

Submission to the National Disability Agreement Review



About DCLS

DCLS is a multi-disciplinary service providing general legal advice and assistance, a tenancy service, and a specialised Seniors and Disability Rights Service providing advocacy support in the areas of ageing and disability. We work to promote understanding, create awareness and empower our community, to support access to services and rights, and to advocate for change that promotes fairness and justice.

As service providers we are in a unique position to test policy and strategy, as represented in overarching agreements such as the National Disability Agreement, for impact on the ground.

Overview

The Agreement and the accompanying National Disability Strategy do not appear to have any influence on either policy or service delivery and have not served to inform a coherent or coordinated approach to program and service delivery.

A connected and consistent system has been undermined by the focus on the NDIS, which has drawn all the attention and sucked all the oxygen out of the sector. For the three quarters of NT people with disabilities not covered by the NDIS there is a perception that disability supports and services are being wound down or are somehow inferior and under-resourced.

Current reform priorities, and in particular the roll out of NDIS, seem to have jettisoned the subsidiarity principle. The one size fits all approach of the NDIS, with practice directions emanating from a Geelong office and applied to circumstances in Ampilatwatja, is neither responsive or appropriate. For a tailored service it is particularly inflexible.

A strategy based on competition and choice where there is no competition and choice serves only to disadvantage those who are already significantly disadvantaged. The Agreement needs to fill the gaps and ensure provision of equity of access to a quality disability support system no matter where you live.

Review Scope

- The relevance of the objectives, outcomes and outputs of the NDA in the context of contemporary policy settings

The **objective** is still sound:

“People with disability and their carers have an enhanced quality of life and participate as valued members of the community”

The **outcomes** could be strengthened;

- (a) People with disability achieve economic participation and social inclusion;
- (b) People with disability enjoy ~~choice and~~ wellbeing and the opportunity to live as independently as possible
- (c) Families and carers *are appropriately recognised* and well supported.

DCLS suggests the inclusion of a further vital outcome:

- (d) Build the capacity and skills of the sector and families and carers.

The reference to choice in outcome (b) should be removed. Choice is not an outcome and not often the subject of enjoyment, particularly if you live in the Northern Territory (NT).

The focus on choice and competition in recent policy reform has had a profound effect on some of the most disadvantaged people in the country, A market-based scheme assumes there is a market. In the NT, the services people need often don't exist in regional locations. If the service does exist there is likely to be only one provider. In these situations, monopoly providers are able to exploit the market with over servicing, inadequate service provision, or poor-quality services.

Informed choice is not a reality and should not be a full-time job. It is not very often we are asked “what do we want?”. In terms of health and wellbeing we may not have the necessary advice and expertise to determine what will make a difference. The responsibility has shifted to the disabled person or their family, to design and secure appropriate services. And if services are not available and the choice is between nothing and nothing, there is no choice.

The **outputs** would ideally prescribe that *services are needs-based with equitable access no matter where you live*. Outputs should also include the *development and maintenance of consistent and appropriate quality standards*.

- Progress against the performance framework of the NDA and the extent to which it has supported improved outcomes for people with disability, their families and carers including performance benchmarks and indicators, and associated timeframes and reporting responsibilities;

None of the performance indicators are on track, nor are they credible measures of outcomes. Assessing impact is not possible without identifying people at risk, still an uncharted area, even in relation to the NDIS. Given the extent of disability is largely unidentified (particularly in the NT) performance indicators that reference proportions of an unknown number are not going to indicate anything.

The focus on quantitative KPIs in the Agreement is misguided and does not necessarily reflect the complexities in the system, the impact of policy and program interventions, and the extent of challenges and circumstances faced by people with a disability. Nor do they address confounding factors such as discrimination. The performance framework should be supported by a program logic that both draws on evidence and commits to improved information gathering and review and monitoring.

Figures indicating reductions in people requesting a need for more formal assistance are not surprising to us as people are giving up on the system rather than having their needs met. Requests are low because there is no point requesting where assistance is not available. The low uptake for the NDIS in the Northern Territory, for example, illustrates difficulty and complexity of access, and lack of available services and support.

A particular issue in the NT is support for carers and families. In remote areas there are no or limited services and no respite. Without this it is impossible for carers to participate in the labour force. The irony is that there was some optimism that the NDIS might appropriately recognise the work of family members and the role they play in providing care and support, particularly where there are no services available. Despite a burgeoning industry of largely unregulated private services seeing the NDIS as a cash cow, family and community carers are continuing to do the hard yards, often seeing supports such as access to respite reduced. Since the introduction of the NDIS, DCLS have seen many cases of carers reluctantly relinquishing their guardianship to public guardianship because of a reduction in support and services. The cost to the public purse in these cases is far in excess of even a gold standard of support extended to support the carer's contribution.

In Aboriginal communities where services are few and employment opportunities are limited, community and family members continue to go unrecognised for the significant unrewarded contribution they make to the economy and society. The NDIS held the promise of supporting capacity building and recognising this unpaid work. This has not come to fruition and instead we have seen sharp operators enter the market and praying on

communities in a way similar to the financial services scams that are being played out in the Banking Royal Commission.

Social inclusion and wellbeing are particularly important indicators but are rarely included within government disability policies or programs. While there vary across states and territories, the flagship national program, the NDIS, pays little heed to these areas. State and territory run programs focus more on servicing and disability supports and less on wellbeing, or, importantly in the NT, cultural and community connection. And when it comes to disadvantage, housing is the fundamental social determinant for wellbeing, participation and economic advancement and yet there is no mention of appropriate housing as an indicator.

- **The roles and responsibilities of the Commonwealth, and state and territory governments under the NDA**

NDIS has changed the landscape, shifting responsibility from the State to the Commonwealth to the private sector to the individual, with leakages of services and support along the way. The move divorces policy from delivery, and standards and quality have not been adequately provided. There is a significant loss of transparency and accountability to citizens with the introduction of the NDIS and the consequence that other services are withdrawing or winding down.

Quality and standards are a significant concern where governments leave essential service provision to market forces. The NT is still waiting for the commencement of the Quality and Safeguards Commission and so an interim arrangement operates. When the quality and safeguards framework is applied in the Northern Territory there will be different standards applying to the NDIS and to other disability services. The Agreement also splits responsibility for quality assurance between the Commonwealth and the states. A coherent, consistent and adequately resourced and enforced set of standards is required across all disability service provision and the Commonwealth is in the best position to oversight and fund quality assurance.

There has been a fundamental failing in relation to continuity of care and smooth client transitions. Our current caseload consists in the main of people who have fallen through the gaps because of the introduction of NDIS, including those who are:

- experiencing long delays trying to finalise a plan and whose previous supports have been removed;
- having supports reduced on moving to the NDIS;
- seeking a review of their plan and have had their supports suspended; and
- outside the coverage of the NDIS but have seen a withdrawal of investment in supports and services.

The Productivity Commission has previously acknowledged unclear boundaries about the responsibilities of the different levels of government and evidence of service gaps. We agree with the PC's recommendation that "Governments must set clearer boundaries at the operational level around 'who supplies what' to people with disability, and only withdraw services when continuity of service is assured."

The review of the Agreement provides an opportunity to provide greater clarity around roles and responsibilities and also set out a clear delineation of the types of services and how these are delivered. There are some significant gaps that should be addressed in reviewing the agreement, particularly in relation to mental health, a major area of disability amongst Aboriginal and Torres Strait Islanders and in remote communities.

It is noted that the Commonwealth has funding responsibility under the Agreement for contributing to the objectives and outcomes, and for disability services by the states for Indigenous Australians aged 50 and over. We support this ongoing commitment outside of the NDIS.

The Barkly trial identified that levels of unmet demand for supports was high amongst NDIS participants. Evidence of new providers entering the region was limited, their entry deterred by the small numbers of NDIS participants in the trial site. An inadequate provision in NDIS pricing structures for remote service provision further compounded the problems. Persistent shortages in the disability workforce have been accentuated by a staffing cap on the NDIA workforce encountering challenges with recruitment and retention.

The trial evaluation deemed the implementation of the NDIS trial in the NT had been ineffective. However, the rollout rolled on unchanged.

Long term health conditions affect 9 in 10 (88%) of Aboriginal and Torres Strait Islander people over the age of 55 years in Australia¹ with the rate of dementia 3-5 times higher than the general population.² There are few dedicated aged care facilities, no culturally appropriate facilities, and the waiting list for home care packages is such that it is not even worth putting people on the list. It is therefore unlikely that older Aboriginal peoples will receive the disability supports they need without program tailored to remote communities and specific needs that is appropriately resourced.

Bilateral agreements relating to NDIS provide opaque arrangements for providers of last resort. In the NT, the NDIA needs to assume responsibility as the default service provider and provide greater clarity about service

¹ <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diverse-groups-of-older-australians/aboriginal-and-torres-strait-islander-people>

² Radford K, Mack H., Draper B, Chalkley S., Daylight G., Cumming R, Bennett H, Delbaere K, Broe G., 11 (2015) *Prevalence of dementia in urban and regional Aboriginal Australians Alzheimer's & Dementia* (2015) 271-279

and Lo Giudice D , Smith K, Fenner S, Hyde Z, Atkinson D, Skeaf L, Malay R, Flicker L (2016) *Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: A follow-up study of 5 years Alzheimer's & Dementia* 12 252-261.

guarantees as there is no functioning market and people who may be eligible are not accessing the NDIS.

It is not expected that a market will emerge anytime soon - costs are high, population numbers low and sparsely spread, it is difficult to recruit skilled staff and, in many places, basic infrastructure is not available. These services are not interim services and more sustainable services need to be underwritten with clarity about who is responsible.

- Whether the NDA needs updating in light of these considerations, to reflect the changing policy landscape, including the introduction of the National Disability Insurance Scheme (NDIS) and the National Disability Strategy (NDS).

The NDIS has put the cart before the horse. Fundamental change to disability service provision, roles and responsibilities, and funding requires an overarching articulation of purpose and strategy with some underpinning guarantees to ensure that people don't fall through the gaps.

As indicated above, roles and responsibilities have changed or need to be re-assessed and review provisions should be included to monitor the impact of the NDIS as it is rolled out.

If nothing else the NDA should clarify who is responsible when the market does not provide.