Anglicare Australia
in every Community

Submission to National Disability Agreement Review

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About Anglicare Australia

Anglicare Australia is a network of independent local, state, national and international organisations that are linked to the Anglican Church and are joined by values of service, innovation, leadership and the Christian faith that every individual has intrinsic value. With a joint budget of $1.48 billion, a workforce of over 18,000 staff and more than 11,000 volunteers, the Anglicare Network contributes to more than 50 service areas in the community. Our services are delivered to more than one million Australians, in partnership with them, the communities in which they live, and other like-minded organisations in those areas.

Anglicare Australia has as its Mission "to engage with all Australians to create communities of resilience, hope and justice". Our first strategic goal charges us with reaching this by "influencing social and economic policy across Australia…informed by research and the practical experience of the Anglicare Australia network".

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Introduction

Anglicare Australia is pleased to contribute to the Productivity Commission's review of the National Disability Agreement.

This submission draws on the experience of the Anglicare Australia Network, delivering services to people with disability and their carers in every state and territory. In 2016-17, the Network supported over 16,600 people through a range of disability support, disability employment, carer support and respite services. The Anglicare Australia Network has been active in supporting clients to transition to the NDIS and in advocating for an effective disability support system. We would particularly like to thank Kate Rush at Anglicare South Australia for her work in co-authoring this submission.

Anglicare Australia firmly believes there remains a need for a national agreement which provides clear accountability for each level of Government for their responsibility of working towards the full inclusion of people with disability in society. This agreement must particularly give assurance of support for those for whom mainstream services are not appropriate or not accessible, whether due to ineligibility for the NDIS, residence in a rural or remote area, the nature of their disability or level of care requirements, or other vulnerability. It is the fundamental responsibility of government to ensure the availability of appropriate support services for every Australian who needs them, with particular consideration for those who are most vulnerable.

However, in the introduction of the NDIS, attempted cost-shifting between State, Territory and Commonwealth Governments has left many people without access to necessary supports. The debates around who pays for what must be resolved in the new agreement, such that a reviewed NDA ensures no-one is left without appropriate support. The agreement should emphasise a person-centred approach which prioritises the needs of individuals above bureaucratic systems, as was the intention of the NDIS reform.

Scope of the NDA

Anglicare Australia supports the continuance of a National Disability Agreement which is broad in scope, covering all people with a disability in Australia. It is imperative to retain a national strategy for the full participation of all people with a disability in the Australian community, particularly as the NDIS now defines "who is in and who is out" of core support services primarily based on an actuarial insurance model, rather than being inclusive for all. The NDIS must be accountable to the aspirations of a higher level strategy to support the full participation of people with a disability, and a strategy that provides direction for the provision of support outside the NDIS is essential.

In covering all people with a disability, this strategy should refer to the entire range of supports and interventions, from intensive individual support services to enforcing building standard codes and the provision of appropriate infrastructure to ensure accessibility. All levels of government have a responsibility to ensure that all of the services they provide and fund are supportive of inclusion of people with a disability. For example, the lack of sufficient provision for transport including insufficient funding in NDIS participant plans, or the lack of available transport for people with disability not funded by the NDIS, is an extremely significant barrier to participation that must be addressed more broadly, with clear goals and responsibilities for all levels of government identified and acted on.

NDIS and other services

The Anglicare Australia Network provides an extensive range of social support services and so witnesses the impact on clients of the (dis)connection between the NDIS and other service systems. Anglicare Australia is extremely concerned for individuals who have lost access to services as the State, Territory and Commonwealth Governments all try to shift and shirk responsibility for funding. We have noted particular impacts in mental health/psychosocial support services, health services, employment services, the justice system and Out of Home Care (OOHC), impacting both people who are eligible and ineligible for the NDIS.

The lack of appropriate pathways for people accessing mental health support services who are not eligible for the NDIS is of utmost concern, and remains a crucial issue despite continuous advocacy from the sector. This has severe consequences, for example one member has supported several hundred clients through the Personal Helpers and Mentors program. It is expected that about 30% of these clients will not be eligible for the NDIS, and there is no clear pathway of alternate support for them. While some funding for continuity of support was announced in the 2018-19 Federal Budget,[1] this is nowhere near what is needed or even what was previously available.

There are also issues facing those who are eligible for the NDIS. Anecdotal evidence from Anglicare Tasmania workers supporting clients with psychosocial disability is that the process of establishing and reviewing an NDIS plan is very demanding, and some clients disengage as it is too difficult. At present, the NDIS system is not suited to everyone with psychosocial disabilities, but governments are withdrawing other significant support systems (such as community mental health services) – leaving a chasm for those who do not access the NDIS.

[1] In the 2018-19 Budget the Government announced $92.1 million over five years from 2017-18 “to ensure continuity of support for people who are not eligible for the National Disability Insurance Scheme (NDIS), but are currently receiving support under programs that are transitioning to the NDIS” (Budget Paper 2, p 176)

The introduction of the NDIS and removal of other support services has also impacted the ability of people with a disability to access necessary health supports. For example, Anglicare Southern Queensland supports clients who in their transition to the NDIS lost access to health support for routine nursing care such as for catheter changes and wound care, previously funded through Queensland Community Care Services (QCCS). While a person becomes ineligible for QCCS once their NDIS plan is approved, the NDIS does not cover these supports which were previously the responsibility of health. Anglicare Southern Queensland supports a number of clients to access existing health services as an alternative, however this is not possible for every client. An interim Health Interface Support arrangement is now in place which allows agencies to continue to provide nursing services where there is a gap following client transition to the NDIS, and no alternative arrangement is possible. A long-term agreement is needed which ensures ongoing access. It is understood that Queensland Disability Services and the Department of Health are working with the NDIA and Commonwealth Department of Health to develop such an agreement, which must confirm responsibility of funding and ensure ongoing access to necessary health services for NDIS participants.

There are similar difficulties in the area of employment services. For example, an Anglicare Australia member reported a concern where a client had previously been funded for support in her workplace through disability services, but their NDIS plan did not provide funding for this on the basis that employment services should be responsible. The client was in a regional area where there was no alternative option and the Local Area Coordinator did not have strong enough local networks to assist. EPIC Assist, a member of the Anglicare Australia Network, is working with the Department of Social Services and the NDIA to ensure an appropriate pathway is established for NDIS participants to engage with Disability Employment Services (currently funded by DSS for people with a disability who are able to work a minimum of 8hrs per week). Participants who want to work but are not yet capable of working 8 hours in a week should be able to be supported through their NDIS Plan to improve their capacity, and then transition to DES and long term sustainable employment. There is currently a lot of uncertainty about this pathway and access to employment services previously funded by state governments, while negotiations on funding responsibility continue between DSS and the NDIA.

Similar issues in negotiating who funds particular services are impacting children and young people in the OOHC system. It is much harder to collect the information necessary to prove eligibility for the NDIS for children or young people in OOHC. Further, there is no funding to access psychometric testing necessary to prove eligibility in many cases, as for example in NSW, there is a lack of consistency with the NDIA planners and NSW Department of Family and Community Services identifying it is the responsibility of the other to fund this. In most cases this is being paid for from the funding provided to OOHC services.

One of our members has also seen a lack of support coordination for young NDIS participants in care, as while the NDIA Planners are stating this should be covered by the OOHC case management role, this is an entirely different kind of support to disability services support coordination, as the need is disability specific and as such, requires the coordination of a person with strong skills in the area of disability.

These examples demonstrate the complexity and consequences of the interaction between the NDIS and other service systems, and the detriment of cost-shifting and removal of services where funding for these supports does not exist under the NDIS. These funding and service changes impact both people who are eligible and ineligible for the NDIS.

It is imperative that there is clear agreement moving forward as to what Federal and State and Territory Governments are responsible to fund and deliver. This agreement should be informed by mapping the interface between services and jurisdictions to ensure governments build appropriate service capacity and expertise, and can provide clear advice and support to any person with a disability, regardless of which service they first approach - a " no wrong door" ethos. Without this, the current situation will continue, with significant gaps in services for people with a disability to the great detriment of personal and societal wellbeing.

Role of Government

The NDA should clearly articulate and differentiate the roles of State, Territory and Federal Governments in working towards the full participation of people with a disability in our society. The role of all governments in supporting the objectives of the NDA must include:

1. Monitoring and safeguarding the rights of people with a disability and ensuring all services are compliant with measures that protect these rights and promote intended NDA outcomes. This includes the funding of independent advocacy services for people with a disability to ensure personal rights. It also entails the enforcement of broader regulations designed to enable these rights to be exercised - such as accessible building standards, public transport and discrimination laws.

2. The provision of services that are identified market gaps (or potential market failures) in the NDIS; or not included within the NDIS but are critical to the objectives of the NDA, for example community-based mental health services.

3. Ensuring a positive and beneficial interface between the NDIS and mainstream services, including but not limited to child protection, health, legal services (including prisons), employment and education.

4. Determining the provider of last resort in each jurisdiction for the NDIS – currently it seems no-one has clear responsibility, leading to great uncertainty and vulnerability for participants, as providers have the option to refuse service. This is particularly concerning for example for people in need of significant positive behavioural support where this is not recognised in the funding allocation in in their plan.

Outcome and performance measures of the NDA

In general, the objectives, outcomes and outputs of the NDA remain relevant. However, greater detail is required to ensure performance measures achieve meaningful improvements in the lives of people with a disability and their communities. Outcomes should be defined as achievable within set timeframes where they are attached to funding and where they are aimed at addressing people's needs or circumstances that pose immediate risk to health and human rights. Outcomes or goals should be defined as aspirational where they relate to broader societal benefits (comprising government, business and community groups), such as the economic, health and productivity benefits of societies that are actively inclusive of people with a disability.

In relation to the 3 specific performance benchmarks of the NDA, further detailed commentary is provided below:

1. People with disability achieve economic participation and social inclusion
Clarity needs to be provided on the expected contributions of stakeholders of the NDA in realising its outcomes and measuring performance indicators. Most notably, NDIS service providers must be held accountable for their engagement of NDIS participants and their contribution to improving participant economic participation and social inclusion.

This is critical to progressing the outcomes of the NDA. Given the current lack of focus on this in the NDIS, it is not surprising that the Performance Dashboard reported that the proportion of people with disability who participate in social and community activities has declined, from 76.6 per cent in 2009, to 71.4 per cent in 2015.[2] Currently the NDIS pricing for most supports barely covers operational costs, and this would need to be increased to include an investment element to allow providers to expand service provision and built assets that facilitate social participation.

[2] SCRGSP 2018

As a contributor to the NDA objectives, evaluation of the NDIS must include:

- Measurable change or improvement in economic and community participation
- Community participation that includes increased levels of participation in non-disability specific activities (i.e. inclusion in 'mainstream' opportunities)
- Measurable increases in the number of people with a disability who are in employment
- Measurable decreases in the number of people with disability living on or below the poverty line in Australia this is currently twice the national OECD average
- Outcome measurements defined above to include specific measurements relating to economic and community participation of Aboriginal and Torres Strait Islanders and culturally and linguistically diverse people

2. People with disability enjoy choice, wellbeing, and the opportunity to live as independently as possible

In addition, the NDA outcome measurement of 'choice' must be better defined, particularly for people with a disability who are considered most vulnerable and isolated such as people with a disability who are:

- residing in regional and remote areas;
- living in accommodation services that place them at risk of homelessness due to a lack of tenancy rights or agreements (for example, Supported Residential Facilities);
- not eligible for the NDIS; or
- for whom their primary diagnosis is a psychosocial disability.

The definition of choice must include evidence that demonstrates (including on investigation) that participants have shown capacity and willingness to make decisions regarding services accessed, and that barriers are actively addressed where appropriate choices are not available (such as for young people with a disability living in aged care facilities).

3. Families and carers are well supported

A measurement for this benchmark must be developed and included in the Performance Benchmark, noting that it is not currently included. Outcomes must include a focus on:

- Carers, including family members, being supported to actively support those they care for, recognising that in a majority of cases, this form of support is highly valued by people with a disability. Support for carers must include training and development opportunities (which includes the provision of respite to enable carer participation), the provision of informal peer-to-peer support which is highly valued by carers and the provision of respite to promote the sustainability of the carer relationship and role.

- The capacity for carers to choose to participate in community, through employment or social means, should they wish to. This provides support for the carer's personal and mental wellbeing and offers economic and social benefits to the community. Respite or community participation of people with a disability who are being cared for by informal carer supports must be directly acknowledged as a key factor in realising this outcome.
- A pathway for carers to transition from needing to provide essential care, should it be desired by either the person with a disability or the person providing informal care. There is a severe over-reliance on informal care by relatives within our community that is taken for granted, and ignores the reality that at times these arrangements are harmful to both carer and care receiver. Assumptions that relatives are always the preferred and best forms of support need to be challenged within the NDA to ensure that governments fund sufficient professional care for people with disability so that genuine choice is available to both people with disability, and their family.

Reporting performance outcomes

As discussed above, Anglicare Australia firmly believes it is possible and essential to distinguish the performance objectives and outcomes of the NDA and the NDIS. The NDIS must be accountable to the higher level objectives of the NDA to promote the full participation of people with disability and their families and carers.

A national performance reporting system that is actively contributed to by all key stakeholders in the NDA, including NDIS providers, would have marked benefits in monitoring markets and NDA performance indicators. Currently the datasets made available provide limited information and do not provide enough detail on both market activity and intended outcomes for people with a disability. Greater opportunities for collating data from all stakeholders is needed, and this includes the provision of funding to enable active participation in reporting data on a regular basis.