Anglicare Australia submission to the Joint Standing Committee on the NDIS inquiry into the provision of services under the NDIS for people with a psychosocial disability relating to a mental health condition

- Attachment 1
AnglicareSA comments prepared for the Anglicare Australia response for the Joint Standing Committee on the NDIS inquiry into “the provision of services the NDIS for people with psychosocial disabilities related to a mental health condition”.

Overall comments

AnglicareSA supports approximately 58,000 vulnerable and at-risk South Australians annually, including more than 850 children and adults with physical and/or intellectual disabilities. Many of our services continue to evolve through co-design and collaboration with consumers and their primary carer/s.

People with psychosocial disabilities related to a mental illness are amongst the most vulnerable individuals in our communities, particularly those who experience mental illness alongside co-morbidities such as homelessness, contact with the justice system, alcohol and other drug dependencies, family breakdown etc.

Accessing NDIS requires a level of ability to understand and navigate complex systems, and to articulate and advocate for one’s needs, either by participants or by families/guardians. Without this, they are vulnerable to exploitative behaviour, and experience increased barriers to access NDIS.

AnglicareSA has observed some concerning trends in the roll-out of the NDIS, which will create extra burden on and barriers for people with psychosocial disabilities (and other vulnerable individuals). These include:

- **Unmet needs for psychosocial disabilities:** Based on figures from Mental Health Australia, that “approximately 625,000 people in Australia experience severe mental illness, the NDIS at full roll-out will support only 10% (64,000) of Australia’s (current) population experiencing mental illness”\(^2\).

  AnglicareSA believes it is imperative to recognise this unmet need and acknowledge the likely repercussions such as increased presentations to emergency services such as hospitals and homeless shelters and the likely increase in crime if funding for alternative community-based mental health services is discontinued.

- **Price-driven behaviour:** NDIS pricing assumptions assume up to 95% of income is spent on client facing time. This, together with the comparatively low standard support rate of

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\(^1\) 46% (290,000) access some form of community support (individual, group or non-acute residential) – this excludes the 153,000 mental health carers who require some form of support.

\(^2\) Mental Health Australia “The implementation and operation for the psychiatric disability elements of the National Disability Insurance Scheme: A recommended set of approaches”
$43.58/hour (significantly less than the majority of current social service contracts), will potentially impact organisations’ ability to invest time, patience and effort in communicating with and helping individuals understand the process and opportunities available through NDIS. It may also trigger exploitative practices by agencies in the way they engage staff and support customers. This could also contribute to agency’s ‘cherry picking’ high needs or high-value customers, thereby, overlooking individuals less likely to secure high value support.

- **ILC and LAC focus on sector capability building:** The ability for Information, Linkages and Capacity (ILC) and Local Area Coordinator (LAC) funding to fill the gap in supporting individuals ineligible for NDIS is to-date unproven. If the responsibility for ‘case coordination’ for people ineligible for NDIS falls entirely to LAC’s, the system will fail for the following reasons (i) no new capacity is being created in mainstream or community services to support this cohort; and, (ii) some of these people will have high and complex needs that require intensive, specialist support that exceeds LAC’s ability for case coordination.

AnglicareSA believes that unless a portion of ILC/LAC funding is reconfigured to fund some continuity of community based mental health services; or, alternative funding is secured, vulnerable clients will fall through the gaps, impacting emergency and acute services.

- **Planning via Phone:** NDIA planners’ preference for conducting planning meetings over the phone is heightening anxiety for participants, and potentially disadvantaging participants who are unable to understand or articulate their needs well.

- **Limiting support agency roles in planning:** AnglicareSA understands the intent of NDIA to limit the involvement of agencies in planning processes, however, doing so can potentially increase the risk for and vulnerability of some cohorts, particularly those who are socially isolated or have limited family/support networks.

1 That the joint committee inquire into and report on the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition, with particular reference to:

a the eligibility criteria for the NDIS for people with a psychosocial disability;

The NDIS eligibility criteria for a condition identified as “always resulting in permanent impairment and substantially reduced functional capacity” contradicts existing mental health recovery frameworks and practice. Furthermore, the episodic nature of mental illness, means classifying it as a permanent impairment contradicts both what we understand about mental illness and a recovery framework. Therefore, the eligibility criteria for people with a psychosocial disability is narrow and restrictive. This was illustrated by the Mind Australia NDIS report “Supporting mental health recovery 2014”, which demonstrated a relatively good recovery rate for people experiencing a single episode of major depression (35-75%), in contrast to schizophrenia which had the lowest recovery rate of 14%. This evidence indicates the inherent challenge of the current eligibility criteria for the NDIS for people with psychosocial disability, and pays little recognition to the extensive evidence based recovery models developed to-date, which have helped to both destigmatise mental
illness, and enable effective and lower cost community support services rather than traditional clinical models of support.

b the transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular;

i whether these services will continue to be provided for people deemed ineligible for the NDIS;

AnglicareSA believes a policy commitment across Federal and State Government is needed to clarify how people with psychosocial disabilities will be supported outside of NDIS. Defunding current community based mental health services will generate a significant gap in service delivery, resulting in increased acute presentations to emergency facilities, including emergency departments, homeless shelters and prisons (where we know people with mental illness are already over-represented).

AnglicareSA can speak to the need for this from direct experience. For example, PHaMs has been classified as 100% in-scope for NDIS, however, a participant audit of our PHaMs services indicate that the clinical ‘psychotic’ disorders anecdotally deemed ‘in-scope’ for NDIS such as schizophrenia, bipolar and schizo affective disorder account for approximately 30% of participant’s diagnosis. Depression and anxiety, often experienced together account for nearly 70% of client’s diagnosis. Our two PHaMs services support 150 participants at any one time with a waiting list of up to six weeks.

In contrast, AnglicareSA’s Exceptional Needs service provides supported accommodation for people with high and complex needs experiencing homelessness. The majority of these participants have clinical psychotic diagnosis, however, due to the depth and breadth of their needs and co-morbidities, including ‘safety risks’ for self and community, initial financial modelling suggests the level of support required may exceed the supported accommodation rates provided by NDIS. A planned and collaborative approach between NDIS, current funders and providers is needed to ensure the most vulnerable are supported to access the level of support required. For example, South Australia’s Exceptional Needs unit within the Department of Community and Social Inclusion has traditionally been responsible for sourcing funding for high and complex needs individuals who interface with multiple different service systems. This approach recognises the interdependencies between multiple risk factors and the need to manage them holistically.

For example, John* was referred to our Exceptional Needs supported accommodation when he was experiencing homelessness. John* arrived battered and bruised, and had just been released from hospital due to his injuries. John* had moved 20 times in the last 5 years and had a long history of transiency and frequent placement breakdowns due to his erratic behaviours. John* subsequently became homeless, associating with drug taking peers where he was vulnerable to abuse, assault and exploitation. John* frequently referred to himself as a “loser” and felt that he was unable to achieve what others in the community achieved such as a job, a home and family. He became agitated easily, was verbally aggressive and
threatening resulting him being banned from several premises including banks, supermarkets etc.

On accessing accommodation through AnglicareSA, John* had a thorough Mental Health assessment and is now receiving appropriate treatment which has improved his mood and anger to the point where he has been able to participate in social activities and groups for the first time. Positive reports have been received with regards to his behaviour and he has been described as polite and helpful. Due to the rapport he has built with accommodation staff, his mistrust has diminished and his social skills have grown, improving his positive interactions, which in turn have improved his self-esteem. He now goes to the shops on his own to purchase items and is connected with and accepted within the community.

John* has recently moved into his own house where he receives Outreach support to help maintain his home and learn cooking skills. In just over 12 months John* has come such a long way in his journey for independence and acceptance with AnglicareSA’s help.

The probability of NDIS only funding the highest needs people with mental illness was further alluded to in the recent Mental Health Coordinating Council’s (MHCC) report, ‘Navigating the NDIS: Lessons Learned through the Hunter Trial’, consistently referencing that NDIS will support people with high psychosocial disabilities.

It is absolutely critical for Federal and State Government, and the sector to work together to plan for and secure ongoing funding for community mental health services such as PHaMs, PIR and Mental Health Respite to operate outside the scope of NDIS.

c. the transition to the NDIS of all current long and short term mental health state and territory government funded services, and in particular;

i. whether these services will continue to be provided for people deemed ineligible for the NDIS;

AnglicareSA believes it is both unrealistic and undesirable to transfer all current long and short term mental health state and territory government funded services to the NDIS, particularly when it is clear that NDIS will only support 10% of Australia’s experiencing a severe mental illness.

Community based mental health services are more affordable, effective and provide the added benefit of keeping people out of tertiary services such as hospitals, and in their homes and communities. They do this by keeping people connected to their communities, their support networks and working with them to ‘self-manage’ their fluctuating health needs.

AnglicareSA believes the financial and operational sustainability of both the NDIS and Australia’s health system, hinges on continuing to fund evidence-based, community driven services. To achieve this, AnglicareSA welcomes the opportunity to work with the Government in the scoping and
redesign of community based mental health and other services to ensure resources are invested in the most relevant and cost effective services.

The South Australian Government recently announced it’s intention to continue providing supported accommodation services in a competitive NDIS environment. This creates a potential conflict of interest between the Government being a provider and funder of services, and will need transparent governance and accountability processes to ensure sound management.

A further limitation of not funding community based programs, is foregoing the intellectual property evidence that has been amassed through these services. AnglicareSA is particularly concerned about the long-term viability of peer learning and group programs through the NDIS. Current sector feedback involves common themes of very poor viability, high risk and limited room for community-based supports. AnglicareSA’s Mental Health Respite (MHR) program has developed an excellent dual support approach for participants and carers. The program is highly successful and recognises the need to work holistically and inclusively with individuals and their support networks; strengthening and supporting them together increases the resilience and capability for them to function better and more sustainably over the longer term, as illustrated in the following case study:

Jane*, who has been diagnosed with paranoid schizophrenia, depression and severe anxiety, lives in the family home with her 64 year old mother Mary*, her primary carer, and father Ron*, who has a significant physical disability. Mary contacted AnglicareSA in significant personal crisis in 2010, in a desperate plea for help. Mary’s extended family had turned their backs on her many years ago as they didn’t understand her situation and she had essentially been housebound in her carer role for over 18 years. Mary had limited involvement in the community other than going to the shopping centre for groceries at night whilst her husband and daughter were sleeping. Mary discussed her feelings of worthlessness and fatigue. Mary contemplated whether her family appreciated her support as she fielded verbal and emotional abuse daily and wondered how long she was able to endure this day in day out. Mary discussed her ongoing suicidal thoughts as she believed the system would take over the care of her family, if she was no longer able.

Jane* is 32 years old. She had not left the home since she returned from high school one day in 1999, after being bullied by classmates and constant feelings people were following her. Jane experienced hearing voices which became louder and more intense once she opened the front door and had refused to go near the door for many years. Jane spent her time watching Netflix and drawing comics. Jane played the Xbox and talked to people online daily. Jane was significantly overweight and found it difficult to get along with her parents as she felt they didn’t understand her and asked too many questions.

AnglicareSA through DSS funding of the Mental Health Respite program, was able to implement both immediate and ongoing holistic supports that met both Mary and Jane’s needs. A staff member was able to provide immediate counselling assistance over the phone to Mary de-escalating her heightened state of distress and reassuring her that assistance was available. The staff member organised a worker to attend the home the following day to discuss the support needs of Mary and Jane, and to plan initial goals which would pave the way for a brighter future for the family. Respite support began that week with a worker attending the home to build rapport with Jane whilst Mary was able to spend time cleaning or supporting Ron. Over time, Jane began to increasingly trust the worker and agreed to slowly tackle her anxiety relating to leaving the home. At first the worker talked to Jane through a crack in the door, and then as Jane became familiar with this, the worker sat in the patio and talked to Jane whilst she held the door open. 4 months later, Jane held the worker’s arm and walked behind her to the letterbox collecting the mail for the first time since high school. Jane and her worker had their first coffee at the local shopping centre 6 and a half months after support began. Jane then began attending the AnglicareSA
Mental Health Respite day community engagement groups once a week which gave her mother a day to herself. Almost a year after joining the group, Jane announced that she was enrolling in TAFE and wanted to complete a certificate. Jane is currently working 4 days a week now, has her driver’s license and takes her mother to the coffee shop she first went with the worker regularly. Jane lives in her own unit now and comes in to visit AnglicareSA every now and then to give an update on where she is at.

Mary was linked in to counselling immediately and encouraged to contact the program whenever she felt the need for extra support or just an ear to listen. Initially two support workers attended the home to provide support both to Jane and Mary although, as Jane’s dependence on her mother decreased Mary was able to engage in the Carer programs also. Mary attended the I am..Caring 6 week wellbeing program, the self-defence classes which helped to boost her confidence and several other carer events where she cemented friendships and was able to reduce her social isolation.

Mary and Jane’s level of support increased and decreased over several years however, they always knew that they had an ongoing, trusting relationship with the program. They were both able to discuss support needs and choose the intensity of their support. They continue to attend events and educational programs where they have built connections and feel able to discuss their journey with others who are just beginning.

*names have been changed for confidentiality

d the scope and level of funding for mental health services under the Information, Linkages and Capacity building framework;

AnglicareSA is not aware of any funding for mental health services under the ILC building framework. From our experience, one of the original intents of the ILC was to provide funding for services that are best suited to block funding, i.e. their viability and model of service would be compromised under an individualized funding arrangement, such as peer support programs or innovative services which have evolved from block funded programs (such as AnglicareSA’s Mental Health Respite service) which offer dual support for both participants and carers.

As indicated above, AnglicareSA believes that a strong policy and funding commitment is needed for community mental health services which extends beyond the significant limitations of the ILC building services.

e the planning process for people with a psychosocial disability, and the role of primary health networks in that process;

AnglicareSA’s experience is that the cognitive barriers experienced by people with a psychosocial disability together with a recurring theme of social isolation compromises their ability to access NDIS. Primary health networks have a role to play in this by way of referral, however, AnglicareSA’s experience is that significant time is needed to support people with psychosocial disabilities to understand and engage in the necessary steps to access NDIS – combined with barriers such as transport, social isolation, anxiety etc, there is a very high probability that referrals will not be pursued to the extent required to engage many of the target cohort.

f whether spending on services for people with a psychosocial disability is in line with projections;
Outreach services are absolutely essential to identifying and supporting participants with psychosocial disability. This is particularly challenging in an NDIS environment, where transport is poorly funded, and providers are facing severe financial restrictions in accommodating transport without putting pressure on participants or workers to personally absorb transport costs. AnglicareSA believes current pricing arrangements will reduce the viability of outreach, thereby, further marginalizing participant’s who are socially or physically isolated. This could also incentivise providers to take advantage of workers, which could act to further marginalize one of Australia’s lowest paid and increasingly insecure (by way of casualisation) group of workers.