

Productivity Commission Review of the National Disability Agreement

**Joint submission by
Children and Young People with Disability Australia &
Young People in Nursing Home National Alliance
Submission – August 2018**

INTRODUCTION

The *National Disability Agreement*¹ (NDA) currently contains the agreed outcomes, aims, reform priorities and delineated responsibilities of Australian governments in relation to specialist disability service provision. However, the introduction of the National Disability Insurance Scheme in 2009 has seen transformational change in the disability service system.

The NDIS has fundamentally altered how disability services are provided in Australia. Commonwealth, State and Territory roles have changed to incorporate individualised funding and a market approach to the provision of specialist disability services. The role of the States and Territories in workforce development, quality assurance, direct service delivery and policy making is markedly different in the NDIS environment.

Another fundamental consideration in this review is the *National Disability Strategy 2010-2020*² (NDS). The strategy is a high level policy framework to 'guide government activity across mainstream and disability-specific areas of public policy'³ and articulates how Australia meets its obligations under the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD)⁴.

At present, the NDA does not reflect these significant reform and changes in public policy. Nor does it address the National Disability Strategy's intention of guiding government activity across mainstream and disability-specific areas of public policy. With the NDIS' sustainability dependent on the active engagement of non disability or mainstream programs, a more congruent relationship between the NDA and NDS is needed. Relationships, roles and accountabilities are presently ill defined and require rationalisation.

Children and Young People with Disability Australia (CYDA) and Young People in Nursing Homes National Alliance (YPINHNA) welcome this review of the NDA as an opportunity for the NDA to redefine its relationship with both the NDIS and the NDS; examine how disability service provision will be articulated for those Australians ineligible for the NDIS; interrogate the NDIS market's interactions with the broader community sector; and reveal how outcomes are measured across the different reform initiatives.

CHILDREN AND YOUNG PEOPLE WITH DISABILITY AUSTRALIA

CYDA is the national representative organisation for children and young people with disability, aged 0 to 25 years. The organisation is primarily funded through the Department of Social Services and is a not for profit organisation. CYDA has a national membership of 5300 and a growing social media presence with 22 500 followers across the three major platforms of Facebook, Twitter and LinkedIn.

CYDA provides a link between the direct experiences of children and young people with disability to federal government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences and challenges faced by children and young people with disability.

¹ Council of Australian Governments 2009, *National Disability Agreement*, <https://bit.ly/2wlr9EE>

² Commonwealth of Australia 2011, *National Disability Strategy 2010-2020*, Canberra, <https://bit.ly/2wtW5BM>

³ Ibid, p. 9.

⁴ United Nations General Assembly 2006, *Convention on the Rights of Persons with Disabilities*, <https://bit.ly/1qmcT8Z>.

CYDA's vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CYDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

- **Listen and respond** to the voices and experiences of children and young people with disability;
- **Advocate** for children and young people with disability for equal opportunities, participation and inclusion in the Australian community;
- **Educate** national public policy makers and the broader community about the experiences of children and young people with disability;
- **Inform** children and young people with disability, their families and care givers about their citizenship rights and entitlements; and
- **Celebrate** the successes and achievements of children and young people with disability.

THE YOUNG PEOPLE IN NURSING HOMES NATIONAL ALLIANCE

The Alliance is a national peak organisation that promotes the rights of young disabled Australians with complex health needs living in residential aged care facilities or at risk of placement there (YPINHNA); and supports these people to navigate service systems.

As Australia's first national peak representing younger people with disability and high and complex health and other support needs, the Alliance draws its membership from all stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representatives, members of various national and state peak bodies, government representatives and advocacy groups.

We encourage a partnership approach to resolution of the YPINH issue by State and Commonwealth governments; develop policy initiatives at state and federal levels that promote the dignity, well-being and independence of YPINHNA and their active participation in their communities; and ensure that young people living in nursing homes and their families have

- A voice about where they want to live and how they want to be supported, the capacity to participate in efforts to achieve this, and
- 'A place of the table', so they can be actively involved in the service responses needed to have "lives worth living" in the community.

As the pre-eminent national voice on this issue, the National Alliance's primary objectives are to

- Raise awareness of the plight of YPINHNA
- Address the systemic reforms required to resolve the YPINHNA issue and address the urgent need for community based accommodation and support options for young people with high and complex needs
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver 'lives worth living' to young people with high and complex clinical and other support needs
- Provide on-going support to YPINHNA, their friends and family members.

Since its inception in 2002, the Alliance has argued for a lifetime care approach to development of

supports and services for disabled Australians; and for collaborative arrangements between programs and portfolio areas including health, disability, aged care and housing to provide the integrated service pathways YPINHNA and others with disability require.

LEGISLATION & POLICY CONTEXT

Policy Architecture

CYDA and YPINHNA sees the characterisation of the NDIS in Figure 1 as an entity equal to and separate from the NDA and NDS, as inaccurate.

The NDIS is an operational entity not a policy mechanism. While its implementation has focussed attention away from the NDA and NDS, the latter's capacity to set policy objectives to improve the lives of Australians with disability, cannot be underestimated.

As an instrument of government, the NDIS addresses only one aspect of disability policy: that of service provision. While the transformative nature of the NDIS is acknowledged, it cannot deliver on the objectives and outcomes of the NDA by itself. Lest it overshadow the more important policy imperatives represented by the NDA and the NDS, this review must remain cognisant of the limited place of the NDIS in the wider disability and human services policy arena.

Assessment Framework

As it is stated, the framework proposed for assessing the NDA lacks a clear international human rights focus.

As a Party to the CRPD, Australia has an obligation to ensure the human rights of people with disability are upheld. Australia's commitment to its obligations under the CRPD is embedded in the NDA⁵, the NDS⁶ and the *National Disability Insurance Scheme Act 2013*⁷.

The CRPD is therefore fundamental to framing and assessing the actions and responsibilities of Australian Governments under the NDA.

Both CYDA and YPINHNA believe the Productivity Commission should adopt a rights framework in relation to the NDA review. This includes assessing the agreement through a human rights lens and providing an explicit commitment that a future NDA will align and give effect to Australia's obligations under the CRPD.

Recommendation 1: The Productivity Commission adopt a rights based framework to assess the NDA.

Recommendation 2: A future NDA clearly articulates that the Agreement gives key consideration to and aligns with Australia's obligations under the CRPD and other relevant human rights obligations.

Establishment of Second National Disability Strategy

A Second Disability Strategy is currently being reviewed to provide a framework beyond 2020⁸. The NDA review process offers an important opportunity to inform a renewed NDS.

⁵ Council of Australian Governments 2009, *National Disability Agreement*, s. 17(f), <https://bit.ly/2wlr9EE>

⁶ *National Disability Strategy 2010-2020*, Canberra, p. 40, <https://bit.ly/2wtW5BM>

⁷ *National Disability Insurance Scheme Act 2013* (Cth), s. 3(1)(a)

⁸ Social Policy Research Centre 2018, *Review of the National Disability Strategy 2010-2020*, Social Policy Research Centre, UNSW, viewed 31 August 2018, <https://bit.ly/2NwRgz6>

PURPOSE AND SCOPE OF NDA

The arrival of the NDIS and the changed roles of governments since the original NDA was agreed demonstrates the need for a differently invigorated NDA. Indeed, the implementation of the NDIS has raised a number of issues including how people with disability who are not participants of the scheme will receive individual services as well as be able to access community support.

As example, when the NDIS is fully implemented in 2019-2020, around 475 000 people with disability will receive individualised support under the scheme⁹. This represents only 11% of the 4.3 million people with disability in Australia¹⁰. Many people with disability who are not NDIS participants will continue to require specialist disability services.

Despite strong cross-jurisdictional commitment to the principle of continuity of support, service gaps have emerged where services and supports are not being provided or have been withdrawn due to uncertainty about who is responsible for funding them.

CYDA and YPINHNA believe that a key purpose of a future NDA should be directed toward addressing and resolving this issue and defining the roles of governments in the NDIS environment vis-à-vis the CRPD. This is the missing element of the NDIS reform as recommended by the Productivity Commission in 2011 and called Tier 2.

There also exists a significant degree of uncertainty regarding the current and future direction of the NDIS' Information, Linkages and Capacity Building (ILC) program, including the purpose and scope of ILC funded projects and whether they will be provided to NDIS participants, other people with disability or both.

Unresolved issues relating to the interface of the NDIS and mainstream services only compound challenges regarding the withdrawal of specialist disability services. While the *National Disability Insurance Scheme Rules (Supports for Participants) 2013*¹¹ and the *Principles to Determine the Responsibilities of the NDIS and Other Service Systems*¹² set out high level guidance for the delineation of responsibilities there remains significant uncertainty at the operational level.

There is an urgent need to provide clarity and certainty about the provision of services and supports to people with disability across the NDIS and other portfolios in this evolving context. We are seeing governments approaching this task with the aim of drawing hard lines and divisions rather than looking at collaborative solutions to the administrative grey areas. This is old bureaucratic thinking linked to traditional siloed program delivery that is becoming less relevant in the NDIS environment. We believe that incentives for collaboration are needed in a future NDA to ensure that governments are more person centred and innovative in their thinking.

In summary, CYDA and YPINHNA see a revised NDA

- Articulating the obligations, roles and responsibilities of government to ensure the provision of specialist disability services to people with disability who are *not* participants of the NDIS;

⁹ Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs: Productivity Commission Study Report Overview*, Productivity Commission, Canberra, p 3.

¹⁰ Australian Bureau of Statistics 2016, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, ABS, Canberra, viewed 28 August 2018, <https://bit.ly/2pblaP8>

¹¹ *National Disability Insurance Scheme Rules (Supports for Participants) 2013* (Cth)

¹² Council of Australian Governments 2015, *Principles to Determine the Responsibilities of the NDIS and Other Service Systems*

- Establishing requirements for governments to implement cross portfolio collaboration to resolve and clarify issues of interface between the NDIS and non disability/mainstream services; and
- Providing a governance framework to ensure governments deliver policy and practice for inclusive communities where people with disability meaningfully participate in all aspects of economic, social and cultural life.

Recommendation 3: That the Productivity Commission recommend that a future NDA define the roles, accountabilities and outcomes for disability services outside the NDIS; collaborative resolution of NDIS interface arrangements; and government action to deliver inclusive communities,

Funding

Funding for services provided under the NDA through the National Disability Specific Purpose Payment (SPP) are being redirected to the NDIS as jurisdictions reach full scheme. Consequently, at full scheme there will be no funding attached to services provided under the NDA. These changed funding arrangements and uncertainty around interface issues have contributed to cost-shifting by both the jurisdictions and the NDIS to the detriment of people with disability.

The withdrawal or redirection of SPP funding has substantial implications for a revised NDA that provides for the delivery of specialist disability services to non-participants of the NDIS. Without funding attached to the NDA, there is limited incentive for governments to meet the objectives, outcomes and outputs set out in relation to service provision...particularly for Australians with disability who are ineligible for the NDIS.

A new funding arrangement for individuals ineligible for the NDIS must be developed and attached to the NDA that is separate to the bi-lateral and multi-lateral NDIS agreements.

Recommendation 4: specific funding must be attached to the NDA to enable the creation of an identified service system for people with disability outside the NDIS, and for improved collaboration between governments and inclusive community outcomes.

OBJECTIVES, OUTCOMES & OUTPUTS

The objectives, outcomes and outputs of the NDA must be updated to reflect the revised purpose set out above. Greater clarity and connection between the objectives, outcomes and outputs and accountability measures is also needed to ensure the NDA is a robust and effective accountability mechanism.

As they currently stand, the NDA's objectives, outcomes and outputs lack clarity and their relation to each another and to existing performance indicators and benchmarks, is unclear. The terms 'enhanced quality of life' and 'live as independently as possible' are, for example, difficult to define and quantify. On the other hand, Outcome C and Output D's reference to families and carers, does not have an associated benchmark.

In addition to aligning the objectives, outcomes and outputs to the revised purpose, two specific policy priorities must be reflected in a revised NDA. These are the safety and well being of people with a disability and the provision of advocacy.

Safety and Wellbeing of People with Disability

At present, the NDA contains no mechanism to protect the safety and wellbeing of people with disability. International research,¹³ Australian statistics¹⁴ and multiple government inquiries¹⁵ have all revealed that people with disability experience shocking rates of violence and abuse. Children with disability are 3.4 times more vulnerable to abuse than children who do not have disability¹⁶. It is vital that a revised NDA explicitly describe the safety and wellbeing of people with disability as a key outcome.

Advocacy

The future direction and funding of systemic and individual advocacy services in Australia is a significant issue that must be addressed. The NDIS' implementation has seen growing concerns about the loss of funding for local advocacy services. In NSW, for example, funding for disability advocacy services was set to expire earlier this year as that State moved to full scheme. Following significant community pressure, the NSW Government extended advocacy funding for a further year. But the future of advocacy funding in NSW remains uncertain.

While the advent of the NDIS was initially thought to reduce the need for advocacy services, this has not proven to be the case. Indeed, the implementation of the NDIS has significantly *increased* the workloads of systemic and individual advocacy organisations as the demand for their services has grown. Yet this increased need has not been reflected in similar growth in Commonwealth, State and Territory disability advocacy funding arrangements.

Systemic and individual advocacy services are critical to ensuring the rights of people with disability are upheld. The provision of disability advocacy services must be an explicit output of a revised NDA. Delineation of government funding obligations for disability advocacy services must also be included.

Recommendation 5: the NDA include safety and wellbeing and advocacy as shared responsibilities for government, establish performance benchmarks and funding obligations for advocacy services

LOCAL GOVERNMENTS

Specialist disability service provision, such as the delivery of services through the Home and Community Care (HACC) and the HACC Program for Young People, often occurs at the level of Local Government.

To enhance accountability and to ensure the adequate provision of specialist disability services across all levels of government, Local Government's service provision role must be incorporated in a revised NDA and should articulate the obligations of Local Government. The Australian Local Government Association should be a party to the NDA agreement.

Recommendation 6: the Australian Local Government Association is a party to any future NDA.

¹³ Sullivan et al. 2000, *Maltreatment and disabilities: A population-based epidemiological study*, p. 1257.

¹⁴ Australian Institute of Family Studies 2015, Children's exposure to domestic and family violence, CFCA Paper No. 36, Commonwealth of Australia, Canberra, viewed 10 August 2018, <https://bit.ly/2Mcvkfa>.

¹⁵ For example, the Senate Standing Committee on Community Affairs 2015, *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, <https://bit.ly/2MECnhK>

¹⁶ Children and Young People with Disability Australia 2012, *Enabling and Protecting: Proactive Approaches to Addressing the Abuse and Neglect of Children and Young People with Disability*, p. 12.

PERFORMANCE REPORTING FRAMEWORK

The current performance and reporting framework must be revised to provide clearer connection between objectives, outcomes and outputs and performance indicators and benchmarks. As they presently stand, the NDA's indicators and benchmarks lack nuance and a clear connection to the lived experience of people with disability.

For example, the degree to which people with disability achieve economic participation, the quality of that participation and the action required to address poor employment outcomes cannot be captured by the percentage of people with disability participating in the labour force. Rates of underemployment, self-employment or related issues around discrimination¹⁷, negative attitudes, and barriers to accessibility such as transport and standardised job assessments, limited resources and access to information and low expectations, are rarely taken into account.¹⁸

The fundamental principle underpinning a revised NDA performance and reporting framework must be accountability. A revised NDA framework should therefore seek to provide maximum transparency and accountability to ensure that governments meet their NDA obligations.

Data

A strong performance and reporting framework needs a robust and comprehensive data set to draw from. As part of its review of the NDA, the Productivity Commission should identify data gaps and determine how the NDA could better utilise existing data sets. Having identified these data gaps, the Productivity Commission should recommend a detailed audit of existing data collection methods.

For example, the NDIS collects a significant amount of data for reporting purposes that is currently outside the scope of data used to report against the NDA. This data may provide important insight about the use of specialist disability services, unmet need and outcomes for people with disability that is directly relevant to the NDA.

Should an audit of data gaps be undertaken, it should align with Australia's obligations under the CRPD. This includes:

*'The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.'*¹⁹

While the Survey of Disability, Ageing and Carers (SDAC) remains an important mechanism for the collection of data regarding people with disability, the utility and relevance of SDAC could be further enhanced by increasing the regularity with which it is undertaken. Broadening the scope of data collected would also give a more comprehensive picture of the systemic barriers experienced by people with disability.

Recommendation 7: The Productivity Commission analyse data sets relevant to disability services and recommend a framework for data collection for the NDA.

¹⁷ Australian Human Rights Commission 2016, *Willing to Work National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability*, p. 12

¹⁸ Ibid

¹⁹ Ibid, Article 31(2).

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