



OPTIMISING SUPPORT FOR PEOPLE WITH PSYCHOSOCIAL DISABILITIES PARTICIPATING IN THE NDIS

Literature Review

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1 Context

1.1 Background to the Current Project

This literature review forms part of the evidence base to a ‘provider driven’ project to optimise the supports to people with a psychosocial disability within the NDIS. A primary aim of the project is to advocate for alternative funding and support models predicated on an investment driven approach that identifies gains over a lifetime. This alternative approach is intended to result in improved outcomes for participants compared to those currently being achieved in existing psychosocial support programs and in the trial NDIS sites.

1.1.1 Project Purpose

To prepare an alternative set of policy and procedural reference points for the NDIS, which better reflect the needs of those with a psychosocial disability.

1.1.2 Project Output

An optimal list of psychosocial support services for people with a psychosocial disability, aggregated into ‘packages’.

1.2 Introduction

Since the commencement of the rollout of the NDIS, there has been evidence of low levels of participation among people with mental health and psychosocial disability. The NDIS Independent Advisory Council (IAC) reports that data from the trial sites indicates ineligibility rates from access requests from people with primary mental illness that are significantly higher than other disability types with 1 out of 4 applications being determined as ineligible compared to 1 out of 9 for applicants across the rest of the Scheme.

The number of participants with disabilities related to mental illness in the Scheme to date is lower than projected by the Productivity Commission, with NDIA data indicating a 6.4% overall participation rate. This is less than half that originally forecast by the Productivity Commission in 2011.

The low levels of engagement have been attributed to a number of factors including that the current policy parameters do not adequately provide for the support needs of people with psychosocial disability. Current support packages are designed to meet a broad set out outcomes, for any type of disability.

Many sector advocates, consumers and service providers are concerned that the profiles, prognoses and support needs for people with psychosocial disability are not optimal for supporting individuals to attain improved recovery-oriented outcomes and functioning.

1.3 Overview

1.3.1 Policy Context

As the NDIS is in its early implementation phase, there is much work going on to ensure a responsive Scheme is developing through continual monitoring of impact and outcomes. Several recent and concurrent activities provide relevant context to this current task including:

- Psychosocial Supports Design Project
- The Productivity Commission Inquiry into NDIS Costs
- The Joint Standing Committee on the NDIS: Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition
- The McKinsey Independent Pricing Review of the NDIA
- The Psychosocial Pathways Project

1.3.2 NDIS Evaluation

In February 2018 an evaluation of the NDIS was released. The main objective of the evaluation was to assess the impacts of the NDIS trial and to examine high-level processes, focusing on elements of the NDIS, which contributed to or impeded the intended positive outcomes. The evaluation report focusses on 10 main themes arising from key evaluation questions, with the most relevant including:

- Supply and demand of support services
- The disability sector and its workforce
- Choice and control (including self-management)
- Reasonable and necessary supports
- Wellbeing
- Participation (social, economic and educational) and aspirations (goals)
- Fairness, equity and access
- Mainstream interface

Whilst the overall picture of the NDIS trial rollout is one of increased supports and improved outcomes, for people with mental health and psychosocial disability, the following notable findings were identified¹:

- Both the qualitative and quantitative data indicate that people with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants.
- In particular carers of people with a mental/psychosocial disability reported lower than average satisfaction with their choice and control. Furthermore, around a quarter of families and carers reported that their choice and control had declined with longer time in the NDIS.
- People with an intellectual or mental/psychosocial disability were least satisfied that their supports were reasonable and necessary.

- Participants with mental/psychosocial disability, those living in rural areas, or with unmet demand for supports have poorer average levels of wellbeing. Furthermore, carers of participants with mental/psychosocial disability had lower levels of wellbeing than those caring for people with other types of disability. Anxiety about the long-term sustainability of the NDIS and the administrative burden associated with NDIS processes were found to have a negative impact on carer wellbeing.
- In terms of the experience of transition to the NDIS, people with psychosocial disability were identified to be particularly struggling with the complexity of NDIS processes and documentation.
- The qualitative evidence indicated that people with psychosocial disability were experiencing poorer outcomes under the NDIS and were receiving a lower level of services than previously. This was in part attributed to individuals being unable to effectively advocate for services on their own behalf and/or those people who struggled to manage the new and sometimes complex NDIS processes.
- A lack of NDIS funding for supports such as respite, support coordination, positive behaviour support, employment skills, and psychosocial support for families was reported.
- Exercising choice was also constrained for those living in non-metropolitan locations with fewer service providers.
- Wellbeing measures (psychological, personal and social connection) were well below that recorded for other disability groups on all three measures.
- Lower levels of social connection were reported on all measures.
- Concerns were raised about the difficulties individuals had in participating socially, and developing friendships. Some participants observed that whilst they may have been able to engage more in social activities, these were often with people with similar types of issues rather than in more “mainstream” activities or in the general community.

2 Access to Support

The matter of optimising support options under the NDIS for people with psychosocial disability has been the subject of much discussion. Maximising the opportunities that the NDIS represents means ensuring that the system is designed to provide optimal psychosocial disability support for individuals with severe mental illness.

For people experiencing psychosocial disability due to their mental illness, this means providing support that enables them to be able to effectively manage the impacts of mental illness and participate meaningfully in everyday life.

2.1 NDIS Support Categories

The NDIS is designed to be flexible and to meet each participant's individual needs. Given the often episodic of mental illness, the NDIS 'participant plans' intend to account for these changes by providing a flexible budget to enable incremental supports as necessary. Goal setting and support planning is determined between the participant and the support provider with access to services being considered in conjunction of available informal support (family and friends) and existing mainstream service systems.

The NDIS Outcomes Framework has been developed to measure goal attainment for participants and overall performance of the Scheme. There are 8 Outcome Domains to guide individual goal determination and assist planners to explore where support currently exists and where further supports may be required:

1. Daily Living
2. Home
3. Health and Well-being
4. Lifelong Learning
5. Work
6. Social and Community Participation
7. Relationships
8. Choice and Control

The 2017 NDIS Price Guide provides an overview of how NDIS price controls work for determining services and supports for participants, with an intent that the supports will map to achieving the outcomes identified in the outcomes framework. Participant budgets are broken into three overarching support purpose categories, with 15 different sub-categories of support:

1. **Core Support:** enables a participant to complete activities of daily living. Participant budgets are flexible across the four sub-categories:
 - ✓ Assistance with daily living, except where a budget is allocated to Supported Independent Living (SIL), which is always Agency managed;
 - ✓ Transport;
 - ✓ Consumables; and
 - ✓ Assistance with Social and Community Participation.

A participant may choose how to spend their core support funding, but cannot reallocate core support funding to other support purposes.

2. **Capital Support:** budgets are restricted to specific items identified in the participant's plan. Most items require quotes, which means that providers must negotiate a price. Supports may include items such as:
 - ✓ Assistive technologies
 - ✓ Equipment,
 - ✓ Home or vehicle modifications, or
 - ✓ Specialist Disability Accommodation
3. **Capacity Building Supports:** enables a participant to build their independence and skills. These supports include:

- ✓ Support Coordination,
- ✓ Improved Living Arrangements,
- ✓ Increased Social & Community Participation,
- ✓ Finding and Keeping a Job,
- ✓ Improved Relationships,
- ✓ Improved Health & Wellbeing,
- ✓ Improved Learning,
- ✓ Improved Life Choices and
- ✓ Improved Daily Living Skills.

A large proportion of the supports currently listed in the Price Guide fall within the Core and Capital support categories, many of which are unlikely to be relevant for people with psychosocial disabilities. For this cohort, the majority of support needs are likely to be contained within the Capacity Building category.

In 2015 the NDIA and Mental Health Australia embarked on a joint project to identify optimal packages of support for NDIS participants with a psychosocial disability, known as the *Psychosocial Supports Design Project* (the Project). The Project was initiated in response to concerns expressed by mental health providers operating in NDIS trial sites about the applicability of the NDIA Price Guide to the types of support services likely to be chosen by participants with psychosocial disability.

The Project identified a number of critical considerations that are of relevance to ensuring that the supports made available to people with psychosocial disability are able to flexibly respond to the different and often fluctuating needs of people with psychosocial disability.

People with psychosocial disability who are eligible for the NDIS can generally be characterised as having:

- Combinations of ongoing and episodic or cyclical functional impairments that manifest in a variety of forms that are only loosely related to the individual diagnosis.
- Relatively unpredictable recurrence of urgent/acute exacerbations of symptoms that fluctuate in type, severity, duration and impact.
- Opportunities for recovery, where the ability to live well in the presence or absence of symptoms, can be enhanced by recovery focussed support.

While individual journeys are unique, the Project described at least three common or 'typical' journeys, with associated needs that could be met through the provision of appropriate individual support packages:

1. **Substantially reduced functioning resulting in disability** described as 'prominent disablement experienced at all times'
2. **Fluctuating, unpredictable patterns of relative impairment.** This corresponds to what NDIA describes as a 'deteriorating course' or 'late improvement after a period of disablement'.
3. **Cyclical pattern of functioning,** as typified by affective disorders where periods of substantial disability are followed by periods of relative capability,

although some underlying functional impairment is likely to remain that may not be consistent with the NDIS access criteria.

2.2 Outcome Domains

Determinations regarding support needs within the NDIS are made on the basis of functional impairment. Representations from across the mental health system have consistently been made that there are significant boundary issues between the mental health and disability paradigms. Reconciling these presents significant systemic and implementation challenges and importantly, potential barriers to engagement of consumers.

There is a strong message coming out of the available evidence and advocacy from the mental health sector that the most effective responses to people with severe mental illness (SMI) and psychosocial disability are those that are flexible, holistic and integrated and conducive to recovery outcomes.

The following discussions seek to integrate the above within the existing NDIS support categories, identifying any current gaps and aligning these with additional interventions supported by the available evidence.

2.2.1 Functional Impairment

For a person with a psychosocial disability to access the NDIS, they need to have a permanent or likely-to-be permanent disability as a result of their mental health condition. The condition must have a significant impact on their day-to-day life and the person's ability to participate in the community. It also needs to be likely that the person will need support for the rest of their life.

Functional impairment is determined in accordance with section 24.1 of the NDIS Act, which defines impairment as 'the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities':

- (i) communication;
- (ii) social interaction;
- (iii) learning;
- (iv) mobility;
- (v) self-care;
- (vi) self-management;

Support needs are determined on the basis of functional impairment. Advocacy from the mental health sector has highlighted that there are currently no validated or standardised instruments to quantify the degree of functional impairment or the nature of impairment as a result of mental illness. Available tools tend to be focused on diagnostic or assessment based categorisation. This is problematic, particularly in the context of identifying 'reasonable and necessary supports' and in consideration of the fluctuating nature of symptomatology and individual experiences of illness.

There are a number of ways to practically match the level of impairment to the intensity of support required. Broadly, this can be considered in hierarchical terms using the following categories (as is currently used by some mental health service providers):

- *Early intervention or low to moderate support:* for individuals who have a relatively stable mental state, with no apparent risks of harm to self or others and a demonstrated willingness to engage in support and capacity or willingness to improve capacity for independent living.
- *Medium levels of support:* for individuals who may need medium levels of assistance to successfully participate in the community. Individuals may already be engaged in some level of support and be characterised by poorly developed assisted daily living skills, moderate levels of judgement/decision making and some history of harm to self or others.
- *High levels of support:* targeting individuals who have high levels of instability and psychiatric disability, who may only have minimal engagement in support and medication adherence. Their illness is impacting upon their capacity for activities of daily living and increasing risk of harm to self or others.
- *Very high:* Individuals in this category would be significantly unwell with substantial impairment that may result in the individual being of consideration risk to themselves or others, with substantially impaired judgement and cognition. It is likely that responsibility for the support needs for this group may rest with the health system.

Individuals with SMI are going to have a fluctuating hierarchy of support needs and variable levels of engagement. Engagement will be impacted by a range of factors including willingness, cognitive capacity and also by service accessibility.

To ensure that the NDIS is adequately providing for the support needs of people with psychosocial disabilities, it is important to ensure access to evidence based interventions offered along a continuum. Stepped care approaches may be the most reliable framework to ensure people with psychosocial disability are matched to a service commensurate with their need.

2.2.2 Recovery Oriented Practice

One of the most commonly cited definitions of recovery is the one articulated by William Anthony (1993):

“Recovery is a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness”

In Australia, the National Framework for Recovery-Oriented Practice articulates a number of components of mental health care, thatⁱⁱ:

- Recognises and embraces the possibilities for recovery and wellbeing created by the inherent strength and capacity of all people experiencing mental health issues
- Maximises self-determination and self-management of mental health and wellbeing
- Assists families to understand the challenges and opportunities arising from their family member's experiences.

There are 5 main domains of recovery-oriented practice, including:

Promoting a culture and language of hope and optimism: ensuring a service culture and language that makes a person feel valued, important, welcome and safe, communicates positive expectations and promotes hope and optimism.

Person first and holistic: putting people who experience mental health issues first and at the centre of practice and service delivery; viewing a person's life situation holistically.

Supporting personal recovery: personally defined and led recovery at the heart of practice rather than an additional task.

Organisational commitment and workforce development: environments and culture that are conducive to recovery and a workforce that is appropriately skilled, equipped, supported and resourced for recovery-oriented practice

Action on social inclusion and the social determinants of health, mental health and wellbeing: upholding the human rights of people experiencing mental health issues and challenging stigma and discrimination; advocating to address the poor and unequal living circumstances that adversely impact on recovery.

2.2.2.1 Recovery Outcomes

There is much discussion in the literature around the application of the term recovery and its associated outcomes, most notably in regard to the realms of 'clinical' and 'personal' recovery.

Recovery is broadly defined as 'living as well as possible' (South London and Maudsley NHS Foundation Trust 2010), with minimal symptoms of mental ill-health (Slade et al. 2012). As a concept, it introduces notions such as hope, empowerment and aspirations to inspire the consumer to attain a 'meaningful life' (Anthony 1993, Corrigan 2006, Slade et al. 2012)ⁱⁱⁱ

Application of this is about identifying realistic and practical strategies to help consumers cope with and reduce disability using evidence-based interventions (Corrigan 2006).

'Clinical' recovery includes criteria in areas such as remission, stabilisation of symptoms, psychosocial rehabilitation, improved vocational activities, additional social connections and independent living (Bellack 2006, Kopelowicz et al. 2005, Liberman et al. 2002). It is largely biomedical in nature, focused primarily on illness and impact on functioning.

In contrast to clinical recovery, 'personal' recovery has been described as a process or continuum that is subjectively defined by the individual and is 'rated'

by the person who is experiencing the mental health difficulties who is considered the expert on their recovery^{iv}: It is derived from consumer oriented literature, case studies and qualitative surveys. Rather than being focused on biomedical understanding of illness and disability, the focus is on strengths or improvement measures such as mental health and wellbeing outcomes.

Since recovery has a personal meaning for each individual, it can be difficult to find a shared definition. In a Delphi study with 381 participants, all of whom had personal experience of psychosis, the highest number of participants agreed on the statements 'recovery is the achievement of a personally acceptable quality of life' and 'recovery is feeling better about yourself' (Law, 2014)^v.

Influenced by consumer oriented literature and advocacy, the concept of personal recovery is more frequently being prioritised over clinical recovery and is becoming embedded into contemporary policy and service provision.

2.2.2.2 Translating recovery domains into practice

Consistent with the shift towards 'personal' recovery and assisting individuals to find a meaningful life, it is important to align the principles of recovery to a set of processes and outcomes that could articulate to additional supports for people with psychosocial disability.

A systematic review conducted by Slade et al^{vi} explored the evidence base in order to identify key recovery processes and pro-recovery interventions. The result was the identification of five key domains that capture the recovery journey, processes and stages with recommendations for ten empirically supported and targeted pro-recovery interventions. The key components of the recovery framework, collectively described by the acronym CHIME, include:

- Connectedness;
- Hope and optimism;
- Identity;
- Meaning and purpose; and
- Empowerment.

In a paper discussing psychosocial disability and the NDIS^{vii}, Paul O'Halloran suggests that the conceptualisation of recovery should be inclusive of all thematic elements including personal, clinical and functional dimensions of recovery. O'Halloran suggests that outcomes are optimised when consumers and families have choice about and access to whatever aspects of recovery are needed and preferred. Similar to Slade, he suggests framing support determination in the context of recovery needs, outlining a number of recovery dimensions including:

- Recovering hope
- Redefining self and reframing illness
- Meaningful activity
- Overcoming stigma
- Assuming control
- Empowerment and citizenship

- Managing symptoms and disability
- Being supported.

The call by consumers and providers alike to orient services around recovery means that there needs to be a reliable and consistent set of indicators to measure wellbeing and outcome domains such as coping, resilience, empowerment and hope. Many of the domains within the available outcome measures tend to be focused on deficits and disability rather than focused on optimism and positive indicators of a meaningful life.

Feedback provided through a range of forums consistently refers to issues relating to the language of disability and reliance on diagnostic criteria being in conflict with recovery paradigms. Whilst functionality may be a more cogent outcome, developing instruments that support meaningful outcome domains will ultimately result in more a greater understanding of system efficacy in meeting consumer's individual needs and more positive experiences of care.

2.3 Unmet Need

Since implementation of the NDIS commenced, there have been a number of undertakings to further explore the most appropriate support system and optimal engagement strategies for people with psychosocial disability. This includes literature reviews, stakeholder submissions to Government led Inquiries, sector advocacy and position papers.

Whilst there is broad acknowledgement that the NDIS represents significant opportunities, there have been common themes emerging with regard to individual preferences for support and met and unmet needs.

There is a high degree of consistency in the available literature including existing program evaluations, annual report data, evidence reviews and analyses of assessment tools such as the Camberwell Assessment of Need (CAN) and Camberwell Assessment of Needs Short Appraisal Schedule (CANSAS) as to the consumer indicated preferences for life goals and unmet needs.

The *2014 Mental Health and the NDIS: Literature Review* examined the available evidence on the top 12 ranked domains within the CANSAS and identified strong similarities across 11 studies. In all, the company of others, food, looking after the home, physical health, psychological distress and psychotic symptoms were ranked consistently among the top 12 areas of need, with daytime activities; the need for information about treatment, for intimate relationships and money ranked highly in the majority of studies.^{viii}

The Literature Review attempted to identify the types of supports most commonly in use in Australia- based on available limited data and evidence. The Review identified that the most commonly utilised support services by people with psychotic illnesses, were emotional support, employment and housing.

A 2015 Melbourne University study examined the preferences of a group of 41 participants with psychosocial disability^{ix}. Although a small sample size, when asked to consider goals and ideas as to what represented a "good life" the top five identified life goals exemplified the priority areas previously indicated in the

literature. These goals, aligned with recovery needs, will be discussed in this paper:

- Health
- Economic
- Social Connection
- Housing
- Personal Life

Further sources of valuable insight into areas of unmet need and priority arise from existing programs such as Partners In Recovery (PIR), the Personal Helpers and Mentors Program (PHaM), Housing and Accommodation Support Initiative (HASI) and PARC. Of note are the following:

- PIR participants consistently reported psychological distress, company, employment, physical health, accommodation, and daytime activities as areas of highest unmet need^{x xi}
- Enabling increased service interface between sectors has been a significant strength arising from PIR. However, proactive engagement needs to continue to ensure continuation of these gains. There were still some noted gaps, particularly in terms of low referral rates from GPs and Alcohol and Other Drug (AOD) services^{xiii}.
- Support planning must consider the high prevalence of co-occurring morbidities (particularly physical health, intellectual disability and AOD use) for eligible consumers if their recovery is to be supported in a meaningful way through the NDIS.
- Options that enable access through a 'soft' entry approach that is not necessarily reliant on diagnosis may improve engagement and referral processes.

Critical to the discussion of unmet need is the fact that the current understanding of met and unmet needs and consumer preferences is based largely on individuals with some degree of service engagement. There is a potentially large and particularly vulnerable and marginalised cohort of people whose needs are not adequately reflected in current conjecture.

2.4 Matching interventions to need

There is substantial overlap between the positions represented across many of the submissions offered in the context of psychosocial disability and the NDIS. There are similarities across the board in terms of advocating for a recovery oriented approach and there is broad acknowledgement that an integrated and holistic approach to care is critical to ensuring effective service delivery and optimal outcomes.

Whilst the system adjusts to delineating shared responsibility across different sectors, it is important to ensure that potential support gaps are identified and minimised. This is particularly important for people with psychosocial disability as there may be assumptions that their needs can be largely met from within

existing systems, particularly public health funded services and primary health care.

The following review of the available evidence will be themed in accordance with the five domains prioritised as 'life goals', all of which align with a range of recovery needs. Although these goals are described separately, there is a high degree of interdependence between the various domains, particularly in terms of recovery outcomes. Identifying optimal support for people with psychosocial disability will depend on effectively matching intervention to individual need with a high degree of flexibility and understanding of the principles of recovery oriented practice in the specific context of mental health.

3 Capacity Building: Strengthening the System of Support

A common theme raised within sector consultations and advocacy, policy submissions and position papers relates to NDIA processes being potentially prohibitive for people with psychosocial disability. Specific considerations include the lack of mechanisms to support effective engagement, system navigation and support planning and review.

Current NDIS planning is based on a relatively linear process with a reliance on individuals being 'plan ready'. For people with SMI, who present with often multiple and complex needs, this is not always going to be appropriate. Considering the support needs for people with mental health related disability along a continuum, there might need to be some form of advocacy, coordination and assistance at each stage of engagement. This means eliminating or addressing some of the noted access barriers such as readiness, trust, stigma and confidence that support planning will be an individualised and informed process.

Whilst the underpinning principles of the NDIS are aligned with recovery and individual empowerment, one of the limitations of the NDIA frequently described among stakeholders is the limited understanding of mental illness within the current NDIS support structures. This is said to be impacting the level of engagement by consumers and potentially the appropriation of supports through the existing support planning processes.

The NDIS Independent Advisory Council (IAC) specifically recommends that there be designated items for mental health support roles that will enable more effective engagement and support planning within the NDIS. The IAC suggests three specific support roles that are not currently covered in the NDIA support items list: peer workers, life coaches and advanced independent living practitioners^{xiii}.

3.1 Advocacy and Support Planning, Review and Coordination

Strong representations have been made that advocacy and support planning and coordination are significant gaps in the current NDIA structures. There is a sense that there is some incompatibility between existing planning processes and the needs of people with SMI. Given the complexity of the system to navigate, the nature of mental illness and the fluctuating needs of individuals and their families and carers, having designated structures in place is critical.

A 2006 evaluation of direct payment schemes in the UK found that whilst exercising choice and control is a desired approach by consumers, the benefits of direct payments and independent living requires significant adjustment. The shift may be a long and difficult learning experience for both for providers and service users. The evaluators suggested that whilst direct payments are a viable option for many mental health service consumers this needs to be supported by a robust support infrastructure to enable service users to navigate the system^{xiv}.

In addition to infrastructure that supports a system that is recovery oriented, person-centred, family-inclusive, culturally secure and trauma-informed; there needs to be a high degree of flexibility to respond to fluctuating needs. Support plan development needs to be an iterative and evolving process that is adaptable to fluctuating needs. Planning and review processes need to account for changing cognition and degrees of impairment, including times of both wellness and greater illness acuity. Embedding structures to support this will entail ensuring there is adequate competency and capability to understand these needs.

3.1.1 Advance Directives

Given the vulnerability of people with SMI to experiencing periods of crisis or illness acuity, there are times when they may not have the capacity to make informed decisions about their care.

Healthcare technologies and processes have been developed to support people to remain in control during crisis. One such example is an advance directive, which involves specifying actions to be taken for an individual's health if capacity is lost in the future. Actions may involve treatment or specify a proxy decision-maker and collaborative crisis planning.

Advance directives have strong empirical support with Cochrane reviews determining benefits for reduced involuntary treatment and service use, and increased control (Campbell & Kiseley, 2009, cited in Slade)^{xv}. Research has also shown that consumers who have executed advance directives experience feelings of self-determination, autonomy, and empowerment. Although promoting individual choice and control, advance directives have also been associated with implementation challenges, although not insurmountable, at both service and system level^{xvi}.

3.1.2 Considerations for Specific Populations

Engagement of harder to reach populations, including those who may be living in rural and remote areas, Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse (CALD) populations, individuals with significant trauma may require targeted advocacy and support.

Consultation processes accompanying many of the NDIS policy discussions have commonly highlighted the need to address the particular needs of specific population groups. Many of the submissions to the *Joint Standing Committee: Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition (JSC)* stressed the need for appropriate supports to meet the needs of hard to reach populations, particularly those previously mentioned.

In the final report on the Independent Pricing Review for the NDIA, McKinsey and Company (released February 2018) noted that *there are cohorts of participants for which supply shortages are high-risk due to the increased cost of service provision and limited availability of workforce*. The report specified the following population groups: people living in outer regional, remote or very remote areas; people with complex needs; CALD; Aboriginal and Torres Strait Islander Australians; or those with acute care needs such as in crisis situations.

Each of these groups of people are likely to have particular challenges in receiving the appropriate supports to meet their individual needs, particularly when compounded with mental illness. The McKinsey report noted that one of the critical issues raised by respondents relates to current loadings for complex participants not adequately reflecting the additional costs of serving these participants.

3.1.2.1 Aboriginal and Torres Strait Islander

Representations indicate that people who identify with Aboriginal and Torres Strait Islander heritage are not accessing the NDIS at a rate that is reflective of the needs in these communities.

Responding to the requirements of Aboriginal and Torres Strait Islander participants and their communities has been identified as a priority issue in many of the consultation processes and through evaluation of a number of trial sites. Although participation is guided by the Aboriginal and Torres Strait Islander Engagement Strategy there still remains underutilisation of the Scheme.

A February 2017 report from the Australian Indigenous Health Bulletin details twelve factors that can overcome barriers and influence the participation of Aboriginal people in disability services. The twelve factors were identified as:

1. Conceptualising Disability
2. Family and Kin
3. Colonisation and Trauma
4. Racism
5. Choice of Workers
6. Choice of Organisations
7. Community Connections
8. Trustworthiness of mainstream services
9. Multiple Agency Intervention
10. Trusting Workers
11. Mobility
12. Affirmative Action Policy

It is critical that service delivery approaches for people from Indigenous communities are designed and delivered in a manner that is culturally sensitive and responsive to their needs. A number of strategies can be instated including leveraging off existing local community initiatives and optimising the engagement and building the capacity of networks such as the Aboriginal Community Controlled Health Services in the disability area, especially in rural and remote locations.

3.1.2.2 Forensic Disability

The JSC specifically looked at the provision and continuation of services for NDIS participants in receipt of forensic disability services. Submissions highlighted the potential that the NDIS has to decrease incarceration rates for people with a cognitive and psychosocial impairment, particularly Aboriginal and Torres Strait Islander people who are overrepresented amongst those in prison and a historically difficult to reach group.

Given the lack of clarity around the interface between the NDIS and support for people engaged with the criminal justice system, the JSC maintained there was a need for reconciling this before opportunities within the forensic system could be realised. The Committee recommended the NDIA to establish a unit specialising in the interaction of the Scheme with the criminal justice system.

3.1.2.3 Rural and Remote Communities

It is well established that rural and remote areas do not have the same level of existing infrastructure and availability of appropriate supports as metropolitan areas. This presents particular challenges to potential NDIS participants living in these areas as well as strain for the existing providers. Addressing geographic limitations and associated issues will require strategies that can build engagement by potential providers as well as innovative approaches to facilitate access for participants.

Modes of delivery for existing services may need to be adjusted with options for outreach, expanded use of technology, or hub and spoke approaches. Incentives or grants may also need to be considered to encourage support services or practitioners to engage.

3.1.3 Transition of Existing Programs

It is important to consider key learnings and the value that targeted programs due to be transitioned in to the NDIS brought to the system and to ensure that these elements are built in to the NDIS.

3.1.3.1 Partners in Recovery

The Partners in Recovery (PIR) program is delivered through a national network of 48 PIR consortia. Each consortium is comprised of local service providers who commit to the implementation of PIR in their local area.

PIR supports people who experience severe and persistent mental illness and have complex support needs, as well as their families, to access services and supports to assist them in their recovery.

A 2014-15 Annual Report prepared by Urbis for the Department of Health concluded that PIR is an innovative model that results in transformational change for many of the intended target population, particularly in terms of recovery outcomes. One of the key strengths of PIR is its effectiveness in supporting populations that have been traditionally very difficult to reach and engage.^{xvii}

The program operates on person-centred recovery based approach and is focused on coordinating and integrating services to deliver improved outcomes. The Urbis report and local evaluations of PIR have demonstrated a range of improved personal, social and health and wellbeing outcomes for consumers and carers.

Certain key domains of activity and infrastructure have been attributed to effectively engaging consumers, including: skilled workforce; presence; localised needs assessment; advocacy; brokerage and flexible funding.

Many stakeholders have discussed issues of note or concern regarding the transition of PIR to the NDIS over the coming years. Many have emphasised the importance of recognising critical success factors as well as minimising risk of people falling through the gaps due to ineligibility. These issues correspond to some of those highlighted in local evaluation processes, including^{xviii} ^{xix}:

- Many items required in mental health service delivery are not covered under NDIS. Significant areas of expenditure were not covered including: household items, gym membership, education related expenses and accommodation related expenses^{xx}.
- The intervention provided in projects not only supported a person's recovery but also had an impact on the person's natural supports including families and carers, who benefitted because programs offered 'informal respite and education around the illness, and their roles and responsibilities, as well as referrals on to respites.
- Flexible based funding resulted in improved person-centred, consumer outcomes and played a significant role in capacity building of mental health and non-mental health sectors due to improved service connectivity.
- Peer workforce and co-design projects successfully pushed the boundaries of what is possible in service delivery.
- Enhancing the role of carers to become care planners under the NDIS may improve client engagement and better support the carers to undertake this role.
- Localised approaches to planning ensured services were responsive to local needs and priorities.
- PIR strengthened the support delivered to individual consumers, because Support Facilitators provided individualised assistance and ensured access to other services.
- The flexibility of brokerage funding has contributed to the wellbeing of individual consumers by securing appropriate supports and services that would otherwise not have been available.
- The participation of Aboriginal and Torres Strait Islander and CALD organisations in support facilitation enabled culturally safe, responsive and valued support to these communities.

- Sustained resourcing is needed to improve the support provided to people who are experiencing homelessness and sleeping rough, and to address experiences in squalor and hoarding.

3.1.3.2 *Personal Helpers and Mentors*

Personal Helpers and Mentors (PHaMs) involves the provision of practical assistance to people with severe mental illness to help them achieve their personal goals, develop better relationships with family and friends, and manage their everyday tasks. One-to-one and ongoing support is provided with the aim of increasing recovery opportunities and improved functionality. PHaMs services take a strengths-based recovery approach to helping participants better manage their daily activities and reconnect with their community.

PHaMs services provide coordinated access to a range of integrated and holistic support services. PHaMs has had demonstrated success in improving outcomes across a number of recovery domains for participants. Wellways undertook an internal evaluation of outcomes for PHaMs participants in November 2016. Data were analysed for 161 participants over a 12 month period using the Recovery Star, a validated and widely used measure. The findings indicated that participants experienced a statistically significant increase in overall recovery and statistically significant increases in recovery in 9 areas including trust and hope; self-esteem; responsibilities; relationships; work; social networks; living skills and physical health.

One of the key noted benefits of PHaMs is that it does not require a person to have a formal diagnosis to access the service. This has enabled a 'soft' entry point for those who otherwise may not approach traditional mental health services. It also allowed PHaMs to operate on a 'no wrong door' approach by welcoming people in, and supporting them to access appropriate services through a warm referral process using advocacy and personalised assistance.

Concerns have been expressed that a significant number of people currently using the PHaMs program would not be eligible for the NDIS because they would not meet the permanency criteria. Reconciling a range of issues around permanency has been the subject of ongoing discussion since the commencement of the NDIS.

3.2 Support service engagement strategies

Improved engagement can be achieved through establishing a network of support people that have a good understanding of mental illness, appropriate competencies and can work with individuals with psychosocial disability to build trust and support them through their individual journeys.

There are a number of enablers that could be considered part of this network including advocates; assertive outreach; personal assistance; support facilitators; and coordinators peer support and enhancing the role of carers.

The matter of advocacy, outreach and coordination services was one of the critical areas of investigation in the 2017 *Joint Standing Committee: Provision of services under the NDIS for people with psychosocial disabilities related to a*

mental health condition, particularly in the context of programs due to be transitioned to the NDIS.

In its Final Report document, the Committee recognised the critical role that advocacy and outreach services play in identifying and engaging people, their families and carers with NDIS services. Stakeholder submissions consistently highlighted the critical gaps that are likely to arise from the transition of existing programs such as the PIR or PHAM, where facilitated engagement featured prominently both in terms of program intent and operational strengths.

The Committee report acknowledged that there were risks of emerging service gaps and that current operational systems to engage with hard-to-reach cohorts through assertive outreach could be greatly improved.

In a recently released report regarding transitional arrangements for the NDIS, the Committee made the following recommendations:

Advocacy Recommendation: The committee recommends the Council of Australian Governments (COAG) Disability Reform Council work with the Department of Social Services to address the expected funding shortfalls for advocacy services beyond transition.

Assertive outreach Recommendation: The committee recommends the Department of Social Services and the NDIA develop and publicly release a plan outlining how assertive outreach services will be delivered beyond transition to ensure people with disability who are hard-to reach can effectively engage with the NDIS and / or other support programs.

Support coordination Recommendation: The committee recommends the NDIA ensure support coordination is adequately funded in Plans to meet Participants' needs and not limited to a fixed period.

3.2.1 System Support

3.2.1.1 Assertive Outreach

Assertive Community Treatment (ACT) is an intensive form of Case Management that assesses need and coordinates relevant services for a person living with severe mental illness (SMI). It involves the provision of high levels of treatment and support for people who have intensive and complex needs in the community. This type of intervention is frequently referred to as 'outreach', involving mobile supports, sometime referred to as Mobile Support Teams (MST), or Mobile Intensive Treatment Team (MITT).

According to the evidence review conducted by Hayes et al (2016), there is extensive RCT evidence for Outreach, approaches. Positive outcomes associated with Outreach and ACT support include: increased contact with services, decreased hospital based care, improved quality of life, increased housing stability and reduced symptoms. Outreach is well suited to participants with difficulties in community living, difficulties in engaging with services and people with higher levels of impairment (Rosen et al. 2007 cited in Hayes et al).

Outreach may be usefully adapted to both directly support and coordinate supports for NDIS participants when there is a need for more intensive or

assertive approaches to care. Examples include people who are living with complex or severe psychosocial disabilities or when there are particular accessibility challenges such as social or geographic isolation and homelessness.

3.2.1.2 Advanced System Management

Assertive approaches to care management are important mechanisms for facilitating and maintaining engagement of individuals in treatment and support. This includes empowering participants to navigate what can be overwhelming systems of care.

‘Patient navigation’ is a form of system management intended as a mechanism to reduce barriers and to bridge gaps in services, which can be particularly challenging for individuals with complex needs. Individuals with complex needs may experience fragmentation and gaps in service delivery, thus system navigation may support this population to better manage their needs.

Navigators can assist with fragmentation of the psychosocial support system through various methods including: liaison and communication with multiple agencies, facilitating access to and coordination of care, navigating the system and services, or assisting individuals with administrative needs.

Navigation roles have been demonstrated to assist in addressing unmet needs for coordination and facilitation of care, particularly in relation to populations for whom social determinants of health create additional barriers to accessing appropriate social and health care services and supports^{xxi}.

The role of support facilitator (SF), which sits at the heart of the design of the Partners In Recovery (PIR) program, exemplifies a critical navigation role. The intent of the role of facilitator is to assist consumers with complex needs to identify their needs and then access the services required. In facilitating access to support, the role seeks to address challenges faced by individuals in accessing and navigating the highly complex service systems.

PIR was designed to integrate fragmented community mental health and other human service organisations in order to better identify, connect with and support people with SMI. Analysis of two local PIR evaluations provides insight that PIR has been successful at connecting with the intended target populations, thus indicating that there is benefit in roles designed to facilitate system access, navigation and management^{xxii}.

3.2.1.3 Personalised Supports

According to a range of qualitative reports, people with mental illness have consistently noted a support preference for personalised support or a support person/worker to provide one-one non-clinical support, assistance and interaction as a means of fostering a better quality of life.

Personalised supports, or Personal Assistance are recovery-oriented interventions provided by a worker with specific competencies in delivering individualised support. The support provided by such a person may include living skills, community access, emotional support and advocacy. Such approaches can be seen as an alternative model of outreach and an intensive

support that encompass values such as self-determination and non-coercion (Fisher & Ahern 2000 cited in Hayes et al).

Both the 2014 and 2016 Literature Reviews commissioned by Mind refer to a review published by Siskind et al in 2012 that assessed the effects of personalised support on outcomes for people with a severe and persistent mental illness. The authors concluded that overall there is moderate evidence to suggest that personalised support services can promote patient satisfaction with services and reduce illness acuity. Evidence also indicated, to a lesser extent, that personalised support can improve personal functioning, such as interpersonal interactions, problem solving and living skills.

Some concern has been expressed that the friendship and support of the support worker may inadvertently reduce the need for recipients to foster external friendships and relationships with family (Siskind et al. 2012). However other studies have found the reverse to be the case where the befriending aspect that PAs can provide can be of comfort to individuals experiencing social isolation^{xxiii}.

Whilst there is not a substantial evidence base for other outcomes arising from personalised support, Personalised Assistance may be a useful strategy for encouraging participants to engage with their chosen supports and achieve their goals, as is the case with the current PHaMs program. They can also have a potentially critical role in assisting with pre-planning support, decision making and planning review support- both highlighted as NDIS system gaps that require attending to.

3.2.1.4 Decision Making Support

Recovery oriented practice emphasises the importance of autonomy and the right of individuals to have choice and control over important decisions relating to their treatment and care. This means the person concerned is always the primary decision-maker (Pathare and Shields, 2012). Many factors can undermine an individual's control over decision making, including functionality, cognition, stigma and discrimination, clinician perception of risk and capacity, along with responsibility to duty of care.

There are times when access to decision making support is vital for individuals to empower them to assess the range of considerations in making the right choices about their care and treatment, particularly during periods of fluctuating need. A study by Kokanovic et al (2017) explored the enablers of the decision making experience for people experiencing severe mental health problems, families and other informal supporters and mental health practitioners.

A common theme that emerged was the importance of strengths based interactions and interpersonal experiences of care that build trust and instilled a sense of confidence within people experiencing mental illness to make decisions. With empowerment, confidence and trust as foundations, some of the decision support strategies identified to be beneficial were^{xxiv}:

- For services to focus on providing personalised, continuous care, sensitive use of language and sharing information with families, carers and other informal supporters.

- For practitioners to support individuals to express their views and preferences, and to take responsibility for the consequences of their choices by assisting people to:
 - Access credible information that will help with decision making;
 - Access peer support and other mechanisms for normalising and sharing experiences; and
 - Encourage self-advocacy.
- Assisting staff to balance their concerns about risk and meeting their duty of care with respecting the ‘dignity of risk’ in the decision-making of people experiencing severe mental health problems.
- Involving families and other informal supporters in decision making by recognising their expertise and engaging/consulting with them as key sources of support for people’s treatment decision-making.
- Information about legal and rights based mechanisms such as advance directives, nominated persons, advocacy and second opinions should be promoted throughout mental health services.

3.2.2 Peer Support Services

The role of peer support is of relevance across all domains within a support framework. There is potential utility for peers to offer both structured and informal support to individuals with psychosocial disability along a continuum- from facilitating engagement with the NDIS, navigating the system, community based mentoring and supporting personal recovery outcomes.

To some extent, peers may be one of the most critical enablers to recovery for people with mental illness and the evidence base to support this is growing. Peer support can play a significant role in supporting individuals to recover hope, gain social empowerment, overcome stigma and manage the symptoms of disability.

The 2014 Mind Literature Review concluded that the evidence for peer support is mixed and is particularly limited by the minimal number of high-quality studies. Hayes et al (2016), provided an alternative perspective, concluding that the evidence for Peer Support is growing substantially and shows great promise. The outcomes of peer support programs vary greatly depending on facets such as research methodology, or the nature of the program and the peer provider. However, it appears that Peer Support is particularly effective in encouraging recovery and restoring hope and provides an important sense of rapport that can be uniquely satisfying for participants.

Hayes et al (2016) refer to the definition of a peer as “individuals with histories of successfully living with serious mental illness who, in turn, support others with serious mental illness” (Chinman et al., 2014) and discuss the variability in scope and participation of peers. The evidence review describes six peer categories of peer support service (Solomon, 2004):

- Self-help groups: small groups formed by peers that physically come together, in a community setting, to offer mutual support to overcome a common issue. Peer support in this context is generally unpaid.
- Online support groups: usually conducted through email or online forums and offer anonymity through lack of face-to-face interaction. Peer support in this context is generally unpaid.
- Peer-delivered services: delivered by trained, paid peers who identify with having mental ill health, have received (or are currently receiving) treatment and are further along in their process of recovery.
- Peer-operated services: these services are planned, administered, operated and evaluated by consumers and are based on the principles of peer control and freedom of choice. Services are usually structured, skill based and found within larger organisations and may include crisis services, drop-in centres, vocational and employment services and psychoeducation.
- Peer partnerships: services whose administration, governance and service delivery are shared between peers and non-peers.
- Peer support workers: individuals who identify as peers are employed in paid positions within mainstream mental health services. Examples of roles are peer advocates, peer companions, peer specialists, peer mentor, peer coach or peer consultant.

It is important to recognise the various roles that peers can fulfil, including recovery mentors, family/carer peer support and Aboriginal peer support. For participants in the NDIS, peers can offer valuable structured/skill-based and informal support for individuals and family carers during any stage of participation. In this regard, consideration also needs to be given to distinguishing between paid and unpaid peer support. The above list includes a combination of both trained paid workers and unpaid or community based voluntary support.

3.2.2.1 Peer Workforce

According to the National Mental Health Commission (NMHC), the peer workforce is the most rapidly growing workforce in the mental health sector. Peer support workers are generally skilled people with both training and expertise by experience, who are paid to deliver peer support. A 2014 report from the NMHC called for an expansion of the peer workforce and for more formalised and structured frameworks to be placed around their roles, capability training and support systems within the workplace.

Evidence reviews of the role of peer support workers have been relatively equivocal in the past with limitations identified in terms of lack of heterogeneity of models of outcome measures, making comparison difficult (Pitt et al, 2013)^{xxv} Peer workers were identified as having some positive influence in terms of decreased use of coercive interventions, lowered service delivery costs, fewer re-hospitalisations, improved crisis planning and better engagement with services.

In his 2015 review of the empirical evidence about recovery, Slade emphasises the positive findings in relation to peer support. The review highlighted seven RCTs evaluating the impact of peer support workers, which found consistent benefits in relation to clinical outcomes (engagement, symptomatology, functioning, admission rates), subjective outcomes (hope, control, agency, empowerment) and social outcomes (friendships, community connection) (Repper, 2011). RCTs on peer-led self-management interventions in the Netherlands and USA showed benefits in relation to having a recovery role model, pursuing recovery, hopefulness, self-perceived recovery, symptom scores and quality of life^{xxvi}.

A systematic review and meta-analysis of peer support conducted by Lloyd-Evans et al (2014.) looked at eighteen RCTs of peer delivered and peer support services. The conclusions were similar to previous findings, with recommendations that more rigorous research be conducted in the future. Among the positive findings of the review, was evidence that peer support was associated with positive effects on measures of hope, recovery and empowerment at and beyond the end of the intervention^{xxvii}.

One analysis highlighted that whilst there is a lack of qualitative and quantitative empirical evidence of the unambiguous efficacy of peer workers, the majority of research that is undertaken largely ignores social and recovery-based outcomes^{xxviii}. This point was further reiterated in other studies where the suggestion has been made that further research consider outcome measures that focus on impact and recovery oriented outcomes rather than traditional measures of functioning and symptoms. (Chinman, 2014; Pitt et al. 2013).

In Australia, Flourish, a peer support program delivered across a number of Neami service sites, involves paid Peer Support Workers delivering a self-development program developed by the University of Wollongong. The strengths based structured program includes group work, online support (podcasts) and coaching and is designed to help participants develop a sense of wellbeing, through equipping them with skills to achieve positive change.

An internal evaluation of the program was incorporated into the delivery of Flourish, with information gathered from recovery measures (*Self Identified Stage of Recovery-SISR*, and the *Mental Health Continuum Short Form*) and participant and facilitator interviews. An evaluation report from October 2011 indicated that the Flourish program was well received by participants and that it had positive impacts toward supporting recovery processes.

Data collected from 39 participants across 8 sites showed statistically significant increases in all four of the recovery domains within the SISR-B namely 'hope', 'identity', 'meaning' and responsibility'. Based on this data and insights offered by participants and facilitators, the strengths of the program were derived from the ability to apply recovery-oriented principles and positive psychology to empower individuals to identify their strengths and values to develop a clear vision of what recovery means to them.

3.2.2.2 *Aboriginal Peer Support*

The *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023* articulates strategies that strive for better mental health and social and emotional wellbeing outcomes for Aboriginal and Torres Strait Islander individuals, families and communities. Social and emotional wellbeing is the foundation for physical and mental health for Aboriginal and Torres Strait Islander peoples across the lifespan. It is a holistic concept, which results from a network of relationships between individuals, family, kin and community. It also recognises the importance of connection to land, culture, spirituality and ancestry, and how these affect the individual.

The Framework models social and emotional wellbeing across seven overlapping domains including: body; mind and emotions; family and kin; community; culture; country; and spirituality and ancestors. For Aboriginal and Torres Strait Islander people with weakened social and emotional wellbeing, care is most effective when multidimensional approaches are taken. This includes conceptualisation of mental illness in terms each of the wellbeing domains. Support offered should build on existing community, family, kinship and individual strengths and capacity. This may include engaging with Elders, peers, cultural healers or combining traditional healing and treatments informed by culture with western, clinical approaches for the wellbeing of the whole Aboriginal and Torres Strait Islander person.

One of the key action areas of the Framework includes care for people living with severe mental illness, with a number of relevant outcomes described. Notably, the Framework articulates the importance of ensuring that recovery is facilitated within a social and wellbeing framework. This includes recognising the importance of culturally appropriate support and the pivotal role of the extended family and community networks for Aboriginal and Torres Strait Islander people. In particular, reference is made to ensuring that carer respite and other support programs have Aboriginal and Torres Strait Islander carers as a priority group and that they have reach into communities^{xxix}.

3.2.2.3 *Carer Peer Worker (see 9.1.1)*

3.3 Eligible NDIS support

The range of support facilitators, including outreach, advocacy, coordination and peer support fit within the parameters of the NDIS Capacity Building Support categories. However, it has been commonly suggested that there could be a stronger focus on capacity building within the NDIS, particularly in relation to strengthening engagement, participation and navigation of the NDIS.

Relevant items related to strengthening the system of support within *Coordination of supports*:

- Training in planning & plan management for participants unable to do this independently but who could do all or part of the task with training.
- Assistance to strengthen participant's abilities to coordinate supports & participate in the community. This includes resolving points of crisis,

developing capacity & resilience in a participant's network & coordinating supports from a range of sources.

- Further qualifications/ experience required to strengthen a higher needs participant's ability to coordinate their supports & participate in the community. This may include resolving points of crisis, & developing resilience in the participant's network.

Relevant items within *Increased social & community participation*:

- Life transition planning including mentoring, peer support and individual skill development.
- Establishing volunteer assistance within the participant's home or community to develop skills. For instance, assistance in attending appointments, shopping, bill paying, taking part in social activities & maintaining contact with others.

Relevant item within *Improved daily living skills*:

- Provision of care, training & supervision of a delegated worker to respond to the complex care needs of a participant where that care is not the usual responsibility of the Health System.

4 Health

There is strong recognition of the links between mental, social and physical health both in the literature and among consumers and key stakeholder groups. Whilst responsibility for delivering health services sits within the health system, there are interventions and holistic supports that may not sit within the boundaries of existing services. There are also individuals who, for a variety of reasons, may not be engaged with health services. Thus, it is reasonable to consider that there may be gaps in terms of availability of support to enable people with SMI to effectively address a range of health needs.

People with severe mental illness have significantly higher rates of morbidity and mortality than the general population with much higher rates of chronic diseases such as cardiovascular disease, diabetes and respiratory conditions^{xxx}. The Royal Australian and New Zealand College of Psychiatrists (RANZCP), argue that for people with mental disorders, physical illness comorbidities and their risk factors are the rule rather than the exception. In those patient populations, the mortality rate is 2.22 times higher than the general population, with at least a decade of potential years of life lost^{xxxii}.

Greater exposure to known risk factors for chronic physical diseases, such as smoking, poor nutrition, higher sedentary behaviour and lower levels of physical activity, contribute to relatively poor health. While such behaviours are often considered related to 'lifestyle choices', it has been found that socioeconomic and clinical influences can have a significant impact on health behaviour^{xxxiii}.

Major barriers to achieving good health included stigma and discrimination, medication and cost as well as challenges that arise from the complexity of need. Common co-occurring health conditions, particularly physical health and alcohol

and other drug (AOD) use, can exacerbate impacts of illness and create challenges in matching support to need, particularly in the context of service fragmentation.

Obtaining high quality integrated care for complex conditions can require an individual to be confident, resilient and persistent; characteristics that are associated with wellness and not with mental illness^{xxxiii}.

Consumers have identified health as encompassing physical, mental and social health and indicated holistic and wellness models as support preferences for achieving good health, some of which are out of scope for the NDIS, including^{xxxiv}:

- A good doctor and/or psychiatrist, along with psychotherapy/counselling.
- A good personal carer or support person.
- Peer and consumer support groups.
- Financial support, including access to low cost medical and dental.
- Information/advice to enable individuals to make good health decisions, including physical exercise, nutrition, medication and controlling use of AOD.

The World Health Organisation identifies a number of modifiable risk factors associated with chronic diseases including smoking, high-risk alcohol use, body mass index and physical activity. Given that these factors are all noted to be of high prevalence among people with severe mental illness, it makes sense that modifying these risk factors could result in significant benefits for individuals and more broadly, systemically, by reducing the burden of disease.

Data from the 2010 Survey of High Impact Psychosis (SHIP) supports the findings of high prevalence of physical health morbidity, particularly in relation to modifiable lifestyle risk factors such as smoking and body-mass index. Morgan et al suggest that active monitoring of physical health status needs to commence at the time of first diagnosis of and initiation of treatment for psychosis, and that interventions should be targeting those modifiable lifestyle risk factors^{xxxv}.

4.1 Interventions supported by the evidence

4.1.1 Illness Management

Management of symptoms, medication management or adherence are all aspects of illness self-management, an area often identified by people with SMI as one in which additional support would be beneficial.

The illness management and recovery program (IMR) is an empirically supported standardised intervention to teach illness self-management strategies to people with a severe mental illness (Mueser, 2002). The focus of the intervention is on self-directed problem definition, problem solving and pursuit of personally meaningful recovery goals (Whitely et al, 2009).

It can be provided in individual or group format and comprises a number of strategies including: psychoeducation to improve understanding about mental illness and treatment; cognitive-behavioural approaches to improve medication adherence; training in the prevention of relapses; social skills training to manage

stress and strengthen social support; and teaching coping skills to reduce the distress and severity of symptoms.

Analysis of a number of RCT evaluations indicate IMR can significantly improve symptomatology, functioning, knowledge and progress towards goals for people in a range of settings including supportive housing, outpatient services, and community rehabilitation centres^{xxxvi}

One of these RCTs, conducted on a curriculum based Illness Management and Recovery Program, found that the program is effective in increasing clients' knowledge of their illness and helping them make progress toward personal goals. The program design aimed to teach participants skills to manage their illness and work towards their recovery goals. The primary focus was on self-management, personal goals, social support, appropriate use of medication, relapse prevention, and coping with symptoms. The findings also demonstrated that adhering to the program protocol increased clients' perceived ability to cope with their illness ^{xxxvii}.

4.1.2 Peer Support

There is some evidence that peer support programs may have a role to play in supporting people with serious mental illness in managing their health. A literature review undertaken by the Chronic Disease Illness Alliance (Australia) points to evidence that some models can produce positive outcomes and be cost effective. This review suggests that the major impact of peer support interventions is improved self-efficacy. The reviewers concluded that if this finding is supported by further evidence, incorporating models of peer support into health management and improvement programs holds great promise^{xxxviii}.

In a report prepared by the Royal Australian and New Zealand College of Psychiatrists, a case study highlights the success of a New Zealand primary care intervention, Kia Kaha in Auckland. The program involves peer support workers working with patients with poorly managed long-term conditions to improve self-management. A significant proportion of identified service users were deemed to have 'high psychological distress and high levels of complexity'. The program aims to build the self-management skills individuals and their familial and social networks by employing flexible peer-supporters and outreach methods supported by a consultant psychiatrist based in the primary care setting. In 2013, the program achieved a 45% reduction in the use of emergency services by enrolled participants and a 25% reduction in GP consultation as well as significant reductions in the symptoms of generalised anxiety and depression^{xxxix}.

4.1.2.1 Collaborative Recovery Model

The Collaborative Recovery Model (CRM) was developed over a number of years at the University of Wollongong and is influenced by principles of:

- The Recovery Movement – Power & Autonomy
- Positive Psychology – Hope, Strengths & Wellbeing
- Consumer Participation Movement
- Evidence-Based Practice

- Coaching-style relationships
- Organisational and Workforce Development

The application of CRM varies across services and includes employment of trained Peer Support Workers, family carers and mental health clinicians to deliver support within a collaborative coaching framework. It can be delivered as an individual intervention, as a group program or carer to carer peer support.

CRM is underpinned by the following guiding principles:

- Recovery is an Individual Process: focussing on improving wellbeing.
- Collaboration and Autonomy Support: empowering individual autonomy.

The model has four key components:

- Change Enhancement: support for the individual to explore their relationship to change and build confidence and capacity to engage in a change process.
- Collaborative Strengths and Values Identification: identifying and bringing into focus individual strengths and values as they start to vision a life of meaning and purpose for themselves.
- Collaborative Visioning and Goal Striving: setting goals to enable an individual to further express their strengths and values in their day to day lives.
- Collaborative Action and Monitoring: development of action plans to support the realisation of goals, including the supports the person will need to achieve their goals.

The CRM has been conceptualised as a strength-based person-centred coaching model that is focused on personal goals rather than clinician-centred, clinical goals. It has been received favourably by consumers and has been found to improve staff attitudes towards recovery (Australian Integrated Mental Health Initiative). Furthermore, the change in the nature of service provider relationship to utilise coaching style is seen to have more equal power differential, and is growth and approach based, rather than deficit and avoidance based^{x1}.

4.1.2.2 Peer Health Coaching

SANE Australia developed the Peer Health Coach program and partnered with Neami National to recruit and train Peer Health Coaches (PHC) in community-based support programs around Australia. The aim of the coaching program is to draw on shared lived experiences and strengths in order to address some of the impacts of poor physical health and improve health and wellbeing. The Peer Health Coach program, piloted between 2012-2015 draws on the peer workers' own experience of recovery, enabling people to set their own goals and work towards them in a practical way.

The value that peers bring to health coaching includes:

- Inspiring hope and demonstrating the possibility of recovery

- Being able to draw on their own experiences of recovery as they listen, interact and support consumers
- Empathy and connectedness. Connecting with peers who have lived with similar experiences can be a vital link for someone struggling with their own situation, and
- Being valued for their authenticity because they can relate to the challenges faced by peers.

PHC can provide support in areas where there are modifiable risk factors, such as diet and exercise and support better access to health care. In the coaching role, peers apply the principles and processes of coaching, communication skills and motivational enhancement strategies to the consumer's self-identified health goal. Three key elements that Peer Health Coaches bring include: support, coaching and self-advocacy.

A mixed method evaluation (qualitative and quantitative) found that PHC was successful at enabling consumers achieve identified health goals including^{xli}:

- Started regular exercise independently (walking, cycling and swimming) and at community venues
- Tried new exercise (e.g. yoga and swimming)
- Started cooking healthy meals independently
- Lost weight
- Requested a medication review which resulted in significant weight loss
- Reduced number of cigarettes smoked
- Went on to get a physical health plan from their GP
- Reduced smoking
- Felt confident to pursue their goals beyond coaching session.

In addition to this, consumers reported that their mental health and general wellbeing had improved as a result of PHC. Consumers felt PHC assisted with their other goals and values, such as social inclusion and connection with nature.

4.1.3 Wellness Recovery Action Plan (WRAP)

The Wellness Recovery Action Plan (WRAP®) is a self-determined prevention process designed to provide tools for individuals to better understand and manage their recovery journey. Individuals, often with support from a peer or group of peers, learn to identify issues that are intrusive or troubling and to implement coping strategies. Personal plans incorporate strategies for increasing empowerment, quality of life, and the achievement of personal goals.

Findings from local evaluations in the US and the UK refer to similar gains identified by participants, largely in the acquisition of tools for building self-awareness and skills for self-management. For many, these skills translated to a sense of empowerment from taking greater responsibility and ownership over one's wellbeing. One RCT involving WRAP showed it is associated with decreased symptoms and enhanced hope and quality of life (Cook et al. 2011; Jonikas et al. 2013 cited in *Well Together*).

4.1.4 Addressing Comorbidity: Alcohol and Other Drug Use

High prevalence of co-occurring mental health conditions and problematic alcohol and other (AOD) drug use is widely considered to be the expectation rather than the exception.

The impacts of comorbidity- on individuals, their families and society- are significant. Individuals with comorbidity face substantially higher rates of morbidity and mortality and complex clinical profiles. People with SMI face continued risk of poor treatment outcomes and illness course unless they receive appropriate care.

Trauma often underlies AOD use, in particular post-traumatic stress disorder (PTSD), which is a commonly occurring comorbidity. Studies show significantly increased rates of PTSD amongst individuals with substance use disorders (Reynolds, 2011; Schaefer, 2010), with lifetime prevalence ranging from 26% to 52% (Driessen, 2008; Reynolds, 2011). Similarly, prevalence rates of comorbid drug use among PTSD-diagnosed populations range from 19% to 35% and comorbid alcohol use from 36% to 52% (Breslau, 1992; Pietrzak, 2011).

Individuals with both disorders have been found to have a more severe clinical profile than those with a single disorder with impacts including lower general functioning, poorer wellbeing, and worse outcomes across a variety of measures. Given the complexity of presentations with co-occurring trauma and AOD use, it is important that interventions seek to target both conditions.

Evidence highlights a number of specialised psychological therapy approaches that have been developed targeting people with underlying trauma and AOD use. Three different types of treatment approach are identified in the literature (Gulliver, 2010): sequential, concurrent, and integrated.

Evidence reviews suggest some positive findings in relation to integrated and trauma-focused psychological therapies for comorbidity, although findings are based on studies with methodological limitations. Effective interventions include those based on CBT that aim to promote changes in thinking and support constructive coping strategies. These approaches have been shown to facilitate attitudinal and behaviour change by targeting belief systems underlying trauma memories, ideas about substance use and situational risk factors/triggers associated with patterns of AOD use, particularly those associated with past trauma. A Cochrane review of the evidence suggests that psychological therapy that includes a trauma-focused component alongside intervention for AOD use can help reduce symptom severity for people with comorbid PTSD and substance use disorders^{xlii}.

In Australia the health system predominantly approaches treatment of comorbidity as a single disorder sequence, with treatment delivered either sequentially or in parallel. A 2015 Evidence Review of Comorbidity Models of Care commissioned by NSW Health determined that the evidence base suggests integration of treatment and/or stepped care approaches are ideal for optimal client outcomes and to avoid clients falling through the gaps.

Integrated approaches involve combining treatments simultaneously and addressing the range of determinants from a holistic standpoint. One example of

an evidence-based model is the Integrated Dual Diagnosis Treatment (IDDT) Model. This model was developed in the US and has been adapted internationally. Features of the approach include multidisciplinary, intensive case management teams; stepped care; integration of mental health and substance use treatment; individual and group modalities; unlimited time services; assertive outreach; and access to a comprehensive array of services.

The 2015 Evidence Review established a moderate-good level of evidence to support the effectiveness of this approach with the program being associated with a range of positive outcomes including significant reductions in AOD use, hospitalisations, recidivism in the criminal justice system, homelessness, and improvement in symptom severity and overall life functioning (Mueser, 1997).

Similarly, the US Comprehensive, Continuous, Integrated System of Care (CCISC) Model (Minkoff and Cline, 2004) includes residential treatment, medical care, counselling, psychiatric/psychological evaluation, recreational and vocational services, as well as comprehensive discharge planning and assertive community management. Evaluations of the program have demonstrated statistically significant improvements in a number of domains for people with comorbidity. Participants experience improvements in housing status, employment, frequency of substance use and mental health (Harrison et al, 2008; Minkoff 2004)^{xliii}.

Despite widespread recognition of the challenges associated with co-occurring mental illness and AOD use, the system of care in Australia still relies heavily on diagnostic approaches. Improving availability of integrated models of care, particularly those with interventions addressing trauma, may improve prognoses for this population.

4.1.4.1 Smoking

Available evidence supports a strong association between mental illness and smoking with smoking rates among people with SMI consistently reported to be high. Findings from an analysis of the 2010 Australian Survey of Psychosis concurred with the literature, suggesting people who are lonely or socially isolated are more likely to smoke and have other poor health behaviours (DeWall and Pond, 2011)^{xliv}.

From the 2007 Survey of Mental Health and Well Being, the ABS estimated that of those adults with a mental illness, 36.2 per cent were current smokers –almost double the smoking prevalence among adults with no mental illness. People with mental illness represented 32.4% of current smokers.

Whilst smoking rates may be high among people with SMI, the literature suggests that the majority of smokers with mental illness may not be receiving appropriate interventions for their smoking. This relates to a number of factors including that some were not in contact with mental health services; mental health services did not offer targeted smoking cessation programs or referrals to such services. A critical point, highlighted by Lawrance et al (2009) suggests that existing population health efforts outside of the clinical system have not been tailored for people with mental illness and thus may not be relevant or effective^{xlv}, suggesting that further research into more effective and targeted smoking cessation strategies may be required.

4.1.5 Lifestyle Interventions:

The available evidence consistently supports the value of holistic lifestyle interventions and physical activity as a means of both reducing modifiable morbidity and mortality risk factors and improving personal wellbeing outcomes. Addressing preventable lifestyle contributors and removing barriers to maintaining a healthy lifestyle can help to improve overall wellness, functioning and participation. For some individuals with SMI, barriers include lack of awareness of the need to change or limited knowledge and skills required to make lifestyle changes. These, along with a range of other variables including socioeconomic factors, cognitive functioning, medication and access to appropriate support, can be moderated through targeted programs and interventions to improve an individual's overall wellbeing.

Systematic reviews on lifestyle interventions in different populations indicate that, to be effective, a lifestyle intervention should be holistic and contain at least three key components: physical activity, diet and behavioural therapy^{xlvi}. Behavioural therapy strategies that enhance individual behavioural change include building self-management skills targeting particular individual lifestyle areas for improvement, enhancing knowledge, goal setting and practical positive behaviour change strategies. This could include motivational approaches, such as motivational interviewing, CBT and engagement of peer coaches, peer support and/or family support in assisting with goal achievement^{xlvii}.

An Australian evaluation (Curtis et al, 2015)^{xlviii} of a lifestyle intervention offered to young people experiencing their first episode of psychosis has found that weight gain and its health consequences can be prevented or ameliorated. The coaching based program includes dietetic support and a supervised exercise regime and is delivered by a multidisciplinary team including a clinical nurse consultant, a dietician, an exercise physiologist and youth peer wellness coaches.

A New Zealand study has found that combining psychoeducation and nutrition and/or exercise counselling appears to be a cost-effective way to help people with first-episode psychosis to manage their weight (Knapp et al., 2011). Furthermore, a number of clinicians working with young people experiencing their first episode of psychosis have argued that exercise and lifestyle interventions could provide an opportunity to alter the trajectory towards cardiovascular disease and type 2 diabetes (Eapen et al., 2012, Shiers et al 2014b)^{xlix}.

The 2016 evidence review by Hayes et al examined a number of holistic lifestyle intervention types including physical therapy and exercise, diet and nutrition, smoking cessation and weight loss. Although much of the analysis indicated heterogeneity of methods and outcome measures, along with small sample sizes thereby limiting conclusions, there were a number of studies that demonstrated positive outcomes in terms of the mental and physical health benefits of lifestyle interventions.

Overall, the authors concluded that whilst many physical health interventions are likely to be provided by the Health system, the NDIS could offer support for physical health and fitness, as appropriate options for early intervention.

Physical Activity Despite the well-established health benefits of physically active lifestyles, people experiencing mental illness are less likely to engage in physical activity compared to the general population. Coupled with high rates of smoking and poor dietary habits, physical inactivity is a key modifiable risk factor that contributes to the premature mortality observed within this population^l.

Multiple systematic reviews and meta-analyses have identified the positive effects of physical activity across a broad range of disorders, including depression, anxiety, PTSD, schizophrenia and bipolar disorders and comorbid conditions such as problematic AOD use (Gorczyński, 2010; Cooney, 2013; Jayakody et al, 2013).

A 2014 meta-analysis of physical activity interventions concluded that physical activity interventions reduce the symptoms of depression regardless of psychiatric diagnoses. The authors conclude that physical activity improves quality of life and, based on the available evidence, recommend that clinicians refer patients to physical activity interventions to improve both mental and physical health outcomes^{li}.

Vancampfort et al. (2012) found evidence in a systematic review of ten RCTs to suggest that aerobic and strength exercises, as well as yoga, alleviated psychiatric symptoms and improved health related quality of life^{lii}.

The findings of the benefits of exercise and physical activity are also relevant to adults who may have long-standing mental illness. Validated healthy lifestyle programs appear to be cost effective as a means of managing body mass index in people who have been living with schizophrenia for longer^{liii}.

Integrating exercise into clinical and community based programs is gradually becoming more common, with services employing exercise physiologists and physiotherapists. In an editorial in the American Journal of Psychiatry, Bartels (2015) asserted that “It is safe to conclude that behavioural interventions for obesity in people with serious mental illness should be considered an evidence based practice” and furthermore that “the greatest current barrier to increasing the life expectancy of persons with serious mental illness is no longer a knowledge gap it is an implementation gap.”

4.1.5.1 Nutrition

Nutrition is strongly associated with overall wellness, particularly mental and physical health and cognitive functioning. Brophy et al (2015) highlight the strong association between food, diet, nutrition and physical health, with consumers expressing the importance of being well nourished and eating well.

The barriers to achieving good nutrition include lack of nutritional knowledge and skills, financial, anxiety about leaving the house to go shopping, and a general lack of motivation. These can be addressed through multidimensional approaches, including psychoeducation and psychosocial interventions. Many individuals with SMI do not have sufficient understanding of the components of a healthy diet. Dietician delivered support or psychoeducation and nutrition education- targeting both individuals with SMI and their family and support network- can assist in improving awareness and maintenance of good nutrition.

In a 2017 systematic review and meta-analysis examined the physical health impacts of nutrition interventions on people with severe mental illness. The review included a range of interventions including individualised nutrition counselling, group nutrition education, shopping and cooking classes. Findings indicated interventions focussing on nutrition resulted in positive outcomes on physical health including reduction in weight and body mass index and prevention of weight gain following initiation of psychiatric medication^{liv}. Given the known impacts of obesity and weight gain on overall mortality and morbidity, reductions in body mass index can result in positive health outcomes.

4.1.5.2 Sleep

The issue of sleep has been identified both in the literature and among consumers as something that is impacted by, and influences mental illness, in turn affecting physical health and overall wellbeing.

Evidence suggests that sleep disturbances are complex and highly prevalent among people with severe mental illness. It is a common symptom of multiple diagnoses, with impacts on symptom severity, treatment outcomes, cognitive, emotional, and interpersonal functioning and overall quality of life^{lv}

Sleep problems, including insomnia and poor quality sleep are particularly prevalent and pervasive among people with schizophrenia and other disorders with symptoms of delusion, paranoia, psychosis or hallucination. In turn, sleep disturbance can exacerbate experiences of symptoms of mental illness. Despite this, there is limited research on effective treatment approaches for sleep problems among people with mental illness.

Cognitive behavioural therapy (CBT) has been shown to be highly effective for treatment of insomnia (Harvey et al, 2104) and is considered by many as the recommended treatment for this disorder (Morin, 2012), A RCT published in 2015 examined the benefits of using CBT as a treatment for insomnia in patients with current psychotic experiences. The study found that CBT is likely to be beneficial for reducing insomnia in individuals with schizophrenia, with the potential for reducing symptoms of psychosis^{lvi}. Additionally, given the potential for sleep disturbance to impede participation in treatment, treating sleep disturbance among people with mental illness has also been found to be enhance treatment outcomes more broadly^{lvii}

4.1.6 Wellness and Health Promotion Interventions

Hayes et al cite a pilot study of an individually tailored health promotion program undertaken by Van Citters et al. (2010). The program 'In SHAPE' sought to ascertain the effect participation had on physical activity, dietary behaviour health indicators and psychological functioning on 76 adults diagnosed with a range of serious mental illnesses.

In SHAPE promotes "access to community based health and fitness services, recognises the potential for wellness, encourages active participation in health promotion activities and health education, and acknowledges the need for services that are tailored to the individual's personal health goals, needs, and readiness to change" (Van Citters 2010, p4).

Participants demonstrated increased physical activity with a trend towards reduced caloric intake. Although there was no significant change in BMI, positive outcomes included a reduction in negative symptoms of mental ill-health and in waist circumference, in addition to satisfaction with mental health functioning and fitness.

4.1.6.1 Mindfulness

Mindfulness has been described as the self-regulation of attention to focus on the present-moment experience with openness and acceptance (Bishop et al., 2004). Mindfulness-based interventions (MBI) are thus assumed to decrease distress through processes designed to facilitate awareness and acceptance of the present moment (Williams, 2010). Outcome research on mindfulness for psychosis has been limited to date, primarily related to concerns that traditional meditation sometimes being either too difficult or even harmful to this client group (Chadwick, 2014)^{lviii}.

In a review of mindfulness treatments for severe mental illness (including psychosis), Davis and Kurzban (2012) concluded that “mindfulness-based interventions may be uniquely suited to impact distress related to symptoms and internalized stigma that are particularly salient for individuals living in the community with severe mental illness who are susceptible to experiences of social rejection and interpersonal stress”^{lix}.

Implementing mindfulness based treatments (MBT) for psychosis is a growing area, with a range of approaches being applied meditation practices, acceptance based protocols, and compassion based approaches. Such approaches have significant potential for regulating emotion, (Thompson, 1991, 1994; Gross, 2007; Koole, 2009; Hofmann et al., 2012) and improving cognitive handling of emotionally arousing information. Furthermore, compassion activates the self-soothing system, increasing positive emotions such as hope, optimism, warmth, contentment, love, and kindness, and decreasing negative emotions such as shame, fear, and helplessness (Trémeau, 2006).

A 2013 meta-analysis found feasibility and effectiveness of mindfulness interventions for individuals with psychotic disorders. Specific positive outcomes included treating negative symptoms, improved functionality and quality of life^{lx}.

MBT have also been shown to reduce depression, anxiety and physical distress in people with physical illnesses in general. A 2014 randomised control trial demonstrated that Mindfulness Based Cognitive Therapy (MBCT) has the potential not only to reduce psychological distress, but also to improve emotional, psychological, and social wellbeing.^{lxi}

4.1.6.2 Yoga

Yoga is widely associated with a range of mind and body benefits. The practice of yoga can help to reduce the impact of experiences such as anxiety and depression, or other mental health symptoms by modulating the physiological response. Individuals with mental illness can potentially learn valuable skills for self-awareness and self-soothing. Yoga has been demonstrated to be effective as

a complementary or adjunct intervention for a number of mental health conditions including major depression, anxiety disorders, schizophrenia and obsessive-compulsive disorders (Kirkwood et al, 2005; Duraiswamy, 2007; Sared, 2010)^{lxii}

A 2013 systematic review examined the published literature on benefits of yoga for several major psychiatric illnesses including depression, schizophrenia, ADHD and cognitive disorders. The reviewers found that the evidence supports potential acute benefit for yoga in depression and as an adjunct to medications in Schizophrenia, ADHD and sleep complaints. Reported outcomes included significant reductions in anxiety, increased cortisol, reduction in symptoms, reduced levels of aggression and improved medication compliance^{lxiii}.

Yoga has been frequently examined for its potential in alleviating symptoms and improving quality of life for patients with schizophrenia given that many of these patients suffer from persistent symptoms and relapses, particularly when they fail to adhere to prescribed medications.

A systematic review (2012) aimed to assess the effectiveness of yoga as a complementary treatment on general psychopathology, positive and negative symptoms and health-related quality of life (HRQL) for people with schizophrenia. Although the number of RCTs included in the review was limited, results indicated that yoga could be an effective strategy for reducing general psychopathology and positive and negative symptoms as well as improving quality of life for patients with stabilised antipsychotics^{lxiv}.

4.1.6.3 Arts Therapies

'Arts therapies' is an umbrella term used to describe a range of artistic experiences, including art, music, dance and drama, used as part of therapeutic models of care for a range of conditions, including mental illness.

In the area of mental illness, the aim of artistic therapies is to help individuals improve their emotional, cognitive and relational competencies, and to address issues they may not be able to communicate using words alone.

4.1.6.3.1 Art therapy

Art therapy is a form of psychological therapy involving using art-making processes as a form of non-verbal expression, in conjunction with other modes of therapeutic communication. Use of art can be particularly helpful to people who find it hard to express their thoughts and feelings verbally.

Although studies are limited, evidence indicates that use of art therapy is an acceptable intervention for participants, emphasising the importance of expression, that can improve outcomes for individuals with mental illness, including^{lxv}:

- Reduction in depression, anxiety, symptoms of trauma and distress.
- Improvements in mood, self-esteem and overall quality of life.
- Improvements in coping resources and cognitive function.
- Improved relationships with family, carers and friends.

4.1.6.3.2 Music therapy

Music therapy is a systematic intervention that uses music experiences and the relationships that develop through these to promote health. Approaches in music therapy for people with mental illness vary in terms of modality including active production by an individual and receptive listening to music. Listening can be to music played by a therapist or can be pre-recorded. The type of musical interaction, level of structure and amount of verbal discussion may vary depending on therapist's approach, client characteristics and diagnosis. Interventions can be delivered in both group and individual contexts^{lxvi}.

Studies have examined the effects of music therapy for people with severe mental disorders such as schizophrenia, with the following outcomes identified^{lxvii}^{lxviii}:

- Significant results for mental state including positive symptoms, negative symptoms, depression and anxiety.
- The effects of music therapy increase over time and with frequency.
- Positive impacts on general and cognitive functioning.
- Increased interpersonal functioning, including in terms of relational behaviours, social activities and roles.

4.1.7 Recovery Colleges or Recovery Education Programs

Recovery colleges or recovery education programs offer education and training programs for people with mental illness, their family and carers as well as others who may be interested. The strengths based training aims to promote recovery and reintegration and is developed and delivered by people with lived experience of mental health concerns and health professionals.

Recovery colleges assist people with lived experience of mental health concerns to become experts in their self-care, to make informed choices and fulfil their ambitions through educational opportunities. It enables

Courses offered contain a combination of knowledge and practical skills development about recovery, self-care and self-management. According to Slade et al (2014), there is robust supporting evidence for the role that recovery colleges play in improving outcomes resulting from education and skills gained, including illness management^{lxix}. Research has also demonstrated the value of these colleges in moving people with SMI towards a sense of hope and wellbeing as they learn how to better navigate their journey through recovery^{lxx}.

4.1.7.1 Mind Recovery College™

Established in 2013, the Mind Recovery College was the first recovery college in Australia. The College operates on a co-production and consumer empowerment approach meaning that people with lived experience of mental illness are involved in all aspects of the College's operation, including the design and delivery of courses. The premise of the College is recognition of the valuable knowledge and skills that can be gained from first-hand experience of mental ill-health and that learning can aid people to recover a life they value.

The College enables individuals and family carers choice and control to better manage the impacts of mental illness, improve social and economic participation and to help others to do the same. The model fosters innovation and promotes the use of recovery oriented practice across and beyond the mental health system.

The College offers over 50 different courses across 7 campuses. The majority of these are run by people with lived experience of mental ill-health (46 per cent have personal experience and 11 per cent are carers or family). The model also includes people with professional expertise in mental health and education.

An early outcomes evaluation published in 2016 found that there is strong evidence that the Mind Recovery College™ is delivering positive in terms of recovery oriented education and experiences for students, staff, families, carers and community stakeholders. Some of the outcomes identified included direct educational benefits and skill acquisition, increased confidence, feelings of connection and community and social integration. Importantly, the impacts discussed by students demonstrate an improvement across settings including the achievement of educational qualifications, employment, self-care, and social engagement within the community^{lxxi}.

Some of the specific benefits of the College's co-production approach include:

- Tailored and valuable courses and other learning opportunities, catering to the needs and abilities of a broad range of people;
- Use of narrative techniques as an effective tool;
- Increasing personal learning and sense of self-worth by helping others;
- An alternative space, outside of the therapeutic environment, for conversation about mental health topics and issues between people with mental ill-health, family, carers, health professionals and a variety of other community members.

4.1.8 Assistive Technology

Assistive technology (AT) can be used as an innovative way to provide support for individuals with mental health issues. Although the evidence base is very limited, it appears that use of AT is an emerging approach in the mental health field. Use of AT can provide both functional and emotional support and has been associated with improvements in a range of outcome domains, including overall quality of life, self-management and occupational performance.

AT has the advantage of reaching at-risk individuals at any time or place without relying on service providers. It can also provide opportunity for building relationships and social engagement via use of social platforms or applications that have an interactive component.

A 2015 review of emerging technologies looked at 4 categories of interventions where assistive technology proved to be of benefit for people with mental illness^{lxxii}:

Illness self-management and relapse prevention: interventions explored included home messaging devices, online programs and technology aided relapse prevention. Positive outcomes were associated with use of these

technologies including decreased hospital admissions and emergency room visits (Godleski et al, 2012), and reductions in severity of symptoms.

Promoting adherence to medications and/or treatment: interventions examined included use of sensors, SMS reminders, wearable devices and online programs. Improvements were noted in medication and treatment adherence for people using technology. Other benefits included reduction in symptoms, hospital attendance and mood improvements.

Psychoeducation, supporting recovery, and promoting health and wellness: interventions described included web based support programs targeting risk factors for relapse, peer support, online social networking, and expert moderation. Other programs included wearable activity monitoring devices, web based psychoeducation and automated messaging. Findings indicated significant reduction in symptoms, including depression and anxiety, improved perception of control and overall improvements in quality of life.

Symptom monitoring: technologies included SMS, online programs, smartphone applications and automated internet based programs. Improvements were observed in symptom management but most of the findings related to acceptability and usability, both of which were found to be positive.

Examples of ways in which technology can assist people with SMI include:

- Digital hand held devices: smart phones, wearable technologies such as watches, tablets, computers, sound machines, video conferencing, social networking and sleep aids.
- Online applications, or built-in accessibility software, text Reader, colour options and voice guides.
- Low tech: ear buds, Note Pads, Service or Assistance Animals (described elsewhere in this paper).

These can all be used to track emotions or guide lifestyle changes and assist individuals to remain productive, increase independence and social and economic participation. Other functional and occupational benefits described in the literature include cognitive support, task management, skills training and monitoring of risk behaviours. Occupational therapy professionals have been incorporating AT in interventions that promote performance in activities of daily living (ADL), education, work, play, leisure, rest and sleep, and social participation.

It is likely that there is significant underutilization of AT for people with SMI. Reasons for this which are identified in the literature include: lack of awareness of, or knowledge related to use of AT approaches, lack of funding, and lack of education regarding application of AT in programs (Kaye et al., 2008; Long et al., 2007; Polgar, 2002).^{lxxiii}

Although there may be some barriers to use of AT, such as cognitive functioning, social challenges or socioeconomic disadvantage, many technology-based interventions are specifically developed for people with SMI. This is achieved by incorporating simple visual interfaces, using familiar phrasing and content

presented at a low reading level, and avoiding tasks requiring abstract reasoning (Ben Zeev, Kaiser et al, 2013).

4.2 Eligible NDIS support

Currently the NDIS support category of Capacity Building includes supports relating to health listed as: *improved health and wellbeing*. There are five relevant activities, including:

- Individual advice to a participant on managing diet for health and wellbeing due to the impact of their disability (both individual and group based)
- Advice to a participant regarding exercise required due to the impact of their disability (individual and group based)
- Personal training provided to a participant required due to the impact of their disability

5 Economic Security

Finding agency, self-determination and meaningfully participating in society are important personal recovery outcomes. Achieving some degree of economic security can be an empowering step towards these outcomes and life goals. The literature clusters three inter-related categories into economic security, including:

- Training, education and skills development
- Work and employment (including voluntary)
- Financial stability or money.

For people with psychosocial disability there may be a number of significant barriers to accessing these opportunities including: age, capacity and cognition stigma and discrimination, and the cost of education and training. Introducing measures to minimise or remove some of these barriers alongside supports that encourage participation in these activities can go a long way toward improving vocational opportunities for people with severe mental illness.

5.1 Interventions supported by the evidence

Well Together (2016) makes reference to the ‘capabilities theory’ and the importance of enabling support for individuals to develop the capabilities necessary for them to achieve their goals. The theory asks: “Does the individual possess the personal ability, resources, practical means and knowledge required to achieve his or her goals as well as the external circumstances (in the social, economic, and physical environment) to make this possible?” (Burkhardt, 2004)

Building capabilities of individuals with SMI to enable meaningful and productive economic participation has considerable demonstrated benefits.

5.1.1 Supported Employment

People with SMI face much greater challenges gaining and maintaining employment due to a range of factors including educational disadvantage,

stigmatising views in the workplace, and the chronic or recurrent nature of their mental health symptoms. Despite this, many people with SMI indicate a preference to work, albeit sometimes with support. Participation in employment can reap significant benefits for individuals with SMI including improved self-esteem, hope, greater wellbeing, greater social connection and independence, and reduced use of community mental health services.

Supported employment is a structured approach that emphasises rapidly placing an individual into competitive employment and simultaneously providing them with support to maintain this employment. Supported employment has been developed as an alternative approach to traditional pre-vocational rehabilitation models that involves a gradual introduction into workplace.

Individual placement and support (IPS) is a structured and manualised form of supported employment. The key principles behind IPS are the integration of vocational and clinical services to immediately support an individual to succeed in competitive employment of their choosing. Introduction of this support is not reliant on the absence of symptoms to minimise time spent away from a workplace.

There is strong evidence to support the efficacy of supported employment in achieving personal goals and recovery outcomes for people with severe mental illness. There have been randomised trials and reviews demonstrating that IPS is effective in achieving competitive employment for individuals with severe mental illness in the USA (Drake et al, 2012). Two separate Cochrane reviews have provided evidence for IPS increasing rates of employment, (Crowther et al, 2001; Kinoshita et al, 2013) with benefits including job stability, hours worked per week and wages, and decreased healthcare costs for successful users.^{lxxiv}

A 2016 systematic review and meta-analysis sought to determine whether IPS is effective in improving competitive employment rates for people with severe mental illness in different countries with varying health services and economic conditions. Results indicated that IPS was effective in gaining competitive employment for people with SMI in a wide range of settings, with participants more than twice as likely to gain competitive employment as those undergoing traditional vocational rehabilitation. Furthermore, the benefits of IPS can be demonstrated in a wide range of international settings and remained stable across a 2-year period. The authors concluded that IPS is more effective than traditional models of vocational rehabilitation or pre-vocational training regardless of the prevailing cultural or economic conditions.^{lxxv}

The review identified one of the key organisational issues as being the physical and organisational separation between disability employment and mental health services. The success of supported employment would be hindered without some integration between those responsible for coordination of clinical care and those directly involved in job search and occupational support.

Some common components of effective supported employment approaches have been considered predictive of positive employment outcomes, including^{lxxvi}:

- The agency providing supported employment services is committed to competitive employment as an attainable goal for its clients with severe mental illness (Drake et al, 1999; Becker et al, 2001)
- Supported employment programs use a rapid job search rather than providing lengthy pre-employment assessment, training, and counselling (Bond et al, 1995; Mueser, 2000)
- Staff and clients find individualised job placements according to client preferences, strengths, and work experiences (Abrams, 1997; Becker et al, 1996; Mueser, 2001).
- Follow-along supports are maintained indefinitely.
- The supported employment program is closely integrated with the mental health treatment team.

5.1.2 Training and Skills Development

Training and skills development across a variety of domains was frequently referred to in previous literature reviews and related NDIS documents. In the context of economic participation, training and skills development appears to apply to budgeting and skills development for employment. Despite the noted support for the inclusion of such approaches, there was little to no discussion of specific interventions supported by the evidence, aside from minor discussion within the context of supported education and supported employment. There is, however, some correlation between psychoeducation, cognitive and social skills development which are discussed elsewhere in this document.

Traditionally, training and skills development was associated with conventional vocational rehabilitation or pre-vocational training that involved training and skills development to prepare participants for the workforce. Job placement occurs at the conclusion of the training phase. Whilst this approach may still be applied on occasion, the evidence base is stronger for supported employment approaches.

5.1.3 Supported Education and Psychosocial Rehabilitation

Consumers commonly identify education as a critical tool to enable them in recovering hope, self-determination and engaging in meaningful activity.

Psychosocial rehabilitation assists adults with psychosocial disabilities to progress in their recovery through strategies and programmes that support their goals in employment, housing and other aspects of community functioning (Corrigan, 2003; Corrigan et al., 2008; Killackey et al., 2015). Despite the orientation of services towards recovery, evidence-based rehabilitation practices can be used to promote recovery-oriented care by assisting individuals to manage, overcome or live with their mental illness and lead full lives in the community (Davidson et al., 2006; Killackey et al., 2015; Mueser, 2012)^{lxxvii}.

Supported Education (SEd), a form of psychosocial rehabilitation, is comparable to supported employment for education, with rapid placement of a person into a chosen training or study opportunity with the provision of ongoing support.

Successful implementation is dependent on collaboration across systems, with consumers at the centre.

SEd arose in response to requests from consumers and family members for assistance with the process of working towards higher education goals and acquire the tools necessary for achievement in a range of education settings.

Research on a variety of SEd models provides strong evidence of effectiveness including gaining access to and completing postsecondary education, success in competitive employment, increased self-esteem and social adjustment and reduction in hospitalisations^{lxxviii}.

In a review of evidence based practice for supported education strategies, Leonard and Bruer (2007) assessed a number of different approaches to supported education and made the following observations^{lxxix}:

- Community integration approaches based on campus resulted in significant increases in employment, educational status and self-esteem; and significant decreases in hospitalisation rates for people with stabilised illness. This approach enabled students with psychiatric disabilities to begin to define themselves as students rather than patients (Unger et al, 1991).
- Supported education in a hospital setting, operating as a partnership between the hospitals and community colleges successfully engage patients who have not previously been considered appropriate for the classroom. The participants are offered a broad range of subjects and have been observed to be “cogent, focussed and student-like in the classroom” (Gilmur, 1997)

The authors recommended a number of principles associated with positive outcomes from supported education, namely:

- Match intervention to individual cognition, ability and preference;
- Integrate into mainstream education wherever possible;
- Explore partnership approaches, particularly for people in institutional settings;
- Employment role development is more efficacious than pre-vocational training.

5.2 Eligible NDIS support

Currently the NDIS support category of Capacity Building includes relevant supports relating to economic security listed as:

Assistive technology: this category includes one relevant item:

- Assistance animals: assistance dog (including guide dog) (Note this item also appears in the *assistance with daily life* category)

Finding and keeping a job: there are a number of relevant support items within this category including:

- Employment related assessment and counselling
- Assistance in specialised supported employment

- Individual employment support
- Employment preparation and support in a group
- Supported employment start-up fee
- Support in employment
- School leaver employment supports
- In a group setting, build capacity by providing skills training such as transport, time/financial management, self-care to support a participant to get a job post school.

Improved learning: there is currently one support item within this category:

- Provision of skills training, advice, assistance with arrangements, orientation to assist a person with disability moving from school to further education

6 Social Connection

Loneliness and social isolation are consistently associated with people with severe mental illness, and is highly prevalent among people with psychotic illness. The 2010 Australian national survey of psychotic disorders, the Survey of High Impact Psychosis (SHIP), found that 68.8% of participants had not engaged in any social activities in the previous year, citing experience and fear of stigma, social anxiety and mental illness as barriers to their participation^{lxxx}.

One study examining the implications of the findings of the SHIP exposed that people living with psychoses with very restricted socialising experience were less likely to receive NGO support services in addition to mental health services. The same study highlighted associated risk factors for people who are lonely or socially isolated, with a higher likelihood of smoking and other poor health behaviours (DeWall and Pond, 2011)^{lxxxi}.

The consequences of social isolation and impaired social functioning extend across a range of clinical and recovery domains. These impacts highlight the need for specific interventions that focus on building social skills and facilitating greater clinical, social and recreational participation. Supporting an individual to improve their social skills and develop a meaningful connection with themselves and community can build a sense of self and engender hope.

6.1 Interventions supported by the evidence

A report commissioned by Wellways Australia, *Well Together* contained significant discussion regarding the fundamentals of community inclusion. Of note is the importance of having the option of genuine community based activity, not just offerings within institutional settings.

The report provided examples of mainstream community based activities including job training programs, competitive employment, enrolment in degree-earning programs, bingo at a church or community centre, gym membership, joining a hobby club or citizen action group on one's own or with a friend. Caution was offered in too much reliance on 'substitute' or 'approximated' experiences and the potentially 'overly warm embrace of mental health systems' (Baron, 2008).^{lxxxii}

Given that people experiencing social isolation are less likely to actively engage with NGO support services or participate in mainstream community activities, it is likely that assistance will be required through some of the previously discussed capacity enablers such as peer support or assertive outreach. Once a person is engaged, there are also targeted cognitive and skills based supports that could improve social connection, participation and reduce marginalisation.

6.1.1 Social Skills Training

Social skills training involves the development of skills to assist people with psychosocial disability deal with everyday social situations and daily living. Enabling individuals to learn these behavioural skills can greatly assist in building social relationships, reducing loneliness and isolation and improving both social and economic participation.

Social skills training aim to improve interpersonal abilities by creating scenarios that are generalizable to everyday life. Social interactions may be broken down into discrete steps and using role modelling, simulated role plays, behavioural rehearsal, corrective feedback, and homework assignments to practice new skills (Bellack et al. 2013; Mueser et al. 2013, cited in *Well Together*).

The 2014 NDIS Literature Review (commissioned by Mind) cites an evidence review of more than 100 studies of various skill building interventions, including social skills training, which concluded that the level of evidence for the effects of skills building overall is 'high'. Positive outcomes were noted for social and daily living skills including improved behavioural skills, improved social role functioning, improved self-efficacy and moderate effects on social and daily living skills and community functioning (Lyman et al, 2014).

The discussion of social skills training within the 2016 Evidence Review by Hayes et al demonstrates a strong evidence base supporting the value of this approach in improving social functioning and quality of life. Several meta-analyses and RCTs were cited with the following notable findings:

- A Cochrane meta-analysis (Almerie et al. 2015) of 13 RCTs (975 participants) showed improved social functioning, reduced relapse rates and improved mental state and quality of life compared with standard care.
- Another meta-analysis of 27 studies showed that undertaking social skills programs is useful for people with persistent mental health conditions (Heinssen et al. 2000).
- Effectiveness of skills training can be improved if it is performed in-situ and within familiar environments (Heinssen et al. 2000).
- In a meta-analysis of high-quality trials for structured behavioural training, Kurtz and Mueser (2008) found improvements in social cognition outcomes, including community participation and management of symptoms.
- In a summary of all meta-analyses that were published between 1990 and 2005, Pfammatter et al. (2006) found that Social Skills Training has a significant, consistent and enduring impact on the improvement in social

skills for people living with SMI. This benefit extended to social functioning as well as improvements in clinical recovery outcomes.

6.1.2 Social Cognition Training

Cognitive functioning impacts an individual's ability to participate in many different activities including vocational activities, daily living and interpersonal relationships. Similar to social skills training, social cognition training seeks to improve social functioning for people with SMI by intervening at the level of thinking, perceiving and interpreting the social world.

6.1.2.1 Cognitive Remediation

Cognitive remediation is comprised on behavioural interventions that aim to teach individuals enhancement of key cognitive skills such as attention, memory, language, and problem solving. Cognitive Remediation (CR) is often used to improve functioning and manage cognitive impairment that is commonly associated with serious mental illnesses, particularly schizophrenia and bipolar disorder.

Cognitive remediation has been found to be a useful approach for self-management and skills building, which, in the context of a recovery framework, can have benefits for managing uncontrolled symptoms, coping with everyday situations, finding employment and psychosocial skills and thinking.

Given the frequency of cognitive impairment among individuals with serious mental illness, a growing number of studies have explored the use of CR approaches to build capacity and improve functioning. CR approaches range from computer-assisted, group based programs to one-one administration and utilise a range of constructive cognitive skills training techniques. Over 40 RCTs to date support the efficacy of this intervention (Wykes et al, 2011) thus the evidence base is considered to be high.^{lxxxiii}

Given the strong association between impairment in attention, memory, reasoning, problem solving and social cognition with participation in a range of functional domains, Hayes et al (2016) explore the evidence for improving outcomes^{lxxxiv}:

- Cognitive interventions can support access to and participation in employment (Tan 2009).
- Several reviews highlight the potential improvements in a range of functional outcomes across a number of diagnoses including social functioning, employment and management of symptoms (Medalia & Saperstein 2013; Pfammatter et al. 2006; Chan et al, 2015).
- Although a clinical intervention, findings support the potential benefit of CR as a capacity-building support.

6.1.3 Human Occupation

Occupational therapists work with individuals to promote health and wellbeing through occupation. The approaches used aim to enable clients to experience empowerment, self-discovery, and greater means of expression within a

supportive environment. Interventions used by occupational therapists are based on areas of human occupation including activities of daily living (ADL), work and leisure.

Evidence indicates that the use of occupations that provide space for healing, self-rediscovery, identity formation, and participation in the wider community, delivered by occupational therapists is favoured by clients over short psychological-based interventions focused on case management and the assessment of mental stability, which are experienced as restricted, unhelpful, or superficial in scope.

Examples of interventions that have been found to result in positive recovery outcomes (cited in Wimpenny et al, 2014)^{lxxxv}:

- Creative activity such as art or craft: was valued by clients as an important means of expression; providing meaning and purpose, develop agency and instil hope (Lloyed et al, 2007; Griffiths, 2008)
- Vocational rehabilitation: viewed by clients as supporting transition to a new and improved place (Imman et al, 2007) particularly when delivered in a supportive and non-judgmental manner (Heard et al, 2001).
- Physical activities: clients noted that it is important that they be delivered in a manner that is respectful of individual values and interests and performance capacity (Cole, 2010).

A Canadian model of occupational therapy called 'Do Live Well' is based on the fundamental message is that "what you do every day matters" to health and wellbeing. The model aims to capture "meaningful dimensions of experience" and encompasses a broad range of occupations, including physical, mental, social, cognitive, and productive activities.

Whilst there have not been any known program evaluations, the holistic framework has strong empirical foundations. There are four main sections in the framework that are designed to improve health and wellbeing outcomes:

- Eight dimensions of experience: related to health and wellbeing that are linked to meaningful participation in diverse occupations and everyday experiences. Examples include connecting with others, activating body, mind and senses; self-care such as yoga, meditation, being in nature.
- Activity patterns: five key concepts related to characteristics of activity patterns that shape optimal health and wellbeing.
- Health and wellbeing outcomes: moving beyond illness and disability to a range of health and wellness outcomes that consider not only physical and mental health but social, emotional, and spiritual well-being
- Forces influencing activity engagement: determinants of participation.

6.1.4 Life Coaching

One of the specific mental health support items recommended by the NDIS IAC for inclusion on the support items list was life coaching. Life coaching is an

emerging approach, derived from across multiple disciplines, to improve lifestyle behaviours.

Life coaching involves working with an individual to facilitate the attainment of self-identified goals. Coaching can be delivered in person both individually or within a group, by telephone or online. The approach incorporates a range of cognitive, emotional, and behavioural change strategies to challenge any distortions in thinking and enable the participant to learn alternative ways to help them achieve their goals. Life coaching tends to ascribe to strengths based, positive approaches rather than being illness or deficit oriented.

As a relatively emergent area, the evidence base for life coaching is limited. One systematic literature review sought to examine published studies describing coaching interventions designed to improve health behaviour, patient self-care, and/or health outcomes. Only a limited number of trials were identified through the review with wide variation in life coaching process thus the reviewers were only able to present tendencies for patient outcomes and a preliminary description of an effective life coaching intervention. Notable observations included promising qualitative and quantitative results in terms of objective health outcomes and overall wellbeing. In terms of recovery goals, participants showed improvements in illness management, resilience, goal attainment, self-reported adherence, and improved health status and self-esteem^{lxxxvi}.

6.1.5 Assistance Animals

Animal-Assisted Intervention (AAI) is broadly defined as any intervention that includes a trained animal as part of the process. Whilst there are numerous definitions associated with AAI, there are three distinct components, including:

- Animal Assisted Therapy (AAT): AAT is a goal-directed intervention in which an animal that meets specific criteria is an integral part of a therapeutic process. AAT is directed and/or delivered by suitably qualified professionals.
- Animal Assisted Activity (AAA): AAA provides opportunities for motivational, educational, recreational, and/or therapeutic benefits aiming to enhance quality of life. AAAs are not specifically goal oriented and can delivered in a variety of environments^{lxxxvii}.
- Service or Assistance animals: involves the provision of animals to assist with specific tasks related to activities of daily living. Dogs and cats are most commonly used in service settings however a range of animals are utilised for AAI.

The use of AAI has been associated with positive outcomes including increased social interaction, reduction in symptoms and increased emotional wellbeing such as reduced anxiety and fear in people with a range of conditions, including mental illness. There is still a relatively limited evidence base around the effectiveness of AAI for people with serious mental illness, thus findings need to be interpreted with some caution. Some of the specific benefits attributed to the presence of animals includes^{lxxxviii}:

- Reduction in anxiety and arousal: evidence suggests that the presence of certain animals can produce calming effects in some contexts.
- Social mediation: studies show that animals can increase positive social interactions, including in clinical context.
- Attachment figure and transitional object: the bond that an individual can form with an animal is important in the context of unconditional positive regard (Allen, 2000); whereas the transitional impact can be beneficial by offering a diversion or comfort in certain situations.

One of the most commonly targeted populations for animal assisted therapy is for individuals who have experienced trauma, including those with posttraumatic stress disorder (PTSD). (Tedeschi et al, 2010). In a systematic review of the use of AAI for trauma, O-Haire et al (2015) found consistent evidence to support short-term, subjective benefits including reduced depression, PTSD symptoms, and anxiety^{lxxxix}

6.2 Eligible NDIS support

Currently the NDIS support category of Capacity Building includes supports relating to social connection listed as:

Increased social and community participation. There are five relevant activities, including:

- Establishing volunteer assistance within the participant's home or community to develop skills. For instance, assistance in attending appointments, shopping, bill paying, taking part in social activities and maintaining contact with others.
- Training for the participant in a group of 2 or more to increase their independence in daily personal activities.
- Mainstream services that promote inclusion of people with disability to expand opportunities for community participation and employment.
- Individual life skills development and training including public transport training and support, developing skills for community, social and recreational participation.
- Participation in community based activities that build skills and independence.

Improved relationships. The relevant activities include:

- Skills development with an individual, for participation in community and social activities.

Improved daily living skills. The relevant activities include:

- Program to empower participants & improve interactions between participants & their social networks. Assistance to engage effectively in the community through a group approach to help achieve goals, gain insight into their lives & make informed decisions.

7 Housing

Having stable accommodation and more importantly a home, provides a strong foundation from which individuals with mental illness can work towards recovery. Through being supported to find, manage and maintain accommodation responsibilities, a person can gain hope, independence and a sense of empowerment to work through other recovery goals.

Stable housing is often inaccessible to people with severe mental illness for reasons including expense, availability and limitations with social and economic functioning. Programs that are targeted towards improving access and supporting daily functioning can significantly benefit the longer-term opportunities for finding foundation.

Brophy et al (2015) outline consumer preferences for housing related supports including financial advice and assistance (moving, relocating, rent, mortgage, maintenance and housekeeping); a housing support worker and finding housing that can be a home, ideally living independently.

Data from the 2010 Survey of High Impact Psychosis (SHIP) indicated a high degree of housing satisfaction among those who have stable housing, however there was also high rates of housing instability. Of those surveyed, 27.4% had changed housing in the previous year, 22.7% were on public housing waiting lists for independent accommodation and a high proportion had been homeless in the previous 12 months (12.8%). Additionally, 41.8% of participants who had had a psychiatric admission in the previous 12 months could not recall accommodation options being discussed with them at the time of discharge, with 7.5% not having anywhere to stay.

Responses highlighted some mismatch between current and preferred accommodation with participants indicating low preference for supported group accommodation and a stronger desire for independent accommodation with in-reach support as required (Sylvestre et al., 2007). Moreover, the relatively high rates of homelessness create significant barriers to recovery and wellbeing for this vulnerable population^{xc}.

There are distinct differences in need among the cohort groups requiring accommodation- those at risk of homelessness and those needing support to live independently. To that end, there are a number of types of housing support and matching these to individual need, balanced with preference, is an important consideration for NDIS support roles.

7.1 Interventions supported by the evidence

Overall the evidence base for any type of supported accommodation is moderate, with findings generally demonstrating positive outcomes across a range of recovery domains.

A qualitative study (2017) examining effective practice in mental health specific supported accommodation described a tension between the various models and promotion of self-determination. The authors reviewed the international literature on various models and found some degree of discrepancy across

service types in terms of balancing of safety and support whilst promoting independence. In some instances, providing a safe and supportive home risks reducing a consumer's desire to move on to more independent accommodation. However, although consumers may have a preference for independent living, they expressed concerns about the lack of support and loneliness outside of staffed settings.

Step up, step down and incremental service delivery models were considered a viable option for avoiding dependency and anxieties about moving on from the service. This might entail gradual reduction in support hours, transitional support and the use of purpose-built step down accommodation^{xci}.

7.1.1 Supported Accommodation or Residential Care

Hayes et al (2016) refer to the definition of 'Supported Group Accommodation' (SGA) or 'Supported housing schemes' whereby a number of people with mental illness live in self-contained accommodation on one site. Professional support such as counselling, group therapy, information and emotional support is available to residents. Part of the rationale of such programs is to provide a 'safe haven' while a person engages in productive changes in their life (Chilvers et al. 2006).

7.1.1.1 Prevention and Recovery Care (PARC) Services

The Prevention and Recovery Care (PARC) service model is a mental health step-up step-down service. PARC services are short-term, recovery-oriented residential treatment services located in the community. PARC services provide early intervention for consumers who are becoming unwell and for those in the early stages of recovery from an acute psychiatric episode.

PARC offers a safe and supportive environment for consumers to start their recovery journey and resume their role in the community by providing coordinated, recovery-oriented treatment and support.

Through a partnership approach between clinical mental health services and recovery services, PARC enables consumers with severe mental illness to receive both clinical intervention and treatment and active support for their recovery by linking in with consumers' natural supports and facilitating their participation in community life.

The Joondalup PARC service commenced operation in March 2013 as the first of its kind in Western Australia. The recovery-oriented service is run by Neami National, a Non-Government (NGO) specialist mental health service provider, and is linked to clinical services. The primary aim of the service is to reduce hospital admissions and/or reduce time spent in hospital.

An independent evaluation of Joondalup was undertaken by the University of Western Australia in 2017. The aim of the evaluation was to build on the limited evidence base regarding the effectiveness of the step-up step-down model of care in terms of patient reported outcomes and satisfaction, impact on hospital admissions and presentations and economic effectiveness.

Overall, the economic analysis incorporated within the evaluation found that the PARC model offered cost savings associated with reduced hospitalisations and hospital length of stay and morbidity savings. The Final Report determined the estimated savings to the West Australian health system to be, on average, approximately \$516,111 for one year of PARC service (primarily derived from the cost savings associated with the reduced number of hospital bed days).

In terms of individual outcomes, patients reported significant reductions in psychological distress, and significantly increased general self-efficacy as well as work and social adjustment, at service exit compared to service entry. Patients reported a high level of satisfaction with their stay overall. Results also demonstrated reduced hospitalisation rate and length of stay, as well as reduced risk of presenting to hospital emergency departments. The death rate among Neami Joondalup patients was just over one-quarter of that among other similar/matched psychiatric patients who did not receive the service.

7.1.2 Supported Housing

Supported Housing approaches involve the provision of support to enable people with a mental illness to live independently in the community. A range of support interventions are provided in the form of outreach to build the capacity of individuals to maintain tenancy and live autonomously.

There are existing models of supported housing for people with mental illness in Australia that have been evaluated as highly effective. By showcasing the successful elements and outcomes, there may be some valuable learnings for the NDIS support structures.

7.1.2.1 Housing and Accommodation Support Initiative (HASI)

The Housing and Accommodation Support Initiative (HASI) in NSW was established in 2003 to provide adults with a mental health diagnosis access to stable housing, accommodation support, mental health clinical care and rehabilitation.

HASI recognises the interdependence of stable housing, accommodation support services and clinical mental health services. The program's specific aims are to:

- Provide people with mental illness ongoing clinical mental health services and rehabilitation within a recovery framework;
- Assist people to participate in the community and to improve their quality of life;
- Assist people to access and maintain stable and secure housing; and
- Establish, maintain and strengthen housing and support partnerships in the community.

The HASI model represents a partnership between Housing NSW, NSW Health, NGO Accommodation Support Providers (ASPs) and community housing providers. HASI demonstrates the benefits of a partnership approach in

facilitating improved person-centred, recovery outcomes for people with a mental illness. The joint aims of all partners of HASI include:

- More efficient and effective co-ordination of care for consumers;
- Exploring and enhancing service interface;
- Enabling and facilitating stable housing outcomes for consumers; and
- Facilitation of consumer, family and carer participation.

The program is available to adults with a mental health diagnosis, with varying levels of disability, who require support services to maintain a tenancy and live independently in the community. NGOs are funded by NSW Health to provide low, medium, high or very high intensity packages of accommodation support depending on individual functioning.

Higher support HASI aims to assist people with high levels of psychiatric disability who are homeless, at risk of homelessness or inappropriately housed, including those who may be hospitalised due to lack of access to appropriate housing and support elsewhere. Consumers receiving high-level support are provided with social housing and more accommodation support hours. They need to have the capacity and willingness to live in the community and maintain a mainstream tenancy agreement with appropriate support.

Lower support HASI is aimed at aiding people who are already housed and who may be at risk of being unable to maintain their housing without support. The level of support provided varies depending on individual need, which can change over time.

In 2009, the University of New South Wales, led by the Social Policy Research Centre, was contracted to undertake a longitudinal, mixed method evaluation across all stages of HASI support including low, medium, high and very high support. The purpose of the evaluation was to examine the effectiveness of support for consumers; the benefits and limitations of the service model; and the cost of the program.

The final evaluation report was released in 2012, some of the relevant findings are summarised here^{xcii}:

Consumer profile

A total of 895 consumers participated in the evaluation. Of these, 62 per cent were receiving low or medium accommodation support services. 38 per cent of consumers received high or very high support services. The most common diagnosis of consumers was schizophrenia (65 per cent). One quarter of consumers had a secondary diagnosis and more than half had a co-existing condition, such as alcohol or drug dependency, physical health problems and intellectual disability.

Most people enter the program with a history of unstable housing, including almost half with no home immediately prior to entering HASI, for example, from hospital, prison, living with friends or family, living in a boarding house, in other unstable or temporary housing or primary homelessness.

HASI consumers live in a range of housing types, including social (public and community) housing and private housing. Almost nine out of 10 (88 per cent) HASI public housing residents live alone, compared to one in two public housing tenants (51 per cent) in the general population.

Evaluation outcomes

Positive outcomes for consumers included reduction in hospital admissions and length of stay, improved mental health, stable tenancies, independence in daily living, social participation, community activities and involvement in education and voluntary or paid work. Physical health remained lower than the general population. Most consumers reported improved quality of life.

Specific outcome considerations included:

- *Reduction in hospitalisations*: there was a 59 per cent decrease in the annual average number of days spent in a mental health inpatient unit; and a 24 per cent drop in the number of admissions to hospital per year. Among consumers who were previously admitted to hospital, the average number of days hospitalised per admission decreased by 68 per cent.
- *Cost savings*: Over \$30 million per year has potentially been avoided on the hospitalisation of HASI consumers (estimated in 2009/10 dollars),
- *Improved mental health*: including reduction in psychological distress and behavioural issues and improved life skills as indicated by HoNOS, K10 and LSP16.
- *Accommodation Support Providers (ASP)*: Most consumers attributed some of the positive outcomes to regular contact with ASPs.
- *Use of other mental and physical health services*: almost all consumers used health, allied health and community mental health services appropriately, with more frequent use of psychiatrists and allied health and less frequent use of community mental health services over time.
- *Housing*: the HASI program achieved its aim of stable housing for most HASI consumers. Most HASI consumers were satisfied with their housing and the support they receive from the housing provider. The majority (90 per cent) of consumers successfully maintained their tenancies.
- *Tenancy obligations*: with the support of the ASP and housing provider, almost all HASI consumers met their tenancy obligations – they paid rent on time, maintained their property and were reportedly good neighbours.
- *Daily living skills*: consumers on lower support were more independent than consumers receiving higher support in the activities of shopping, cleaning, paying bills, budgeting, exercise, and taking medication.
 - At least 60 per cent of consumers were reported to be independent or supported less than half the time in all activities of daily living.
 - Approximately one in three consumers required support more than half of the time with shopping, managing their finances, cleaning and exercising.

- *Relationships and social connections:* 86 per cent of consumers had some form of regular social contact with at least one of the following people – a family member, friend, spouse or partner. Men and consumers with higher support were less likely to have regular social contact with a family member, friend or partner.
- *Community participation:* 83 per cent of consumers were participating in at least one kind of community activity and reported improved regular social contact. One in seven continue to be socially isolated, particularly those receiving higher support.
- ASPs continue to rely on participation in activities targeted to people with a mental illness rather than mainstream activities. A greater emphasis on access to mainstream activities would be more consistent with HASI goals and with the aspirations of many consumers.
- *Work, training and education:* 31 per cent of HASI consumers involved in some type of paid or voluntary work, education and training. They were encouraged and supported in these activities by ASPs.

Across Australia there are a number of supported accommodation initiatives similar to HASI including the Victorian Housing and Accommodation Program; Project 300 in Queensland; Returning Home and Housing and Accommodation Support Partnership in South Australia and the Independent Living Program in Western Australia.

7.1.3 Accommodation Supports

7.1.3.1 Housing First Programs

‘Housing First’ models originated in the US and are built on the assumption that stable housing plays a critical role in the recovery of people with SMI. Recipients are immediately housed through the private rental market and receive practical assistance with rent and furniture and community based outreach support.

Several large randomised control trials have been conducted in Canada with findings showing consistent improvements with residential stability, community functioning, social inclusion, and reduced contact with the justice system (Patterson et al, 2013; Somers et al, 2013 cited in Dunt)^{xciii}.

Wellways Australia offer a housing and recovery program in Victoria called Doorway that supports people experiencing mental health issues who are homeless, or at risk of homelessness, in securing and sustaining a home within the private rental market.

Doorway operates as a collaboration between the Alfred Hospital, Latrobe Regional Hospital, Peninsula Health and St Vincent’s Hospital, and is supported by the REIV (Real Estate Institute of Victoria).

Although Doorway is modelled on a Housing First approach, there is some distinction in that participants source and choose properties themselves through the open rental market, with appropriate rental subsidy and brokerage support. A range of support is facilitated through a Housing and Recovery Worker to

enable individuals to choose a home, build personal recovery and develop skills for sustaining a tenancy.

A small scale independent evaluation of the Doorway three-year Demonstration Project, delivered between 2011-2014, highlighted a number of positive outcomes including advancements in housing stability and social inclusion, improved behavioural functioning and mental health and subsequent reduction in the use of clinical services. The evaluation asserted that after entering Doorway “the majority of participants achieved stable and secure private rental accommodation for the first time in their lives”^{xciiv}.

Outcomes were derived using the Behaviour and Symptom Identification Scale (BASIS), HoNOS and the Homelessness Star outcome measures as well as health service utilisation data. Some specific findings included:

- *Health outcomes:* statistically significant improvements were shown in the following BASIS domains: relationship to self/others; depression/anxiety and daily living function.
- *Housing outcomes:*
 - Four of the domains of the Star showed improvements including: motivation and taking responsibility; managing money; emotional and mental health and meaningful use of time.
 - 56% of participants had received 12-month lease extensions by their Property Managers, with three more on a month-to-month basis.
- *Social inclusion outcomes:* participants increased contact with friends and ‘others’, such as neighbours, work colleagues and local shops.
- *Utilisation of health services:* admission to bed-based mental health services (clinical and community) decreased substantially as did the total average bed days of bed based mental health services. There was also a reported decrease in general hospital admissions and presentations to emergency departments.
- *Cost savings:* based on estimates of all health service utilisation costs, and including Doorway direct client care services, cost savings were estimated to be approximately \$3096 per participant per annum.
- Overall, total estimated total cost savings (including housing, health and operational costs) ranged between \$1149 and \$19837 per participant, per annum, depending on the type of social housing used as a comparator- the highest being crisis accommodation.

7.1.3.2 Holistic Models: On Track Community Programs

Many existing NGOs deliver integrated services that recognise the intersection across a range of determinants of wellbeing and the importance of supporting individual recovery needs.

Illustrating an integrated approach to service delivery is the On Track Community Program (OTCP) that offers a range of services for people with

mental health conditions including accommodation, respite, Day2Day Living, Residential Care, Outreach and Clear Minds

Programs delivered under the OTC umbrella aim to support and strengthen social and economic participation with approaches ranging in intensity based on need. Mental health supports range from supported accommodation for those with high needs; to skills-based and creative day programs.

More broadly, OTCP includes a range of holistic supports that facilitate greater community engagement and recovery for a range of target populations. One of these programs, the Tenancy Support Program, has been demonstrated to have a high success rate in relation to both housing and non-housing outcomes including maintaining tenancy, improved physical and mental health, family relationships and social support (Housing NSW, 2013).

Factors that contributed to the success in sustaining tenancies are said to be the related to the emphasis the program places on supporting clients to learn budgeting and financial management skills as well developing affordable debt repayment arrangements.

7.1.3.3 Hoarding and Squalor

Provision of support for hoarding and squalor was noted as a service gap by a number of sources, including within the Psychosocial Supports Design Project and by participants of local evaluations of the South Eastern Sydney and the Inner West Sydney Partners in Recovery programs^{xcv xcvii}

Hoarding and squalor is also known as Diogenes syndrome, characterised by acquisition of and inability to discard possessions resulting in environmental and self-neglect and excessive clutter that impairs social and occupational functioning and may cause substantial health and safety risks. The most recent version of the Diagnostic and Statistical Manual (DSM), DSM5, included Hoarding Disorder for the first time as a unique psychiatric disorder independent from Obsessive Compulsive Disorder (OCD).

Service providers need to routinely consider the possibility of hoarding if indicated, as individuals may not readily offer relevant information. If left alone, people suffering from Diogenes syndrome have a high risk of increased mortality, most likely due to lack of engagement with services and poor compliance with treatment for concurrent physical illness.

Whilst prevalence rates of comorbidity between hoarding and mental illness are not specifically available, it is a growing area of research interest. There is not currently an evidence base substantial enough to undertake any assessment of strengths of interventions to manage or treat hoarding however various opinion pieces and discussions in the context of OCD support the use of CBT as the most effective treatment approach, sometimes in conjunction with medication management^{xcvii}.

While CBT is associated with significant reductions in hoarding severity, clinical levels of hoarding symptoms persist for more than half of treatment completers; suggesting that more efficacious treatments need to be developed. Although

research on pharmacological treatments for HD is an emerging area, results are somewhat mixed.

Family-focused hoarding interventions may be important area for attention given that individuals with hoarding behaviours can have limited insight and motivation and its negative effects on the family. Evidence suggests that a cost-effective and coordinated cross-sectoral response utilising a combination of community-based and individualised interventions may be optimal in order to reach people who are not engaging with services. Such approaches could include incentives and motivation through housing arrangements, use of multidisciplinary providers and stepped care^{xcviii}.

7.1.3.3.1 Innovation Project: Buried in Treasures

One of the commonly cited strengths of the PIR program was the opportunity for local innovation grants. Inner West Sydney utilised some of this funding to introduce a peer support program called “Buried in Treasures”.

This program appears to be adopted from the Buried in Treasure Workshop Program originally written by Dr. Randy O. Frost and adapted for use in several countries around the world, including Australia. The program is a peer led facilitated support group that is structured and time limited. The sessions are facilitated by a person with a current or past hoarding disorder or who holds a special interest in it. Activities include discussion of acquisition, discarding, and disorganisation, and homework between sessions.

Local research from the program authors (based on a 13-week version of the workshop) indicates positive outcomes with up to 73% of participants are much or very much improved by the end of the group (Frost, Pekareva-Kochergina, & Maxner, 2011), and that participants improve significantly more than people on a waiting list for the group.

7.2 Eligible NDIS support

Currently the NDIS support category of Capacity Building includes supports relating to housing listed as:

Assistance with daily life (includes Supported Independent Living). There are a number of relevant activities within this category, including:

- Assist participant to undertake and/or develop skills to maintain their home environment where the participant owns their own home & has sole or substantial responsibility for its maintenance. Includes assisting participant to do basic house & yard work.
- Assisting with, and/or supervising, personal tasks of daily life to develop skills of the participant to live as autonomously as possible.
- Accommodation/tenancy: Transition to NDIS funding: payment of rent and utility accounts. Short-term payment as per participant plan.
- Short term accommodation and assistance, weekday, standard intensity: Integrated support for self-care, accommodation, food & activities in a centre or group residence (note there are several similar items varying in timeframes).

Improved living arrangements. There is one relevant activity:

- Support is provided to guide, prompt, or undertake activities to ensure the participant obtains/retains appropriate accommodation. May include assisting to apply for a rental tenancy or to undertake tenancy obligations.

8 Personal Life

Whilst a common assumption is that recovery, or wellness, involves being independent and self-sufficient, it is important to recognise that being interdependent, establishing relationships with others and a sense of belonging is necessary for wellbeing.

In an article critiquing individualistic approaches to recovery, the notion of 'relational recovery' is discussed as a concept for viewing recovery on the basis of humans being interdependent beings, whose lives and experiences are embedded in the social contexts surrounding them. The authors argue that while current conceptualisations of personal recovery recognise the role of interpersonal relationships, they should more accurately be seen as permeating all aspects of recovery, including experiences of hope, identity and empowerment. ^{xcix}

People with lived experience are likely to assume various relational identities – partners, lovers, friends, children, parents, siblings, aunts and uncles, grandparents, carer – all of which entail complex networks of interdependence. Supporting individuals to navigate these relationships and become more connected and interdependent is an important aspect of recovery.

Distinct from social connection, the domain of personal life includes relationships with family and intimate personal relationships. Without appropriate support, maintaining or repairing family relationships can be particularly challenging- both for individuals with SMI and their loved ones.

Targeting interventions to improve relationships, particularly family functioning, can minimise the impact of mental illness on both the individual and the family unit. Families and carers of people with SMI are central to the experience of long-term recovery. It is critical that measures to enhance the domain of personal life include discrete supports for families and carers of people with SMI, including options for respite, in addition to family inclusive interventions.

8.1 Interventions supported by the evidence

A 2003 review examined a large body of evidence to determine the efficacy and effectiveness of family interventions on the course of major mental disorders. The strategies employed ranged from information and education, to stress management strategies (individual and group), social skills training, crisis intervention and specific cognitive behavioural techniques.

The reviewers concluded that strategies that seek to enhance the caregiving capacity of family members and other people involved in the day to day care of people with a mental illness have a significant impact on the clinical prognosis of mental illness as well as improvements in social functioning. Benefits were also

noted for carers in terms of reduced stress associated with their caregiving roles^c.

8.1.1 Family and Carer Support

Families, carers and informal networks play important roles in the lives of people with mental health issues. Carers offer valuable emotional, personal and practical support, both in terms of activities of daily living and in times of crisis.

In the absence of carers, people with SMI would receive significantly less support or their support requirements would need to be met through formal services, at additional cost to government.

A technical report investigating the cost for informal mental health care in Australia estimated that there were 2.8 million informal carers in Australia in 2015, of whom approximately 240,000 are mental health carers. Overall the report concluded that mental health carers provide 208 million hours of informal care per year, equivalent to 173,000 FTE formal support workers.

Overall, the total annual replacement cost for all informal mental health carers in 2015 is \$14.3 billion. After adjusting for cost offsets of \$1.1 billion, this figure is estimated at \$13.2 billion^{c1}.

The impact of living with and/or caring for someone with SMI can place significant strain on individuals and on relationships. It is important that support is provided that recognises the value of, and strengthens, informal support networks particularly in terms of offering targeted support to family members and carers. This support needs to acknowledge the carer experience as both separate to, and parallel with, their loved one's journey.

Carers should also be supported in a recovery-oriented manner that enables them to maintain their own wellness across the five key domains of recovery: Connectedness, Hope, Identity, Meaningful life and Empowerment (CHIME).

In its submission to the Productivity Commission Inquiry into NDIS costs, the NDIS IAC recommended that it is in the scheme's interest to increase investment in strategies that strengthen, sustain and guide the informal support networks. .

8.1.1.1 Family Psychoeducation

Family members are frequently not in contact with services, even though they often provide substantial support for their relative (Harvey & O'Hanlon 2013). Australian studies show that families may be under stress (Hayes et al. 2015) thus it is important that there be targeted support for families.

Family support includes the dominant approach of Family Psychoeducation which is an evidence based intervention that can be offered in groups, one-one; and as a peer support approach. Interventions seek to build knowledge, social and personal skills to enable families and consumers to work more effectively with the challenges of living with SMI and psychosocial disability.

Review of the available evidence indicates strong support for the intervention however available surveys indicate that it may not be identified as a priority by people with SMI. An evidence review conducted by Hayes et al (2014) refers to

evidence that shows positive outcomes for Peer Support to family members, Family to Family support (Duckworth & Halpern 2014) including improvements in problem focused coping, empowerment, and emotion focused coping, which includes acceptance and reduced distress.

The same report summarised the findings of many randomised controlled trials that indicate that Family Psychoeducation (FPE) interventions are highly successful in reducing relapse in people living with schizophrenia and in decreasing negative caregiver experience and stress in family members (Pharoah et al. 2010). The intervention was seen to reduce distress and improve empowerment, coping and problem-solving skills in carers – all goals that would lead to greater sustainability in carer support.

Positive outcomes highlighted in the report included:

- Reduced relapse and hospitalisation;
- Improvement in carer quality of life and coping;
- Reduction of distress and caregiver difficulty;
- Reduced likelihood of unhelpful family reactions developing as a reaction to participants' psychosocial disability;
- Assistance with maintaining engagement and participation in support;
- Enhanced achievement of recovery goals.

Hayes et al (2014) surmised that Family Psychoeducation is likely to improve the sustainability of carer support and enhance quality of life for both consumers and their informal support network^{ci}.

8.1.1.2 Carer Peer Worker

A carer peer worker is a person employed specifically to work from their lived experience of caring for or supporting a person with a mental illness and recovery. The intent is to draw on their expertise by lived experience in order to provide support and model hope for recovery.

Health Workforce Australia (HWA) acknowledges the value of carer peer work in providing support to family and carers in overcoming feelings of exclusion by connecting with someone who may offer firsthand understanding of the impact of illness on significant others. Peer support can provide people with the chance to discuss their feelings in a safe environment, without fear of being regarded as disloyal or unsupportive. Carer peer workers can provide family education, which supports increased knowledge of families and carers about mental illness or assist with the development of coping strategies^{ciii}.

The evaluation of Building a Future, an Australian program developed by Wellways, found positive outcomes from a family peer education program where families, friends and carers are supported to gain knowledge and skills in relation to their caring role, and supported to focus on their own wellbeing. The peer group sessions for family members resulted in less worry, tension, and distress, which was maintained at three and six month follow-up (Stephens et al. 2011). Participants were also able to build their confidence to fulfill their proactive advocacy and support role. The end result of such interventions is

likely more energy and community engagement that can improve overall quality of life for both family carers and participants^{civ}.

8.1.2 Intimate Relationship Support

Maintaining intimate relationships, including romantic relationships is frequently indicated as an area where people with SMI may need additional support. Intimacy and connection are important facilitators and indicators of recovery, particularly relational recovery.

There is not much discussion in the available literature around targeted supports to assist in establishing and maintaining intimate relationships, however there is a strong association with any intervention that is focussed on improving social functioning. Specific examples of support that have been cited include: funding to help with engaging in recreational activities that may encourage relationship development; information about relationships; and counselling to address relationship difficulties.

Individuals diagnosed with a severe mental illness often experience a lower sense of mastery, or control over one's life, low self-esteem and perceived quality of life. In the context of sexuality and intimate relationships, these experiences can impact upon a person's sexual behaviours. A systematic review of 52 studies reported an average prevalence of 44.9% of individuals diagnosed with a severe mental illness as sexually active in the past three months (Meade & Sikkema, 2005). Further, adults in this population have higher rates of sexual risk behaviours, such as multiple partners and involvement in the sex trade (Perry & Wright, 2006), and are disproportionately at risk of contracting sexually transmitted infections (Meade & Sikkema, 2005) than the general population.

A 2015 study explored factors that play a role in whether individuals diagnosed with a severe mental illness are sexually active, and, if so, their number of partners. The researchers found that a greater sense of control in one's life (mastery) the relative importance of sexuality/relationships and sexual attitudes influence the number of sexual partners in this population^{cv}.

The study highlighted the importance of comprehensive assessment of individual sense of mastery as well as attitude towards sex and perception of its importance. Use of these variables can improve treatment planning and increase opportunities for sexual health information and education and more holistic, person-centred interventions. Better understanding of the perspectives and attitudes of people diagnosed with a severe mental illness regarding sexuality can improve outcomes related to associated behaviours including sexual activity, perceptions of risk, intentions for sexual safety, or romantic relationship functioning.

8.1.2.1 Compeer

Compeer is a community program that was established with the purpose of helping people in mental health care live "happier, more productive lives" (Skirboll, 2006, cited in *Well Together*). Compeer friendships aim to address the stigma and isolation associated with mental illness, and provide a rewarding experience for participants. Consumers are matched to community volunteers

who may or may not have lived experience. Friends meet up on a regular basis for social activities, such as a meal, coffee, going for a walk, to a movie or visiting a local attraction.

Positive outcomes have been found for those who participate in Compeer (McCorkle et al. 2008; 2009), including favourable results from a qualitative study that was conducted in Australia in 2011. The Victorian study was based on interviews with companions, volunteers and mental health workers. The researchers ascertained that the 'intentional companionships' formed through Compeer resulted in increases in overall wellbeing and social connection. Participants described improvements in personal experiences of recovery and resilience, with friendships producing growth in compassion, acceptance and understanding of mental health for all interviewees. This acceptance of mental health was theorised to extend more broadly into the wider community, potentially having flow on impacts of reducing stigma and discrimination ^{cvi}:

8.2 Eligible NDIS support

Currently the NDIS support category of Capacity Building includes supports relating to personal relationships listed as:

Improved relationships. The relevant activities within this category, include:

- Training for carers and others in behaviour management strategies required due the persons disability (note this also appears in the category of improved daily living skills).
- Social skills development with an individual, for participation in community and social activities (previously mentioned).

9 APPENDICES: MENTAL HEALTH ASSESSMENT TOOLS: ANALYSIS

9.1 Purpose

To identify an acceptable assessment tool enables assessment of someone's appropriateness for a given tier of support in the scheme.

Ideally, a tool needs to meet the following criteria:

- ✓ Can be implemented by a non-expert
- ✓ Gives an objective understanding of outcome
- ✓ Measures relevant things
- ✓ Is meaningful to participants

9.2 Challenges

The recovery process reflects an individual's ongoing participation in, and effort towards, meaningful and contributing life. Therefore, the range of interventions required to support an individual's recovery are broad.

Developing data collections and indicators to support recovery-related mental health from both the perspective of individual recovery and recovery-oriented service delivery is a complex task. These issues cannot be captured by a single measure and it has been suggested that It might be desirable for services to invest in two instruments: one designed to measure individuals 'recovery and one designed to measure the recovery orientation of services and to align indicators in each as far as possible (Burgess et al, 2011).

Furthermore, it is critical to ensure that measures used appropriately capture consumer held perspectives and experiences related specifically to the range of domains impacted by psychosocial disability; and not just in relation to functional impairment and/or diagnosis.

There is no consistently agreed outcome measure for consumers of mental health services. A national project has commenced to develop a new consumer rated measure, guided by the Mental Health Information Strategy Standing Committee. The aim is to develop a measure suitable for national implementation, with the potential for inclusion in the National Outcomes and Casemix Collection (NOCC) as a possible replacement for the K10+, BASIS-32 and MHI-38 in public sector mental health services.

This new measure will aim to provide a more comprehensive view of the consumer's perspective; have utility and acceptability for both consumers and clinicians, with the potential to be used in routine practice.

9.2.1 Considerations

The Australian Mental Health Outcomes and Classification Network (AMHOCN) was established to provide leadership to the mental health sector to support the sustainable implementation of the National Outcomes and Casemix Collection (NOCC). The measures that comprise the NOCC are:

- Health of the Nation Outcome Scales (HoNOS);

- Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA);
- Health of the Nation Outcome Scales 65+ (HoNOS65+);
- Life Skills Profile 16 (LSP-16);
- Resource Utilisation Groups – Activities of Daily Living Scale (RUG-ADL);
- Children’s Global Assessment Scale (CGAS);
- Mental Health Inventory (MHI);
- Behaviour and Symptom Identification Scale 32 (BASIS-32®);
- Kessler-10 Plus (K-10+);
- Strengths and Difficulties Questionnaire (SDQ)
- Factors Influencing Health Status (FIHS); and
- Focus of Care (FOC).

In 2010, the AMHOCN was commissioned to conduct a review of recovery measures to assess their applicability in the Australian setting. The review examined instruments that could be useful to individual consumers, carers and service providers in monitoring recovery status and change, and instruments designed to measure the recovery orientation of services.

The following criteria were applied for instruments designed to measure recovery at an individual level (note the review also looked at instruments designed to assess recovery orientation of services):

- Explicitly measures domains related to personal recovery;
- Is brief and easy to use (50 items);
- Takes a consumer perspective;
- Yields quantitative data;
- Has been scientifically scrutinized;
- Demonstrates sound psychometric properties
- Is applicable to the Australian context; and
- Is acceptable to consumers.

The review identified 22 possible instruments designed to assess individual recovery with 4 measures meeting criteria for adoption by Australian mental health services^{cvi}:

- Recovery Assessment Scale (RAS)
- Illness Management and Recovery (IMR) Scales
- Stages of Recovery Instrument (STORI)
- Recovery Process Inventory (RPI)

The AMHOCN and Community Mental Health Australia also conducted a literature review and detailed sector consultation exploring possible tools for application within Community Managed Organisations (CMO). The review considered a total of 136 tools across six primary categories of outcome.

The following tools were recommended as the most appropriate, in most situations, for CMOs delivering mental health or psychosocial disability services in Australia. (note: these tools are available free however permission or acknowledgement may be required)^{cvi}

Outcome Category	Recommended Tool
Recovery	Recovery Assessment Scale (RAS) [†] or Stages of Recovery Instrument (STORI) [†]
Thoughts and Feelings	Kessler 10 (K10+) [†] or CarerQoL (CarerQoL7D+VAS) [†] or Strengths and Difficulties Questionnaire (SDQ) (used in Child and Adolescent services) [†]
Daily Living and Maintaining Relationships	Work and Social Adjustment Scale (WSAS) [†]
Social Inclusion	Living in the Community Questionnaire (LCQ) ^{†#}
Quality of Life	World Health Organisation Quality of Life –Brief, Australian Version (WHOQoL- BREF) [†]
Experience of Service	Your Experiences Survey (YES) [†] or Carers Experience of Service Provision ^{†#}
Multi-Dimensional	Camberwell Assessment of Need – Short Appraisal Scale (CANSAS) ^{†*}

Note: † Consumer or carer rated †* Consumer, carer and worker rated components †# Measure in development

Note: those applying to children and adolescents or people over 65 years are not described in this paper and Carer tools are provided with limited details.

These tools were identified on the basis of them as representing the best balance between ease of use, reasonable psychometric properties and appropriateness for the community sector. An important feature of the measures selected is that they are all completed by the consumer or carer as relevant. They need to be offered by the staff but they collect the consumer’s or carer’s view. These tools also provide opportunity for comparability across services, including public services.

9.3 Overview of Selected Individual Tools

9.3.1 Recovery Assessment Scale (RAS)

The RAS was designed to assess various aspects of recovery from the perspective of the consumer, with a particular emphasis on hope and self-determination

The RAS Domains and Stages (RAS-DS) has been designed to do 3 things:

- To help consumers understand their own recovery progress, and from that, make recovery plans and track their recovery over time.
- To help workers to be more collaborative with consumers.
- To assist services to track recovery outcomes.

The RAS-DS is a validated tool that has been developed through consumer, researcher and mental health service collaborations over more than 8 years^{cix}. It is one of the most published tools that empirically assess recovery.

9.3.1.1 Instrument description

The RAS-DS has 38 items or statements for the consumer to rate. It is a Likert scale with 4 rating categories for consumers to select from: “untrue”; “a bit true”; “mostly true” and “completely true”.

The items are divided into 4 recovery domains and 3 stages (very early – middle-later). Each domain can be used and scored separately as well as collectively for a more holistic exploration:

- Doing Things I Value;
- Looking Forward;
- Mastering My Illness and
- Connecting and Belonging.

9.3.1.2 Instrument administration

This is a self-report measure. However, it is acceptable for staff or peers/peer workers to interview or read the statements to the consumer.

Development data indicates it will take most consumers between 5 to 15 minutes to complete without any support. However, if people want to reflect deeply on items, or if they prefer/need assistance it may take longer.

9.3.1.3 Scoring

Raw scores are used, with each of the 38 items being added up to a total recovery score out of 152. Sub-totals for each of the domains can be used, as can percentage rates.

9.3.1.4 Usefulness and psychometric properties

During development stages the instrument was redesigned several times to accommodate feedback received on its usefulness and relevance.

In the context of recovery, although RAS was not based on a theoretical or conceptual model of recovery, the majority of items reflect the definition of psychological recovery. However, the RAS does not attempt to identify stages of recovery, but is a continuous measure yielding a single recovery score.

The current version has had the following benefits identified:

- Validity: the RAS has been shown to have good concurrent validity

- Reliability: The RAS has been shown to have good test-retest reliability
- Sensitivity to change: the sensitivity to change of the RAS has not been tested.
- Usability/Acceptability: base on testing the acceptability of recovery measures, the RAS has been indicated by some Australian providers as their preferred measure, noting that it was easy to complete, relevant to consumer-defined recovery, used positive language, and measured quality of life and abroad conception of recovery.
- Qualitative data shows clearly that doing the RAS-DS helps almost all consumers to think about and reflect upon their recovery journey
- Qualitative data also shows that staff find the process of talking over RAS-DS results with consumers helpful in gaining a richer understanding of the perspectives, feelings and priorities of consumers.
- The majority of consumers rate it as easy to use.
- The statements/items are all useful to the overall measurement.
- It is OK to add the scores up to gain a total recovery score out of 152. Sub-score totals can be used for each recovery domain to see which domains people are doing better and less well in.

For further exploration/development:

- There is not enough data around sensitivity to change.
- Further exploration is required to better capture aspects of 'later recovery' stages.
- Examining test-retest reliability.

Access to relevant resources, including the tool: <http://ras-ds.net.au/>

9.3.2 Illness Management and Recovery Scale (IMRS)

The development of the IMRS took place within the context of evaluating the US IMR program, which is designed to promote illness management and advancement towards personal goals.

The instrument does not intend to measure cohesive domains, but rather to assess a variety of aspects of illness management and recovery.

9.3.2.1 Instrument description

The IMRS contain 15 items covering personal goals, knowledge of mental illness, involvement of significant others, impaired functioning, symptoms, stress, coping, relapse prevention, hospitalisation, medication, use of AOD.

9.3.2.2 Instrument administration

There are two versions, a self-assessment (client version) and a clinician version. Both versions include the same 15 items.

9.3.2.3 Scoring

Each item is rated based on a 5 point Likert scale. Higher numbers represent better outcomes. A mean score of all 15 items is provided as the primary outcome score for this scale.

9.3.2.4 Usefulness and psychometric properties

- **Validity:** the client version of the IMR has shown significant positive correlations with self-reported symptom distress on similar scales. The clinician version of the IMR correlates with the clinician-rated functioning on similar scales. The client and consumer versions of the IMR also correlate well with each other.
- There is limited evidence for the scale's construct validity.
- **Reliability:** the client and clinician versions of the IMR have both demonstrated good test-retest reliability.
- **Sensitivity to change:** some evidence but relatively untested.
- **Usability/Acceptability:** the scale has been deemed to be understandable, respectful, useful, and as covering sufficient material. It has also been noted that it helps consumers better manage symptoms and recovery.

9.3.3 Stages of Recovery Instrument (STORI)

The STORI is designed to capture the following five stages of recovery from the consumer's perspective:

- **Moratorium** (a time of withdrawal characterised by a profound sense of loss and hopelessness);
- **Awareness** (realisation that all is not lost, and that a fulfilling life is possible);
- **Preparation** (taking stock of strengths and weaknesses regarding recovery, and starting to work on developing recovery skills);
- **Rebuilding** (actively working towards a positive identity, setting meaningful goals and taking control of one's life); and
- **Growth** (living a full and meaningful life, characterised by self-management of the illness, resilience and a positive sense of self).

The five stages of recovery are represented in four component processes:

- Finding and maintaining hope;
- Reestablishment of a positive identity,
- Finding meaning in life; and
- Taking responsibility for one's life.

9.3.3.1 Instrument description

The STORI is a 50-item questionnaire. Ten themes are assessed, each with five items mapping onto the five proposed stages of recovery.

A shorter version of the STORI, the STORI-30, has been developed utilising the best performing items of the STORI.

9.3.3.2 Instrument administration

The STORI is a self-report questionnaire, said to take on an average of 11 minutes to complete.

9.3.3.3 Scoring

The 50 items are rated on a scale from 0 to 5. Items are presented in 10 groups of five (each ranging from 0 'Not at all true now' to 5 'Completely true now') mapping onto the five proposed stages of recovery.

Overall there are 10 items representing each stage, and these are used to create five stage subscale scores. The highest subscale score indicates the stage of recovery that the person is experiencing.

9.3.3.4 Usefulness and psychometric properties

Evidence supports that the STORI has^{cx}:

- Validity: Moderate to good concurrent validity
- Reliability: the internal consistency of the sub-scales has been demonstrated as good to excellent in two separate studies (Anderson et al and Weeks et al, 2011)
- Acceptable test-retest reliability and internal consistency
- Validity as a measure of recovery from consumer perspective
- Individual stage subscales were found to be internally consistent, indicating that items within each subscale reliably measure the same construct
- Useability/Acceptability: consumers mostly rated it as easy to complete, not too long, the items were important to think about and was helpful for staff, although they were not sure that it helped them think about their own recovery.

Limited research (to date) supports the STORI-30 as showing promise as a brief measure of stage of recovery, more feasible for routine clinical use.

A review of the instrument by Slade et al (2009) concluded that the STORI has at least four potential clinical uses^{cx}:

- Identifying the current stage of recovery can inform clinical decision-making about the most appropriate intervention.
- Aggregated data can provide a more recovery-sensitive measure of case mix that can be used for workforce planning, to better match the skill mix in a team with the needs of people on the team caseload.

- Using an explicitly recovery-orientated measure could shift the culture of care; talking about recovery is in itself an intervention.
- Scores could be tracked over time as recovery-focused outcome data.

Limitations:

The measure is not sufficiently sensitive to qualitative differences between the stages of recovery. A cluster analysis of the STORI items produced only three stage-related clusters, instead of the expected five. This could indicate either of two things: recovery takes place in only three stages rather than five; or, there are five stages to recovery, but the STORI does not clearly discriminate between them.

9.3.4 Recovery Process Inventory (RPI)

9.3.4.1 Instrument description

The RPI is comprised of 22 items that aim to measure the following domains of recovery from the consumer's perspective:

- Anguish,
- Connectedness to others,
- Confidence/purpose,
- Others care/help,
- Living situation and
- Hopeful/cares for self.

9.3.4.2 Instrument administration

The RPI was explicitly designed to be completed via an interview between the consumer and provider.

9.3.4.3 Scoring

The RPI comprises 22 items, each of which is rated on a 5-point Likert scale. There is no available information on scoring however it does provide quantitative information.

9.3.4.4 Usefulness and Psychometric properties

- Validity: Some limited evidence for the concurrent validity of the RPI has been established.
- Reliability: the RPI has been shown to have fair to good test-retest reliability across the six sub-scales. The RPI has been shown to have acceptable to good internal consistency across five of its six sub-scales, with the remaining sub-scale having a poor level of internal consistency.
- Sensitivity to change: Little psychometric research on sensitivity to change is available.
- Useability/Acceptability: Little psychometric research on sensitivity to change is available.

9.3.5 Camberwell Assessment of Need (CAN)

The Camberwell Assessment of Need (CAN) has been designed to provide a comprehensive assessment of the complex clinical and social needs of people with severe mental illness.

CAN supports comprehensive person-centred care planning and allows information to be gathered from both the professional and the consumer, providing a tool to support conversations about needs.

The main purposes of CAN are:

- To identify the appropriate level of care to offer;
- As a focus for care planning and negotiating support needs;
- As a review mechanism, to record the service user's needs at a particular point in time and to verify whether Unmet needs are becoming Met needs;
- To inform service developments (in aggregated form), by identifying domains which are common needs amongst people using the service, but which the service does not currently address.

The following criteria informed the development of CAN:

- Have adequate psychometric properties
- Be completed within 30 minutes
- Be usable by a wide range of professionals
- Be suitable for both routine clinical practice and research
- Be easily learned and used, without formal training
- Incorporate both patients' and staff views of needs
- Measure both met and unmet need
- Measure the level of help received from friends or relatives, as well as from services

CAN has been determined to be a validated and reliable instrument for assessing the needs of people with severe mental illness^{cxii}.

9.3.5.1 Instrument description

The CAN is a family of questionnaires that can be used to assess the wide range of problems potentially experienced by people who have mental health problems. There are 22 domains altogether.

Four primary versions have been developed (and adapted for different population cohorts):

- CAN Short Appraisal Schedule (CANSAS): is a one-page assessment that records the need rating for each of the domains. The perspective of staff, service users and informal carers are recorded separately. Information is recorded on CANSAS by staff.
- CANSAS-P: is a two-page assessment designed for self-completion that records the need rating for each of the domains. It assesses the consumer's perceptions of their needs in each of the domains.

- CAN-C: is a 22-page detailed assessment that which measures the need rating, help received from formal and informal sources, and records an action plan for each of the 22 domains.
- CAN-R: is a 22-page detailed assessment that records information about need, support and satisfaction for each of the domains and is for research use;

9.3.5.2 Instrument administration

There is both a clinician administered and self-report version of the CAN. For the clinician administered version (CAN/CANSAS), it is easily learnt by staff from a range of professional backgrounds.

The tool can be administered in a variety of settings. Needs are assessed over the past month.

A complete assessment is said to take, on average, around 25 minutes. The CANSAS takes approximately 5 minutes and the CANSASP up to 10 minutes.

9.3.5.3 Scoring

The adult CAN score is the number of unmet needs (the number of domains rated as unmet – ranging from 0 to 22) and the number of met needs (the number of domains rated as met – again, ranging from 0 to 22).

Staff and consumer need ratings are different and scored separately and can be used individually. Combining them to make a single rating will lose the information about where there are disagreements.

9.3.5.4 Usefulness and psychometric properties

The most useful data to emerge from research using CAN have been the level of met and unmet need. Therefore, CANSAS or CANSAS-P have been determined to be the most appropriate version for most uses.

The following benefits have been identified:

- It is standardised – the reliability and validity have been tested, so it produces meaningful data.
- It is comprehensive – it assesses a full range of health and social needs.
- It is multi-perspective – it separately assesses the perspective of staff, service users and family members.
- It is widely available – it has been translated into 26 languages.
- It is clinically useful – identifying areas of agreement and disagreement supports negotiation of a service user’s care plan.
- It measures the service user’s perspective on their unmet needs.

In terms of the reliability of needs assessment as determined by clinicians versus consumers, needs are very often assessed differently by staff and consumers, which may have implications for how needs are assessed in clinical practice.

The CAN can be used as an outcome measure for 3 summary variables:

- Total number of needs (i.e. Met + Unmet needs);
- Total number of Met needs; and
- Total number of Unmet needs (maximum 22 for each).

Note: Patient-rated Unmet has strong support in the literature as the most useful variable.

9.3.6 Kessler 10 Plus (K10+)

The K-10+ is a version of the K-10, which was developed for use as a measure of non-specific psychological distress. It was originally designed for use as a one-off measure of health status in the US National Health Interview Survey, but was deliberately constructed in a manner that would allow it to have utility in clinical settings as well.

The K-10 is extremely widely used, both as a measure of mental health status in general population surveys and as an outcome measure in primary care settings, suggesting that it is well-regarded by the mental health field.

9.3.6.1 Instrument description

The K-10 is a 10-item questionnaire, which asks the consumer about symptoms of depression and anxiety in the past four weeks. Questions relate to the level of nervousness, agitation, psychological fatigue and depression in the relevant rating period. The K10+ contains an additional 4 questions to assess functioning and the level of disruption and disability resulting from the problems identified in the first 10 items.

The questions are consistent with the notion that symptoms are necessary but not sufficient for a person to be considered as having a disorder; impairment must also be present. They are also consistent with the intent of similar questions used in numerous population health surveys to elicit information on the functional impact of distress and service utilisation related to distress.

9.3.6.2 Instrument administration

The K-10 is a self-report measure of psychological distress, in which the consumer completes questions about symptoms of depression and anxiety in the past four weeks. It is designed to span the range from few or minimal symptoms through to extreme levels of distress, and consequently contains both low-threshold and high threshold items.

The K-10+ includes four additional items (Items 11-14) that constitute follow up questions. These items aim to quantify the level of disruption and disability resulting from the problems reported, in terms of the degree of limitation of normal activity, and/or seeking help for the problems

9.3.6.3 Scoring

Scoring is relatively straightforward. For each item, the consumer indicates the amount of time during the four-week period that he or she experienced the particular problem. There is a five level response scale that ranges from none of the time (1) to all of the time (5).

The total score is the sum of all items. The maximum score is 50, indicating severe distress, and the minimum score is 10, indicating no distress.

The additional Items on K10+ require slightly different responses in terms of number of days; number of consultations. These are excluded from calculation of the total score. However, they are utilised by the clinician and consumer to gauge the impact of the consumer's distress on his or her functioning.

The K-10 is a measure of psychological distress that first should be considered at face value. Higher scores indicate greater psychological distress, whatever the cause.

9.3.6.4 Usefulness and psychometric properties

The K10 has been included in the National Health Survey as it proved to be a better predictor of depression and anxiety disorders than the other short, general measures previously used.

There have only been a few studies looking at the psychometric properties of the K10. Findings from limited studies suggest:

- **Validity:** Strong content validity was a focus of the expert advisory panel set up to construct the measure.
- **Reliability:** the test-retest reliability of the K-10 was examined in pilot work. The individual items demonstrated only fair reliability, but the total score and the standardised total score demonstrated excellent reliability.
- **Sensitivity to change:** the K-10 has demonstrated sensitivity to change
- **Acceptability/Usability:** no published studies were found that have specifically examined the feasibility of the K-10 as a routine outcome measure or that have considered the acceptability and utility of the instrument from the perspective of consumers, carers, clinicians and/or managers. However, given the wide use in a range of settings, suggests that many relevant stakeholders favour its use.

Limitations:

- There is only limited research into the predictive validity and sensitivity to change of the K10+.
- Further research is required into the feasibility and utility, although its brevity and widespread use in a range of settings indicate acceptability.

9.3.7 Life Skills Profile (LSP)

The LSP was originally developed as one-off measure of health status. It primarily assesses functioning.

9.3.7.1 Instrument description

The LSP-16 is derived from the LSP-39. It is designed to measure the level of functioning and adaptation of people with a mental illness living in the community. It consists of 16 items that address issues faced when adapting to life in the community.

The LSP-20, which represents a cut-down version of the LSP39 and an extension of the LSP-16 can be scored in either direction.

The LSP-16 items can be grouped into 4 subscales:

- Withdrawal
- Self-care
- Compliance
- Anti-social behaviour

9.3.7.2 Instrument administration

The LSP-16 is a clinician rated instrument with assessment of a consumer's general functioning (not during crisis or when he/she is becoming ill) on each of the 16 items.

Ratings are based on the consumer's behaviour over the preceding three month period, drawing on direct observation and information from other individuals in contact with the consumer (including family, friends, carers and mental health professionals).

The LSP-16 has no training requirements and may be administered by clinicians of any discipline, providing they have contact with the consumer.

Clinicians who are familiar with the instrument can typically administer it in five minutes or less.

9.3.7.3 Scoring

The clinician rates each item on a four-point scale ranging from 0 (no problem) through 1 (slight problem) and 2 (moderate problem) to 3 (extreme problem).

Individual item scores, subscale scores and total score can then be calculated. Whilst the LSP-39 can be regarded as a measure of strengths, since high scores indicate better functioning, the LSP-16 can be viewed as a measure of impairment, since high scores indicate poorer functioning.

9.3.7.4 Usefulness and psychometric properties

Taken together, studies examining the psychometric properties of the LSP suggest that it has:

- Validity: Moderately good content, construct, concurrent and predictive validity;
- Reliability: High test-retest and adequate inter-rater reliability;
- Sensitivity to change: reasonably good sensitivity to change
- Acceptability: overall feasibility and utility of the LSP-16 have been published as moderately high. The majority of service providers had little difficulty with the language and viewed the questions as relevant, useful and effective in measuring outcomes for consumers.

Limitations:

- Relatively few studies have examined the LSP-16 specifically; far more have been concerned with the LSP-39. Additional analyses are needed to strengthen the evidence base regarding the shorter version.
- The instrument is said to lack relevance in particular settings.

9.3.8 World Health Organisation Disability Assessment Scale

The World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0) is an instrument developed by the WHO to assess behavioural limitations and restrictions to participation experienced by an individual.

9.3.8.1 Instrument description

The tool is a 36-item questionnaire that assesses functioning over the past 30 days in the following major life domains:

- Cognition (understanding and communication);
- Mobility (ability to move and get around);
- Self-care (ability to attend to personal hygiene, dressing and eating, and to live alone);
- Getting along (ability to interact with other people);
- Life activities (ability to carry out responsibility at home, work and school); and
- Participation in society (ability to engage in community and recreational activities)

9.3.8.2 Instrument administration

The tool can be either self-administered or administered via interview.

Each item on the self-administered version of the WHODAS 2.0 asks the individual to rate how much difficulty he or she has had in specific areas of functioning during the past 30 days.

The 36 item version of the WHODAS has been reported to take an average of 20 minutes of time for completion and 5 mins for the 12-item version.

9.3.8.3 Scoring

There are two basic options for computing the summary scores for the WHODAS 2.0 36-item full version.

Simple:

- The scores assigned to each of the items: “none” (1), “mild” (2), “moderate” (3), “severe” (4), and “extreme” (5), are added up without recoding or collapsing of response categories; thus, there is no weighting of individual items.
- The sum of items across all domains constitutes a statistic that is sufficient to describe the degree of functional limitations.

Complex:

- The more complex method of scoring considers multiple levels of difficulty for each item. It takes the coding for each item response as “none,” “mild,” “moderate,” “severe,” and “extreme” separately, and then uses a computer to determine the summary score by differentially weighting the items and the levels of severity. The computer program is available from the WHO Web site.
- The scoring has three steps: Step 1—Summing of recoded item scores within each domain; step 2—Summing of all six domain scores; and step 3—Converting the summary score into a metric ranging from 0 to 100 (where 0 = no disability; 100 = full disability).

WHODAS 2.0 Domain Scores: WHODAS 2.0 produces domain-specific scores for six different functioning domains: cognition, mobility, self-care, getting along, life activities (household and work/school) and participation.

9.3.8.4 Usefulness and psychometric properties

- **Validity:** concern has been noted regarding content validity. It has been found that consumers with psychotic disorders often do not identify impairments in functioning owing to thought disorder or social difficulties. This highlights the potential disparity between clinicians’ and consumers’ viewpoints, and raises concerns regarding the content validity of the WHODAS II in specific consumer groups.
- **Numerous studies have considered the concurrent validity of the WHODAS 2.0/II by examining the correlation of individual, subscale and total scores to that of some other instrument that are viewed as an acceptable measure of similar constructs. The WHODAS II has been shown to perform well against other relevant measures.**
- **Reliability:** the internal consistency and test-retest reliability have been determined as moderately high, with good stability across time, No studies were found that have examined the inter-rater reliability for the self-assessed version compared with the interview version.
- **Sensitivity to Change:** the WHODAS II/2.0 has demonstrated sensitivity to change in comparison with other scales.
- **Acceptability/ Usability:** It has been suggested that WHODASII/2.0 is a useful and suitable tool for assessing disability and functionality, that it may have the potential to aid in a clinical settings, and that including the viewpoint of the consumer provides additional useful information.
- **The WHODAS 2.0 performs well across cultures, different subgroups of the general population and among those with mental health problems or addictions, and provides standard scores for the general population, allowing normative comparisons.**
- **It has been reported that respondents found the questionnaire meaningful and relevant and that the 30-day time from was appropriate.**

Limitations:

- The long version of the tool has been said to be quite time consuming to complete.
- Studies have suggested that the consumers had problems distinguishing difficulties attributable to their health condition from other difficulties. For example, some respondents identified issues other than health impacting on functioning, such as time or money, which is outside of the scope of WHODAS 2.0

9.3.9 WHO Quality of Life Measure-BREF

The WHOQOL-BREF is a shorter version of the original WHOQOL and contains one item from each of the 24 facets in the WHOQoL-100, plus two items from the overall quality of life and general health facet.

The WHOQOL_BREF has been recommended for use at a population level rather than for individual assessment.

9.3.9.1 Instrument description

The Australian WHOQOL-BREF comprises 26 items that measure the broad domains of physical health, psychological health, social relationships and environment for the past two weeks.

9.3.9.2 Instrument administration

The WHOQOL-BREF is self-administered or can be completed via interview.

9.3.9.3 Scoring

All items are rated on a five-point Likert scale. Scores produce a quality of life profile and it is possible to derive individual domain scores.

9.3.9.4 Usefulness and psychometric properties:

- Validity: there is research support for the construct and concurrent validity of the scale.
- Sensitivity to change: evidence supports sensitivity to change.
- Acceptability/Usability: The Australian WHOQOL-BREF is specifically modified and tested to Australian population norms. The WHOQOL instruments have been designed primarily for use at a population level.

Limitations:

- Reliability: whilst the majority of factors (physical health, psychological, and environment) yield good to very good internal consistency throughout a variety of samples, the domain 'social relationships' showed poor to acceptable internal consistency.
- Very good test-retest reliability has been indicated however there have been suggestions of a relatively high degree of error (low reliability) at item level. These findings suggest that the WHOQOL-BREF is not

appropriate for individual assessment and is recommended for use at a population level.

9.3.10 Health Of the Nation Outcome Scale (HONOS)

The Health of the Nation Outcome Scales was developed to routinely measure outcomes for adults with mental illness. Comparable instruments were also developed for children and adolescents (HoNOSCA) and older people (HoNSO65+). All three are being widely used as outcome measures in the United Kingdom, Australia and New Zealand.

The HoNOS can be regarded as a general measure of mental health and social functioning in people with a mental illness.

9.3.10.1 Instrument description

The HoNOS comprises 12 items which collectively, cover the sorts of problems that may be experienced by people with a mental illness. It can be regarded as a general measure of severity of symptoms for this group. The items can be grouped into four subscales:

- Behaviour
- Impairment
- Symptoms
- Social

9.3.10.2 Instrument administration

The tool is a clinician administered instrument, designed to be used by any mental health clinician with appropriate training.

The clinician is expected to draw on all relevant and useful information to make their ratings, and will typically use information obtained from interview with or direct observation of the consumer, medical records, and consultation with his/her family, carer(s) and case worker(s).

The HoNOS can be administered in less than five minutes.

9.3.10.3 Scoring

Each item is rated on a five-point scale resulting in individual item scores, subscale scores and a total score.

In assigning ratings, the clinician makes use of a glossary which details the meaning of each point on the item being rated. The clinician rates the consumer on each of the items in terms of their assessment of the consumer's situation over the recent period (generally 2 weeks).

9.3.10.4 Usefulness and psychometric properties

Extensive testing has been undertaken of the psychometric properties of HoNOS. Collectively, the HoNOS family of measures can assess outcomes for different groups on a range of mental health-related constructs, and can be regarded as appropriate for routinely monitoring outcomes (Pirkis et al, 2005).

In terms of content validity:

- Some studies indicate consumer/carer advocacy groups and mental health professionals support the instrument as being appropriate, well-designed and thorough, and able to indicate changes in mental health status over time.
- The HoNOS has been shown to have reasonably good content, construct, concurrent and predictive validity.
- Studies have found fair to moderate test-retest and inter-rater reliability.

Limitations:

- Certain items have been shown to be consistently problematic (items 8,11,12) due to these specific items not accounting for complexity, accurate depiction of symptoms and presence of multiple problems.
- Anchor points and their associated terminology are subjective and might require clarification.
- Difficulties with knowing which item to use for rating some symptoms.
- The instrument is unable to consider factors such as culture, poverty, abuse, safety and risk, bereavement and medication compliance.
- Too much room for human error if the guidelines are not adhered to.
- Ratings can be influenced by rapport with and knowledge of the consumer, which is likely to increase over time.
- Some respondents have said that the HoNOS is a blunt instrument and may be open to misinterpretation.

9.3.11 Citizenship Measure

Citizenship relates to the strength of people's connections to the rights, responsibilities, roles, and resources that society offers to people through public and social institutions, and relationships involving close ties, supportive social networks, and associational life in one's community ('the 5 R's').

The Citizenship Measure (CM) was developed to assess the degree to which individuals, particularly those with psychiatric disorders, perceive themselves to be citizens in a multifaceted sense. The CM is the only referenced tool specifically designed to assess citizenship.

The authors of the tool used cluster analysis to narrow down 7 primary domains of citizenship:

- Personal responsibilities;
- Government and infrastructure;
- Caring for self and others;
- Civil rights;
- Legal rights;
- Choices, and
- World stewardship.

9.3.11.1 Instrument description

The CM is a scale of 46 items that represent the 7 domains of citizenship. For each item, consumers are asked, “Thinking about your life in general now, rate how much the item applies to you”.

9.3.11.2 Instrument administration

The CM is a self-report measure where consumers are asked to consider their responses based on the current point in time.

9.3.11.3 Scoring

Items are rated on a 5- point Likert scale (5 = strongly agree; 1 = strongly disagree). Each item is added for a total score indicating the degree to which an individual perceives social and community inclusion.

9.3.11.4 Usefulness and psychometric properties

The CM is still relatively new and although a validated instrument, still under-researched.

Limited studies have found the tool to be psychometrically sound and able to capture subjective information about the degree to which individuals experience rights, sense of belonging, and other factors associated with community membership. The measure establishes a platform for interventions to support the full participation in society of persons with mental illnesses^{cxiii}.

One study recommended combining the short CM and the short RAS as an outcome measure for recovery and citizenship-oriented services. The resulting tool would include 10 dimensions: Access to services; Basic needs; Goal and success orientation; Involvement in community; No domination by symptoms; Personal confidence and hope; Reliance on others; Respect by others; Self-determination; and Willingness to ask for help^{cxiv}.

9.3.12 Work and Social Adjustment Scale (WSAS)

9.3.12.1 Instrument description

The WSAS is a self-report scale of functional impairment attributable to an identified problem. It is a five-item scale with each item rated on a nine-point scale from 0 = no impairment to 8 = very severe impairment.

9.3.12.2 Scoring

The maximum score of the WSAS is 40; lower scores indicate higher degrees of functioning.

9.3.12.3 Usefulness and Psychometric properties

- **Validity:** a number of studies have considered the concurrent validity of the WSAS by assessing the relationship between symptom severity and the WSAS, which is designed to measure functional impairment that might be attributable to an identified problem or disorder. The WSAS has shown to be moderately correlated with relevant scales.

- **Reliability:** A number of studies have examined the internal consistency of the WSAS and found a moderately high level of internal consistency and test-retest reliability.
- **Sensitivity to change:** limited studies have examined change in WSAS over time with some indication of sensitivity.
- **Acceptability:** Many authors have proposed that the WSAS is a useful tool to measure disability with a range of consumer populations and additionally is able to discriminate between disorders. The WSAS has been described as brief and simple and has the potential for use in care planning and monitoring of a person's progress.

9.3.13 Living in the Community Questionnaire (LCQ)

The LCQ was developed as a consumer self-report measure that focuses on aspects of social inclusion and recovery.

The tool is a broad measure designed to explore aspects of a consumer's life in the community including social activities, participation in employment or study, living situation and physical health care.

9.3.13.1 Instrument description

The LCQ is a 33 item survey based on social activities, education activities, voluntary work, time spent caring for others, employment and living situation and reported physical health being antecedents of consumers' sense of being part of a community or a group.

The items are grouped to facilitate a person's reflection on the categories of activities in which they have been involved during certain time periods.

9.3.13.2 Instrument administration

As the order of questions and how they are grouped or banked has an impact on the ratings provided, it is essential that the sequence is maintained in all uses of the survey.

The LCQ is structured so that objective questions about the level of social participation are followed by subjective questions about the consumer's feelings regarding their social participation and desire for change.

9.3.13.3 Scoring

The scoring of the LCQ involves some technical complexity. In clinical practice total or subscale scores are somewhat meaningless and it is the individual items that provide a rich source of information to promote and continue a conversation with the consumer about aspects of their life and recovery.

9.3.13.4 Usefulness and Psychometric properties

The benefits of the LCQ for the consumer and clinician include:

- Supporting the process of assessment;
- Demonstrating a genuine interest in the individual's point of view;

- Encouraging dialogue between the clinicians and the consumer highlighting discrepancies between the individual's and clinician's perceptions; and
- Involving the consumer in the process of care planning.

In developing the tool, the draft tool was subject to several stages of testing consultation and development, which informed the final LCQ.

The instrument has been found to meet the minimum requirements for reliability and the changes made to the questionnaire worked as intended^{cxv}:

- Administrative: Rate of missing data and completion time were both reduced.
- Reliability: The questionnaire was found to have high levels of correlation between the test and retest scores, with moderate levels of intra-rater agreement. The stability of the results was found to be high.
- Modelling: The research was able to validate the underlying model of social inclusion. Causal modelling demonstrates that sense of being part of a group or community worked well as a dependent variable, being predicted by logical subjective social inclusion questions and strongly correlating with outcome and recovery questions.

9.3.14 Recovering Quality of Life (ReQoL)

In developing the ReQoL a number of domains were identified as important to quality of life and are aligned with the CHIME framework and include^{cxvixvii}:

- Wellbeing
- Relationships and a sense of belonging
- Activity
- Self-perception
- Autonomy
- Hope
- Physical health

9.3.14.1 Instrument description

The Recovering Quality of Life (ReQoL) measure was developed over four collaborative and inclusive stages, including seeking service user perspectives.

A pool of potential items which best represented the above seven domains was generated from current quality of life and recovery instruments and from service user interviews. After broad consultation, the item set was reduced to 88 potential items for the new 'Recovering Quality of Life' measure.

Two versions exist: ReQoL-10 and ReQoL-20. The measure is validated and capable of capturing service users' recovery in their quality of life in the consumer preferred recovery domains.

9.3.14.2 Instrument administration

ReQoL is considered a Patient Reported Outcome Measure (PROM)/self-reported tool, that has been developed to assess the quality of life for people with different mental health conditions.

9.3.14.3 Scoring

ReQoL-10 consists of 10 mental health questions and one physical health question and ReQoL-20 consists of 20 mental health questions and one physical health question.

Questions are answered by individuals on the basis of a 5 point Likert scale.

An overall index score can be calculated by summing the numbers for the each of the questions. The minimum score is 0 and the maximum is 40, where 0 indicates poorest quality of life and 40 indicates the highest quality of life.

9.3.14.4 Usefulness and Psychometric properties

Both versions of the ReQoL have been found to:

- Achieve acceptable internal consistency, test–retest reliability, known-group differences, convergence with related measures, and were responsive over time.
- Be deemed appropriate for measuring service-user recovery-focused quality of life outcomes.

The ReQoL measures offer a number of important advantages over existing measures, including:

- They have been built around the themes of recovery.
- They have excellent face and content validity and desirable properties in terms of reliability, construct validity and responsiveness.
- The measures have acceptability and feasibility in clinical practice.
- The measures contain a mixture of positive and negative items, a crucial element as people with mental health difficulties identified issues that both enhanced or depleted their quality of life.
- The presence of negative aspects increases the relevance of ReQoL as a patient reported measure of recovery in mental health populations.
- ReQoL was developed in conjunction with mental health service users, and is not based on symptoms from one disorder.

Limitations:

- Patient self-reported measure
- In the testing, respondents were not randomly selected and may not be representative of populations experiencing mental health difficulties.

- The developers had to rely on indirect methods of construct validity and responsiveness to provide evidence to support the properties of the measure.
- The measures need to be validated with different ethnic groups and languages.

9.4 Carer Tools

9.4.1 Carer Quality of Life

The CarerQol 7D+VAS is a 7-item self-report measure with two components.

- The burden component assesses seven burden dimensions, and
- The valuation component uses a visual analogue scale to ascertain level of happiness.

The burden component requires respondents to indicate whether they have no, some or a lot of problems or fulfilment/support regarding the given dimension. For problem-related items, no, some and a lot are scored 3, 2, and 1, respectively. For fulfilment/support items, reverse scoring applies, so a high score indicates a high level of burden. The valuation component allows for the calculation of a score from 0 = completely unhappy to 10 = completely happy.

9.4.2 Burden Assessment Scale

The Burden Assessment Scale (BAS) was developed in the USA to measure the consequences of providing ongoing care to people with severe mental illness, in particular schizophrenia (Reinhard et al., 1994). The questionnaire consists of 19 questions and predominately focuses on "burden of care" rather than the wellness or strengths of a caregiver. This has been cited to be one of the primary limitations of the tools (Dare et al., 2008).

The questionnaire can be completed by the carer/significant other or administered by a clinician; which can help to stimulate conversation about any issues most affecting the carer/significant other (Dare et al., 2008)^{cxviii}.

Questions are asked over the previous four weeks and are grouped into the following categories:

- Disrupted activities
- Personal distress
- Time perspective
- Guilt
- Basic social functioning / Worry

9.5 Other Tools for Consideration

9.5.1 Recovery Star

The Recovery Star was developed as an outcomes measure that enables consumers to measure their own recovery progress, with the help of mental health workers or others.

The 'star' contains ten areas covering the main aspects of people's lives, including: living skills, relationships, work and identity and self-esteem.

Consumers set their personal goals within each area and measure over time how far they are progressing towards these goals. This can help them identify their goals and what support they need to reach them, and ensure they are making progress, however gradual, which itself can encourage hope.

The Recovery Star enables staff to support individuals they work with to understand their recovery and plot their progress and also enables organisations to measure and assess the effectiveness of their services. The 'Star' has been found to be more useful as a care planning tool rather than a global outcome measure^{cxix}.

9.5.2 Questionnaire about the Process of Recovery (QPR)

The QPR was developed in conjunction with consumers specifically to measure recovery from psychosis. There are 2 versions, a 15 item and 22 item questionnaire.

The QPR has two subscales:

- The intrapersonal scale is made up of 17 item scores assessing tasks for which the consumer is responsible and that are carried out to facilitate recovery, and
- The interpersonal scale of 5 items relates 'to individuals' ability to reflect on their value in the external world and on how recovery is facilitated by external processes and interpersonal relationships with others'

9.6 Comparison Table

Tool	Implemented by non-expert	Objective understanding of outcome	Measures Relevant things	Meaningful to participants
RAS	✓	Domain & composite score (D&C)	Recovery	✓
IMRS	✓	Composite score	Illness & recovery	✓
STORI	✓	Domain scores	Recovery	✓
RPI	✓	Unknown	Recovery	✓
CANSAS	✓	D&C	Multidimensional	✓
K10+	✓	Composite score	Cognition & emotion	✓
LSP	✓	D&C	Functioning	Limited

WHODAS	✓	D&C	Functioning	✓
WHOQOL	✓	D&C	Quality of life	Not really
HONOS	✓	D&C	Multidimensional	Limited
CM	✓	Composite	Social inclusion	✓
WSAS	✓	Composite	Functioning	Limited
LCQ	complex	D&C	Social inclusion	✓
ReQoL	✓	Domain scores	Quality of life & functioning	✓

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