusion.

Differences were observed between the importance placed on contributors to social inclusion by professionals and the opinions of participants here. This reinforces the need to understand and be constantly mindful of not only what is considered important and relevant from those with many years of observed, professional experience, but what is actually important and relevant to those who live everyday with, or alongside a person with, mental illness. The differences are not necessarily due to potentially uninformed, or ignorant academics, theorizing on what is important to social inclusion from a privileged position. The differences relate to the personal element, obtaining an awareness of how people with a lived experience really feel about contributors that might appear to be 'essential' to social inclusion, or be expected of individuals to participate in society. This understanding is essential, particularly in understanding how to progress in areas traditionally difficult to improve in people with such complex and inter-related sources of disadvantage.

In addition, identifying potential sources of motivation and change is essential in planning, delivery and implementation of services for people with mental health conditions. Clinical practices may be enhanced by using this knowledge to ensure that clinicians do not follow the same path for each individual. This increased understanding of what is important to each individual may vary from the values, roles and participation in certain activities commonly perceived as important in society. This may assist in engaging clients in more personally beneficial and important roles and activities. A broad understanding of what areas of social inclusion are affected is important, but more specifically identifying what areas individuals might require extra support in, or have the motivation or desire to improve, may greatly assist in making significant progress towards better mental health outcomes.

The information obtained in this study will also be of significant benefit to future research. One significant advancement is progress towards developing a measure of social inclusion. Despite the existence of several tools for measuring social inclusion for people with mental illness (Huxley et al., 2012; Lloyd et al., 2008; Marino-Francis & Worrall-Davies, 2010; Mezey et al., 2013; Secker, Hacking, Kent, Shenton, & Spandler, 2009; Stickley & Shaw, 2006), there remains a lack of measures that have a theoretical basis combined with the input of those with lived experience, and have also been psychometrically assessed. The findings of this study will be used in the development and assessment of such a measure, with the knowledge that the items and areas measured are of significance to social inclusion and relevance to those who the measure will be applied to. The benefit of such a measure will be seen not only with respect to enhancing the methodological rigour of studies but additionally will assist in the identification of which interventions are most

effective, and most cost-effective, and at what stage of illness intervention is most beneficial in terms of improving mental health outcomes. A measure such as this will also be of benefit in a clinical sense, assisting with the identification of which areas of social inclusion would benefit most by receiving some attention for each individual.

Conclusion

We have reinforced the importance of having a strong sense of connection with people and highlighted the significance of finding ways to share important life events together. The value of a stable place to live in was also noted, as was the ability to access support services, and of personal motivation and hope in improving circumstances. As commonly seen in mental health literature, the issue of stigma and discrimination was noted as a problem, a barrier to achieving good social inclusion.

Merging the expertise of those with professional experience working in the field of social inclusion, and those most affected by social exclusion – people with a lived experience of mental illness – was important. It gave us a well-rounded perspective on the important contributors to social inclusion for people affected by mental illness. This insight is essential in effectively determining how to best improve circumstances in individuals and how we can reduce social exclusion in such disadvantaged populations.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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APPENDIX 4

Developing and Testing the F-SIM, a measure of social inclusion for people with mental illness



Developing and testing the F-SIM, a measure of social inclusion for people with mental illness



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ABSTRACT

Social inclusion is an important contributor to good mental health and greater mental health outcomes for people with psychiatric disorders. A psychometrically-sound measure of social inclusion is required to facilitate progress in this area. The aim here was to report on preliminary findings from a novel, user-friendly measure of social inclusion that comprehensively assesses the construct. Preliminary testing of the Filia Social Inclusion Measure (F-SIM) was conducted with ninety participants (30 consumers; 30 family members/carers; 30 community members). Participants completed the self-report measure and a usability questionnaire. Preliminary findings demonstrated poorer social inclusion for people with mental illness compared to those without, with differences seen in each of five domains (housing and services, social functioning, occupational functioning, finances and health). Differences were also seen regarding family members or carers, with consistently poorer social inclusion than general community members observed. Participants reported the F-SIM as easy to use, and considered it to measure social inclusion well, indicating good face validity. The F-SIM demonstrates an ability to differentiate between groups. Implications for use and suggestions for future research are detailed. Following further psychometric assessment, the F-SIM will have wide applicability in clinical and research settings.

1. Introduction

People with severe mental illness are amongst the most vulnerable to social exclusion, commonly experiencing complex and inter-related forms of disadvantage (Social Exclusion Unit, 2004). The concept of *social inclusion* (existing on the other end of a fluid continuum from social exclusion) consists of a number of inter-connected factors including cohesive social networks, social and occupational participation (including education and training), housing, access to and utilisation of well-resourced services, community participation, good health and positive lifestyle factors (Filia et al., 2018).

Social exclusion can increase vulnerability to poor mental health outcomes, with a lack of supports, finances and other protective structures, such as good social capital, stable housing and steady employment. Conversely, social inclusion is beneficial and has protective elements, resulting in more positive mental health outcomes (Dunstan et al., 2017; Fenton et al., 2017; Saeri et al., 2018).

Social exclusion is also experienced by caregivers (Spoehr et al., 2007; Taket et al., 2009), with the burden of care placed on them

resulting in reduced opportunities for social and occupational participation, a loss of finances, negatively impacted housing situations and reduced emphasis on self-care and leisure activities. Differences in social inclusion between consumers, caregivers and members of the general community are assumed, however have not yet been examined.

Understanding of the positive impacts of social inclusion on mental health outcomes is increasing. This has led to a similar increase in efforts to reduce, or reduce the impact of, social exclusion including psychological therapies and psychosocial programs and interventions (Riva and Eck, 2016). Despite increasing understanding of the concept, valid and reliable measures of social inclusion are lacking (Coombs et al., 2013; Cordier et al., 2017; Huxley et al., 2012). This lack of measurement means that it is difficult to: (i) identify populations in need or at risk of social exclusion; (ii) determine targets for intervention; and (iii) measure intervention effectiveness and/or efficacy.

Central to the lack of appropriate measurement tools, has been the absence of a clear, specific and/or operationalised definition of social inclusion (Huxley et al., 2012; Morgan et al., 2007; Vinson, 2009). While other constructs commonly encountered in mental health

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research possess similar definitional fuzziness (e.g., functioning, quality of life, recovery, wellbeing), social inclusion is an emergent concept. Without clear delineation of what social inclusion is, it is difficult to ensure that any measure developed thus far is accurately evaluating this concept (Coombs et al., 2013). In addition, the relativity of social inclusion means that for each population, different elements of social inclusion are of greater importance or relevance, with varying needs and challenges experienced in particular for at-risk groups (Filia et al., 2019). Measures developed specifically for people with mental illness (being a group most vulnerable to social exclusion) are therefore important, particularly with nuances specific to each population potentially impacting psychometric evaluations.

Several measures for use with people with mental health conditions have been proposed (e.g., Dorer et al., 2009; Huxley et al., 2012; Lloyd et al., 2008; Marino-Francis and Worrall-Davies, 2010; Mezey et al., 2013; Secker et al., 2009; Stickley and Shaw, 2006). However, these measures require either re-development to address limitations that restrict their ability to be applied, for example they had been developed with too much specificity, to measure the impact of a particular intervention or service (Dorer et al., 2009; Marino-Francis and Worrall-Davies, 2010; Secker et al., 2009; Stickley and Shaw, 2006), or require further psychometric testing (Huxley et al., 2012; Lloyd et al., 2008; Mezey et al., 2013). Therefore, there is currently no psychometrically sound measure of social inclusion.

In addressing these limitations, our team adopted a systematic approach to developing a measure of social inclusion for use with people with lived experience of mental illness. We conducted a thematic analysis of carefully selected literature relating to social inclusion (academic, peer-reviewed and grey literature) and identified what professionals working to improve social inclusion consider key contributors (Filia et al., 2018). We then conducted a consensus study with consumers of mental health services, carers and general community members to understand, from a personal angle, the importance and relevance of key contributors of social inclusion (Filia et al., 2019). Based on these studies, we have developed a social inclusion measure, named the Filia Social Inclusion Measure (F-SIM). It has been designed for use with people with lived experience of mental illness. Here we provide a preliminary analysis of the measure's validity, with a focus on how items discriminate between people with and without lived experience of mental illness.

2. Methods

2.1. Participants

Participants were from three groups: (i) consumers of mental health services (past or present, 'Consumers'); (ii) people with a close family member with mental illness or carers of a person with mental illness (past or present, 'Family/Carer'); and (iii) and general community members (no diagnosis of severe mental illness, not acting or having acted as a carer, and not identifying as being affected in a day-to-day manner by the presence of mental illness within their family, 'Community'). *A priori* power calculations indicated that a sample size of 30 or more in each group was required to provide sufficient power ($1 - \beta = 0.80$) to reliably detect group differences between three groups with a large effect size and $\alpha = 0.05$ (Cohen, 1992).

Recruitment ran from April to July 2013. The majority of participants in the Consumer and Family Member/Carer groups had participated in an earlier, related study where recruitment had largely focused on inviting consumers and carers through their advocacy roles at mental health outpatient services and support services (Filia et al., 2019). Remaining participants were selected via the techniques outlined in Table 1. Group membership was self-selecting.

Table 1

Number of participants approached to take part in the study using each recruitment strategy.

Recruitment Strategy	Consumers	Carers	Community Members
Previous research participants	31	37	9
Advertisements	2	1	1
Emails and phone calls	4	5	20
Referrals from existing participants	5	6	7
Totals	42	49	37

2.2. Instruments

2.2.1. The Filia Social Inclusion Measure (F-SIM)

The F-SIM was developed based on the team's previous work (Filia et al., 2018, 2019). The aim here was to create a user-friendly questionnaire that comprehensively measured the construct.

The F-SIM was designed as a self-report questionnaire, with additional information/instructions to assist participants in completing the assessment. The F-SIM comprised 126 items, divided into 55 questions. The majority of items pertain to the past month, unless indicated otherwise. Most items were measured on a dichotomous scale with *Yes/No* responses, some were ordinal, e.g., *I don't have a group of friends to call on to do anything socially (Not at all/A little bit/Very much so)* and others nominal. (e.g., *Where do you currently receive an income from?*). A balance of items measuring social inclusion from an objective (e.g., *How much net income do you receive each week?*) and subjective perspective were included (*Do you receive enough income to cover your basic everyday costs?*). Items merged logically into five domains: Housing, Neighbourhood and Services; Relationships, Activities and Setbacks; Employment and Education; Finances; and Health and Wellbeing. Age, gender and diagnosis (for the Consumer and Family/Carer groups) were also obtained.

2.2.2. The F-SIM Experience

The F-SIM Experience is a usability questionnaire developed to examine the utility, face validity and acceptability of the F-SIM. It comprises five questions reflecting participants' experiences of completing the questionnaire, including time taken to complete the F-SIM, perceptions of utility and face validity, and barriers impeding completion. Items were again measured using mixed-measurement, with ordinal (*Yes/No/Maybe a little*), dichotomous (*Yes/No*), and nominal data collected. Prompts were provided to determine which aspects of completing the questionnaire were considered difficult, and a free text response allowed for additional information.

2.3. Procedure

Ethics approval was granted by the Melbourne Health Human Research and Ethics Committee (HREC 2010.105). Participants were contacted via email, phone or mail, with a verbal and/or written description of the study. Most participants completed the questionnaire online using *surveymonkey.com*. One person requested a hard copy via mail. All participants were informed that consent was implied by completing the questionnaire; information regarding study information, privacy and confidentiality was provided. Measures were completed only once.

2.4. Data analysis

Data screening was conducted, and normality assessed for each continuous variable on the F-SIM, looking at skewness and kurtosis of distributions. As per Tabachnik and Fidell (2012), where the ratios of skewness and kurtosis to their respective standard errors were greater than 3, further investigations were conducted to determine where discrepancies lay. Transformations were applied where appropriate, but as

analyses did not yield different results, findings pertaining to untransformed variables are presented here.

The focus of the inferential analyses was on determining differences between the three groups: Consumers, Family/Carers, and Community. Descriptive statistics were used to summarise age, gender and diagnosis (for the Consumer and Family/Carer groups). Chi-square tests (χ^2) for independence and one-way analysis of variance (ANOVA) models were used to determine whether the three groups were matched with respect to gender and age, and to determine differences between groups regarding their responses on the F-SIM and F-SIM Experience. Where the assumption of variance was violated, the Brown-Forsythe test statistic was reported. In a number of cases groups were collapsed to increase cell size (>5 cases in greater than 20% of cells) to enable chi-square comparison tests to be performed. This was only done where the outcome was unaffected by collapsing groups.

Following the identification of statistically significant differences between the three groups, post-hoc comparisons were made within each domain using the Tukey HSD test for parametric variables. Column proportions were compared using Bonferroni adjusted p-values, where chi-square analyses indicated significant differences.

All statistical analyses were conducted using IBM® SPSS® Version 25.0.

3. Results

3.1. Participants

The final sample comprised ninety participants, with thirty participants in each group. Group demographic characteristics are outlined in Table 2, including test-statistics.

Overall, 71.1% of participants were female ($n = 64$) and 28.9% male ($n = 26$); there were no significant groups differences in terms of gender. Participants ranged in age from 24–81 years ($M = 40.76$ years, $SD = 12.15$). Differences in age were seen between groups, $F(2, 87) = 4.07$, $p = .020$: with post-hoc tests indicating that the differences were between the FMC group ($M = 45.27$ years, $SD = 14.64$) and the Community group ($M = 36.63$ years, $SD = 10.14$), $p = .015$. The mean age of participants in the Consumer groups was 40.37 ($SD = 9.87$).

Those in the Consumer and FMC groups most commonly experienced affective disorders such as depression, comorbid depression and anxiety, bipolar disorder and schizoaffective disorder.

Participants from the FMC group were most likely to be caring for a parent with mental illness (40.0%, $n = 12$). 30% of participants from this group reported multiple family members (up to five immediate family members) with mental illness ($n = 9$).

Table 2
Demographic characteristics of participants in each of the three groups.

Variable	Consumer	Family Member or Carers	General Community	Test statistic	p-value
Gender: Female% (n)	73.3 (22)	80.0 (24)	60.0 (18)	$\chi^2 (2, N = 90) = 3.03$ $F(2,87) = 4.07$	.220 .020
Age, years: M (SD)	40.37 (9.87)	45.27 (14.64)	36.63 (10.14)		
Range	(25–60)	(26–81)	(24–65)		
Diagnosis% (n) of consumers and those the carers care for					
Depression	16.67 (5)	16.67 (5)			
Depression & anxiety	13.33 (4)	13.33 (4)			
Bipolar affective disorder	16.67 (5)	16.67 (5)			
Schizoaffective disorder	10.00 (3)	3.33 (1)			
Schizophrenia	10.00 (3)	26.67 (8)			
Psychotic illness	10.00 (3)	–			
Borderline personality disorder	13.33 (4)	3.33 (1)			
Generalised anxiety disorder	3.33 (1)	–			
Autism spectrum disorder	–	10.00 (3)			
- & Depression	–	3.33 (1)			
Dementia	–	3.33 (1)			
Depression & eating disorder	3.33 (1)	–			
Depression, anxiety & PTSD	3.33 (1)	–			
Mental illness due to physical conditions	–	3.33 (1)	–	–	–

3.2. The F-SIM

Table 3 provides details regarding differences on individual items within the five domains of F-SIM, including group results, appropriate test-statistic for each item and significance values.

3.2.1. Housing, neighbourhood and services

There were significant differences ($p \leq .01$) between the three groups with respect to who they lived with, the amount per week spent on accommodation (rent or mortgage), whether they would prefer to be living in another location/area, having experienced neighborhood crime or violence and, using the internet for social interactions. Differences were also seen between groups regarding weekly contact with neighbours ($p = .035$).

Post-hoc comparisons indicated that Consumers were significantly more likely than the Community group to report: living alone, in a location other than where they would prefer, experiencing neighbourhood crime or violence, and using the internet to fill a social need not met elsewhere. With respect to housing costs, Consumers reported significantly lower costs than the Community group ($p = .004$). Members of the Community group reported significantly more weekly contact with their neighbours than those in the Family/Carer group ($p < .05$).

3.2.2. Relationships, activities and setbacks

Differences were observed between groups regarding the experience of setbacks or limitations that interfered in participants' ability to take part in social activities. Differences were seen with respect to: poor self-confidence or self-esteem, feeling unwelcome or like they don't belong, feeling excluded or not part of the group when taking part in new activities or joining new groups, and not knowing what to do to improve their circumstances ($p \leq .01$). Post-hoc comparisons indicated that these differences were all seen between the Consumer and Community groups ($p < .05$) with Consumers reporting more setbacks or limitations than Community members in all instances.

Groups also differed in how often participants spoke to a family member or friend on the phone $\chi^2(4, N = 90) = 10.02$, $p = .040$, but post-hoc comparisons failed to indicate where differences between groups lay.

3.2.3. Employment and education

A large proportion of the sample overall had been employed or enrolled in formal education over the past 12 months (92.2%, $n = 83$). A number of participants reported experiencing some limitations to employment with differences between groups ($p < .01$) noted

Table 3
Differences between groups on the items of the F-SIM.

Section & Question	Consumer	Family Member or Carers	General Community	Test statistic	df	p-value
Housing, Neighbourhood & Services						
Who do you currently live with? (n = 90)	33.3 (10)	10.0 (3)	6.7 (2)	$\chi^2 = 9.12$	2	.010
-Living Alone: % (n)						
How much per week do you personally spend on your rent or mortgage? (n = 87)	197.25 (192.48)	309.33 (289.56)	431.90 (300.00)	$F = 5.61$	2	.005
-M (SD)	(0–800)	(0–1000)	(0–1100)			
-Range						
Would you prefer to be living in a different area or location? (n = 90)	40.0 (12)	13.3 (4)	3.3 (1)	$\chi^2 = 14.07$	2	.001
-Yes: % (n)						
Have you experienced neighbourhood crime and/or violence whilst you've been living in the area? (n = 90)	53.3 (16)	33.3 (10)	16.7 (5)	$\chi^2 = 8.96$	2	.011
-Yes: % (n)						
In the past 12 months I have: Dropped in to a neighbour's house or stopped and chatted to them at least weekly (n = 90)	46.7 (14)	30.0 (9)	63.3 (19)	$\chi^2 = 6.70$	2	.035
-Yes: % (n)						
Does the internet fill a need for you socially that you aren't getting elsewhere? (n = 90)	60.0 (18)	33.3 (10)	23.3 (7)	$\chi^2 = 9.07$	2	.011
-Yes: % (n)						
Relationships, Activities & Setbacks						
How often do you: Talk to a family member or friend on the telephone (n = 90)						
- At least daily: % (n)	50.0 (15)	23.3 (7)	30.0 (9)	$\chi^2 = 10.02$	4	.040
- At least once or twice a week: % (n)	26.7 (8)	40.0 (12)	56.7 (17)			
- Monthly or less: % (n)	23.3 (7)	36.7 (11)	13.3 (4)			
I don't have very good self-confidence or self-esteem (n = 90)	53.3 (16)	26.7 (8)	13.3 (4)	$\chi^2 = 11.61$	2	.003
-Yes: % (n)						
I often feel unwelcome, like I don't belong (n = 90)	53.3 (16)	23.3 (7)	6.7 (2)	$\chi^2 = 16.72$	2	<.001
-Yes: % (n)						
I feel excluded or not part of the group when taking part in new activities or joining new groups (n = 90)	46.7 (14)	33.3 (10)	10.0 (3)	$\chi^2 = 9.84$	2	.007
-Yes: % (n)						
Relationships, Activities & Setbacks						
I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things (n = 90)	76.7 (23)	46.7 (14)	43.3 (13)	$\chi^2 = 8.19$	2	.017
- Yes: % (n)						
I don't know what I need to do to improve my circumstances (n = 90)	43.3 (13)	26.7 (8)	6.7 (2)	$\chi^2 = 10.63$	2	.005
- Yes: % (n)						
Employment & Education						
Poor employment opportunities (n = 90)	56.7 (17)	33.3 (10)	23.3 (7)	$\chi^2 = 7.47$	2	.024
- Yes: % (n)						
Having an illness that is likely to impair your ability to either perform your occupational role or disrupt employment (n = 90)	62.1 (18)	13.3 (4)	3.3 (1)	$\chi^2 = 30.24$	2	<.001
- Yes: % (n)						
Having an illness that has previously impaired your ability to obtain skills or qualifications necessary for employment (n = 90)	50.0 (15)	3.3 (1)	3.3 (1)	$\chi^2 = 28.43$	2	<.001
- Yes: % (n)						
Not having skills or qualifications that are required for employment (n = 90)	33.3 (10)	13.3 (4)	3.3 (1)	$\chi^2 = 10.08$	4	.006
- Yes: % (n)						
Finances						
How much nett income do you receive each week, prior to any deductions? (n = 79)	606.43 (364.44)	940.84 (472.95)	1160.96 (665.91)	$F = 7.96$	2	.001
- M (SD)	(0–1625)	(0–2000)	(0–3200)			
- Range						
Do you receive enough income to cover your basic everyday costs (n = 90)	60.0 (18)	10.0 (3)	96.7 (29)	$\chi^2 = 15.66$	2	<.001
- Yes: % (n)						
Is your income is so low that you suffer from financial strain (n = 90)	46.7 (14)	10.0 (3)	0.0 (0)	$\chi^2 = 23.64$	2	<.001
- Yes: % (n)						
Do you feel that you earn considerably less or suffer more financial strain than others in your community (n = 89)	40.0 (12)	10.3 (3)	3.3 (1)	$\chi^2 = 15.38$	2	<.001
- Yes: % (n)						
Have you experienced long-term poverty (n = 90)	40.0 (12)	6.7 (2)	6.7 (2)	$\chi^2 = 15.20$	2	<.001
- Yes: % (n)						
Have you experienced financial hardship for longer than 5 years (n = 90)	36.7 (11)	16.7 (5)	10.0 (3)	$\chi^2 = 6.94$	2	.031
- Yes: % (n)						

(continued on next page)

Table 3 (continued)

Section & Question	Consumer	Family Member or Carers	General Community	Test statistic	df	p-value
<i>Considering the income that you receive, have you experienced the following financial hardships over the past 12 months?</i>						
Unable to keep up with paying the bills (n = 89) - Yes: % (n)	36.7 (11)	16.7 (5)	3.4 (1)	$\chi^2 = 10.70$	2	.005
Unable to afford healthcare (n = 90) - Yes: % (n)	36.7 (11)	13.3 (4)	3.3 (1)	$\chi^2 = 12.01$	2	.002
Unable to afford a variety of healthy food (n = 90) - Yes: % (n)	26.7 (8)	3.3 (1)	0.0 (0)	$\chi^2 = 14.07$	2	.001
Unable to attend important events such as weddings, funerals, birthday celebrations due to a lack of funds (n = 90) - Yes: % (n)	30.0 (9)	10.0 (3)	6.7 (2)	$\chi^2 = 7.27$	2	.026
Unable to take up a hobby or leisure activity of choice (n = 90) - Yes: % (n)	43.3 (13)	20.0 (6)	16.7 (5)	$\chi^2 = 6.48$	2	.039
No holiday in past 5 years (n = 90) - Yes: % (n)	36.7 (11)	10.0 (3)	3.3 (1)	$\chi^2 = 13.44$	2	.001
Lack of savings for use in an emergency (n = 90) - Yes: % (n)	53.3 (16)	30.0 (9)	23.3 (7)	$\chi^2 = 6.50$	2	.039
Health & Wellbeing						
<i>Do you have any ongoing physical ailments that prevent you from:</i>						
Achieving all you would like in your life? - Yes: % (n)	40.0 (12)	33.3 (10)	6.7 (2)	$\chi^2 = 9.55$	2	.008
<i>Do you feel that your emotional health interferes in your ability to</i>						
Achieve all you would like in your life? (n = 90) - Yes: % (n)	63.3 (19)	33.3 (10)	6.7 (2)	$\chi^2 = 21.36$	2	<.001
Access services that would help to improve your life or circumstances? (eg. health services, public transport, internet) (n = 90) - Yes: % (n)	26.7 (8)	10.0 (3)	0.0 (0)	$\chi^2 = 10.15$	2	.006

regarding: having an illness likely to impair or disrupt their occupational functioning, having an illness that previously impaired their ability to obtain qualifications necessary for employment, and not having the skills or qualifications required for employment. Differences were also seen regarding the experience of poor employment opportunities ($p = .024$).

Post-hoc comparisons indicated that Consumers noted significantly more limitations to their employment than Community members ($p < .05$) as a result of poor employment opportunities, and not having the skills or qualifications required for employment. Consumers noted in greater proportions than both Family/Carer and Community members that their employment opportunities were limited by: having an illness likely to impair or disrupt their occupational functioning, and having an illness that previously impaired their ability to obtain qualifications necessary for employment (both significant at $p < .05$).

3.2.4. Finances

Groups differed with respect to the amount of net income received weekly $F(2, N = 79) = 7.96, p = .001$. Consumers received significantly less than those in the Family/Carer ($p = .048$) and Community groups ($p = .001$).

Group differences were also seen regarding participants' current financial situation ($p = .001$): receiving less income than required to cover basic everyday costs, an income so low that they suffer financial strain, earning considerably less income or suffering more financial strain than others in their community, experiencing long-term poverty and at $p = .031$, experiencing financial hardship for longer than 5 years. More differences were seen regarding financial hardships over the past 12 months including (at $p < .01$) being unable to: keep up with paying the bills, afford healthcare, afford a variety of healthy food, take a holiday over the past 5 years; and at $p < .05$; attend important events such as weddings, funerals and birthday celebrations, take up a hobby or leisure activity of choice, and contribute to any savings for use in an emergency.

Post-hoc comparisons consistently indicated poorer results for Consumers. Consumers reported significantly greater financial stress than Family/Carer and Community members on the following items (at

$p < .05$): receiving an income so low that they suffer financial strain, earning considerably less income or suffering more financial strain than others in their community, experiencing long-term poverty; and an inability to afford a variety of healthy food, attend important events such as weddings, funerals and birthday celebrations and take a holiday in the past 5 years due to financial restrictions. Post-hoc comparisons also revealed that Consumers differed from Community members regarding the experience of financial hardship for longer than 5 years, and the inability to keep up with paying bills, and afford healthcare.

Post-hoc comparisons were not able to differentiate between groups (due to Bonferroni corrections) regarding the items: receiving less income than required to cover basic everyday costs, unable to take up a hobby or leisure activity, or contribute to any savings for use in an emergency.

3.2.5. Health and wellbeing

In the domain of Health and Wellbeing, group differences ($p < .01$) were observed regarding: having ongoing physical ailments that prevent you from achieving all you would like in life, emotional health interfering in the ability to achieve all you would like in life, and emotional health interfering in the ability to access services that would help to improve life or circumstances.

More Consumers and Family/Carer members than Community members reported feeling prevented from achieving all they would like in their lives due to ongoing physical ailments and their emotional health (both significant at $p < .05$). Consumers also differed significantly from Community members regarding their emotional health and ability to access services to assist in improving their lives or circumstances ($p < .05$).

Of the 41 participants who reported receiving a diagnosis of mental illness, over half (51.2%, $n = 21$) had previously been admitted to a mental health facility (Range = 1–50 admissions, $M = 7.90$, $SD = 13.04$). The 21 participants reported lengthy admissions, with the average admission lasting for days for only 19.1%, weeks for 42.9% and months for 38.1% of participants.

3.3. The F-SIM Experience

Participants reported the F-SIM as taking an average of 15.85 min to complete ($SD = 6.40$). Most didn't think it took too long to complete (84.4%, $n = 76$); only 12.2% ($n = 11$) indicated that it may have taken a little too long to complete.

56.7% ($n = 51$) of the sample reportedly considered the F-SIM to measure social inclusion *very well* and 41.1% ($n = 37$) *somewhat well*. One person thought it did not measure it very well; another noted it did not seem to be measuring social inclusion at all.

A large majority of participants didn't find the questionnaire difficult to complete (92.2%, $n = 83$). Of the seven participants that did find it difficult to complete, six were Consumers and one from the Family/Carer group. Reasons for finding it difficult included: wording of items, including the use of double negatives in some situations; switching from positive to negative scoring; questions that were too personal, specific or intrusive; and situations where there was not an answer true for the person's situation.

4. Discussion

This measure of social inclusion was developed for use with people with lived experience of mental illness. Successful pilot testing of the measure was completed, and analyses conducted, to assess usability and preliminary psychometric properties. Clear differences between groups were observed. As the scale has yet to undergo complete psychometric assessment, we present these findings tentatively. We have outlined where findings are in line with previous research, but place a greater emphasis on the ability to demonstrate group differences using the scale, rather than making independent inferences from the data.

4.1. Findings from the F-SIM

Group differences were observed across the five domains of the F-SIM. Differences were consistent, with Consumers faring significantly worse in most cases than the Community group. This is not an unexpected finding; people with mental illness commonly experience significant levels of marginalisation and disadvantage (Stewart et al., 2010).

Group differences were also observed regarding the Family/Carer group. This group was consistently seen falling somewhere between the Consumer and Community groups, with findings demonstrating poorer social inclusion than the Community members. The burden of caring for a person with mental illness has itself been noted as a potential contributor to social exclusion (Dorling and Rees, 2003; Merton and Bateman, 2007; Psychiatric Disability Services of Victoria (VICSERV), 2008; Social Inclusion Division, 2009; Spoehr et al., 2007; Taket et al., 2009). It may be concluded that the burden and impact of caring for, or simply of having a close family member with mental illness, was evident in the findings.

Consumers' living circumstances differed to those in the Community group. About a third of Consumers lived alone and paid less for accommodation, which could indicate the standard of accommodation they live in. They were also more likely to be living in a location other than their preference, and over half of Consumers had experienced neighbourhood crime compared to only 16.7% of Community. This is in line with previous research highlighting an increased vulnerability to victimisation of people with mental illness (Fitzgerald et al., 2005; Morgan et al., 2011).

Where setbacks, limitations or circumstances of stigma and discrimination were outlined, Consumers were more likely to encounter them as compared to Community members. Family/Carer members did not differ significantly from either group, indicating that they were not immune from the experience of setbacks or discrimination - an important reminder to consider as a potential contributor to caregiver social isolation.

While it appears in this sample that Consumers were likely to have encountered greater difficulties in achieving social inclusion due to negative experiences, Consumers reported in more instances than the Community group that the internet filled a social need for them, not met elsewhere. In an increasingly digital age, this mode of interaction was at least seen here as providing social connectedness for those with difficulties in other areas.

Higher than expected numbers of participants, particularly in the Consumer group, were currently employed, as rates of unemployment in populations of serious mental illness reported at or above 85% (Evans and Repper, 2000; Shepherd and Parsonage, 2011). However, this may have been influenced by recruitment bias. Many participants in the Consumer group had participated in previous research where they were specifically recruited in their role as paid consumer advocates. Participants in the Consumer group did report more difficulties with employment though than both Community and Family/Carer members, noting factors related to their illness as limiting them.

Financially, Consumers reported considerably less income on average and noted greater financial strain than the other groups. Consumers not only reported difficulties in keeping up with bills and covering everyday costs but also difficulties with covering the costs associated with taking part in social activities, preventing them from taking part at all in certain situations.

These findings highlight the disadvantages and difficult circumstances people with mental illness too commonly experience. Despite the negative nature of findings, it is reassuring that the F-SIM easily demonstrated significant and expected group differences.

4.2. The F-SIM Experience

The F-SIM appeared to have good acceptability and face validity, based on the F-SIM Experience findings. Participants largely did not consider the measure to take too long to complete, and did not find it terribly difficult to complete. Some difficulties were encountered with item wording. The entire measure has now been reviewed prior to the next stage of its development. Revisions have been made to the wording of items, to increase readability, make responses more intuitive and ensure that it is clear that participants can choose a not applicable option where appropriate. Good face validity was demonstrated, with most participants noting that they thought it was measuring social inclusion.

4.3. Strengths and limitations

As noted, a potential limitation includes the possibility that findings were influenced by sampling techniques, with a large proportion of consumers employed (predominantly in consumer advocacy roles). Outcomes likely affected include employment, finances, and the subsequent impact on housing and opportunities for social interactions. However, differences were still seen between groups with respect to these outcomes.

Strengths of the measure highlighted throughout this research include its versatility and the considerable input provided by consumers and caregivers during development.

The versatility of administration of the F-SIM is a significant strength, in particular the option for it to be completed as a self-report measure online. This is not only cost-effective, it also allows for greater dispersion, larger sample sizes and greater participant convenience. Individuals who may face obstacles to participation such as distance or geographical isolation, a lack of transport, restrictions on their time, or mental health issues that may limit their ability to attend a different setting or welcome an unfamiliar person into their homes have a greater opportunity to participate. This is particularly relevant with respect to social inclusion, allowing for the collection of information from people at greatest risk of social exclusion. As noted by Dorer et al. (2009), collecting information directly from the individual is a much more

socially inclusive and valid method than relying upon interviewer judgement or information sourced from caregivers or source notes.

The most significant strength of the measure however is the considerable input of people with lived experience of mental illness in the development of items, and in initial testing. A large emphasis was placed on obtaining the opinions of people from the population for whom the scale is intended. Also considered an essential element was receiving additional feedback from participants at each step of development. It is expected that the positive responses seen on the F-SIM Experience were a result of this input.

4.4. Implications and future directions

Following a complete psychometric evaluation, there will be many benefits to having a standardised, reliable and valid measure of social inclusion such as the F-SIM. The F-SIM will enable the collection of sound, empirical data, including normative data, data on at-risk and patient groups, and effectiveness data from trials of interventions. Practical implications include those relevant for both clinical and academic settings.

Implications from this study include obtaining the understanding that the measure as it exists currently is able to differentiate between groups, and is acceptable and user-friendly for participants. Feedback from participants allowing for revision of the measure prior to the next stage of its development will assist in improving it.

There are some logical next steps in the F-SIM's development, including shortening and psychometrically evaluating the shortened version. Despite participants reporting the F-SIM as not being terribly burdensome to complete, measures are rarely completed in isolation and not as part of a greater assessment package. It is also important that only the most relevant items are included in the final F-SIM. Once the underlying structure of the measure has been identified, and redundant items removed, the shortened measure will be psychometrically assessed collecting data from participants with and without a mental illness, across a range of ages, to allow for comparisons between groups.

Some progress is being made with respect to this. We have commenced a larger study of the F-SIM, and have reported on some preliminary findings (Gardner et al., 2019). The underlying structure of the measure has been observed in a group of young people without lived experience of mental illness, with dimensions related to interpersonal connection and community integration processes identified (Gardner et al., 2019) and will be confirmed in a larger sample, with data collection underway. (populations include similarly aged young people with non-psychotic illness, older people aged 25+ with severe mental illness and older, similarly aged people from the general community).

4.5. Conclusions

Social inclusion is a concept that shows great promise in assisting people with mental illness to improve their circumstances and reduce the impact of illness on their lives. To facilitate progress, it is essential that a psychometrically sound measure of social inclusion is available for use. As noted by Coombs et al. (2013) "Social inclusion is too important not to measure properly" (p. 918).

Findings presented here indicate that the F-SIM is a measure of social inclusion that is easy to complete, well-accepted by the population for which it is intended and appears to have good face validity. Findings also demonstrate the ability to differentiate between groups expected to differ with respect to social inclusion. It is anticipated that future development and testing of the measure will further demonstrate sound psychometric properties. Findings also reinforced the viewpoint that people with mental illness are likely to fare worse than their counterparts in aspects related to good social inclusion.

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Declaration of interest

None.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.psychres.2019.06.038.

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APPENDIX 5

Scree plot Identifying Three Dimensions of the F-SIM in a sample of Young Adults aged 18 to 25 with Serious Mental Illness

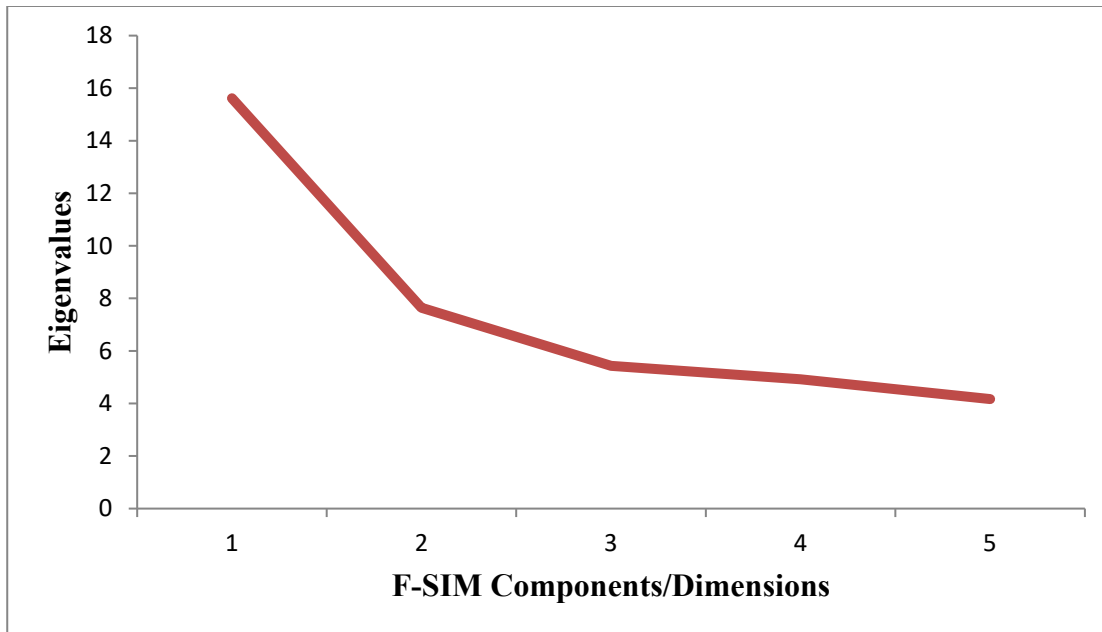


Figure 3. Scree plot of five components/dimensions of the Filia Social Inclusion Measure (F-SIM) among young adults aged 18–25 years with serious mental illness on the x-axis, and the corresponding eigenvalue for each component/dimension on the y-axis