

Submission
No 294

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Organisation: NSW Disability Advocacy Alliance

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NSW Disability Advocacy Alliance

**Submission to the Legislative Council - Portfolio Committee No.2
Health and Community Services**

Inquiry into the implementation of the National Disability Insurance
Scheme and the provision of disability services in NSW

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The NSW Disability Advocacy Alliance is a coalition of independent disability advocacy, information and peak representative organisations currently funded by the NSW government, who have joined together to influence and advocate for the rights of all people living with disability in NSW to ensure they get a fair go, a say in the policies and decisions that affect their lives, and to continue to work towards a better system where people with disability are fully included, valued citizens in NSW community.

Today, and always.

Members of the NSW Disability Advocacy Alliance:

Ability Advocacy

Action for People with a Disability

Blind Citizens NSW – Statewide

Citizen Advocacy Western Sydney – West and North Western Sydney

Deaf Blind Association of NSW – Statewide

Disability Advocacy – Statewide, with offices in Newcastle, Taree, Port Macquarie, Coffs Harbour, Bathurst, Broken Hill, Dubbo and Parramatta

Disability and Aged Information Services Inc (DAISI)– Ballina

Ethnic Community Services Cooperative (ECSC)– Sydney Inner West

Family Advocacy NSW – Statewide

First People’s Disability Network (FPDN)– Statewide

Information on Disability Education and Awareness Services (IDEAS)– Statewide; with offices in Tumut and Campbelltown

Intellectual Disability Rights Service (IDRS) – Statewide

Multicultural Disability Advocacy Association (MDAA) – Statewide

Muscular Dystrophy NSW (MDNSW) - Statewide

Council for Intellectual Disability (NSWCID) – Statewide

Physical Disability Council of NSW (PDCN) – Statewide

People with Disability Australia (PWD) – Statewide

Radio for the Print Handicapped (2RPH) - Statewide

Regional Disability Advocacy Services (RDAS) – Albury/Wodonga and Wagga Wagga

Spinal Cord Injuries Australia (SCIA) – Statewide

Stroke Recovery Association - Statewide

Synapse – Statewide

Introduction:

The NSW Disability Advocacy Alliance (referred to from here on as the 'Alliance') commends the NSW Legislative Council for its inquiry into the implementation into the National Disability Insurance Scheme (NDIS) in NSW, and the provision of disability services in NSW in line with its implementation. We value the opportunity to provide comment through our written submission and would be happy to provide oral evidence should the committee wish us to do so at its upcoming hearings.

As NSW is the first of the States and Territories to fully implement the NDIS we are in a unique position in which to review its initial effectiveness. As of June 2018 the NSW government has effectively removed itself from the disability sector, closing down the Department of Ageing, Disability and Homecare (AHDC) and has chosen to put all of its previous disability funding into the scheme, despite there only being 10% of people with disability in NSW whom are eligible for an individually funded package under the NDIS. This decision has effectively left 90% (approximately 1.2 million) people with disability in NSW whom are not eligible for the scheme with little to no access to disability services moving forward.

All of the Alliance members interact with the NDIS on a daily basis, either directly through supporting their individual membership groups and stakeholders to navigate the scheme; through funding to deliver NDIS ILC projects or NDIS reviews and appeals; or indirectly in providing information, advice and handling complaints from individuals with disability or service providers trying to understand the nuances of the scheme, and in advising and shaping government policy that is constantly changing as the NDIS is implemented in NSW.

The Alliance believes that all governments, both State and Federal, have a part to play in ensuring all people with disability have equal access to services and supports, and that those not eligible for the NDIS do not fall through the gaps, or are disadvantaged by its implementation.

Many Alliance members will submit their own individual organisational responses that speak to their individual cohorts, and to this end the NSW Disability Advocacy Alliance paper will focus on parts (a), (e), (i) and (j) of the terms of reference.

(a) the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability

The NDIS is considered by the members of the NSW Disability Advocacy Alliance to be the largest piece of social reform since the introduction of Medicare, with the capacity to make a substantial difference to the lives of people with disability if fully implemented in accordance with the NDIS Act and its underlying principles of choice and control. Many of our organisations campaigned for its instigation and implementation, and still believe it is a reform worth fighting for.

However, as already indicated, the Alliance is concerned with the speed in which the NSW implemented its roll out, and to date maintain that its success in providing 'choice and control' for its participants has been a very varied experience.

For some this has been due to limited access to a selection of services providers, such as in rural areas where there may only be one registered provider able to provide services within the area. For others, choice and control has been restricted by a poorly executed planning process, where a local area coordinator undertaking the planning process was not experienced in disability requirements and failed to fund vital equipment or supports, or had limited time in which to complete a planning meeting (again due to the need to onboard more than 70,000 participants per year over the past two years) and have not been able to undertake the secondary part of their job role, that of assisting people to understand and implement their plans.

The NDIS argues that funded support coordination (within an NDIS plan) is not necessary for all participants, and will rarely fund this for anyone without complex support needs, however as evidenced in a comment made to an Alliance member by their own individual member (a Paralympic athlete, fully employed and for all intents and purposes extremely competent) implementing her own plan "I don't know where to start, this is all new to me, I'm not sure where I can use my funds flexibly, or who can provide the services I require ... or when I need to sign an agreement or just get an invoice. Can you advise me?" There are inherent challenges for even the most competent of us when navigating a new and complex system and being able to access support to achieve understanding would greatly enhance all NDIS participants' ability to achieve true choice and control over both their plans and their lives.

Additionally, the ability to achieve choice and control could be enhanced by the continued funding of independent community groups whom specialise in disability. Organisations such as those whom are members of the Alliance provide invaluable independent, unbiased information and assistance in linking people with disability to local services and supports that could meet their needs, and whilst government funded – at no charge to the individual requesting the information or support, saving valuable NDIS funds for the individual's required supports/services. Their years of building up local, on the ground knowledge, networks, relationships and developed communities of practice mean they are often best placed to assist in linking people to the services and supports they need.

(e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme

In signing onto Bilateral agreements for the NDIS and agreeing to deliver all its previous State based funding for disability to the Commonwealth in order to implement the Scheme, the NSW government has effectively ‘closed down’ its State based funded disability services. However, people with disability access a range of services within and outside the disability sector.

NDIS eligibility criteria mean that there are many Australians with disability who will not receive NDIS funded supports. Irrespective of NDIS eligibility, people with disability will always need to access mainstream services in their everyday lives, or may have additional needs that are not met under the NDIS.

Prior to, and throughout the implementation of the NDIS, time and again it has been recognised that the not for profit sector, including independent individual and systemic advocacy organisations play an important role in ensuring the success of the NDIS, and in monitoring and evaluating its effectiveness, however they play an even greater part in supporting the 90% of people with disability in NSW whom will not be eligible to participate in the National Disability Insurance Scheme.

The National Disability Strategy (NDS) notes that it is important that people with disability have the opportunity to participate in the decisions that affect their lives, and for some that this may need to be supported by advocacy services. It also states that ‘individual advocacy supports people with disability to understand and exercise their rights, through either one-to-one support, or by supporting people to advocate for themselves individually, or on a group basis. Systemic advocacy seeks to introduce and influence longer term changes to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives. Systemic advocates can influence positive changes to legislation, policy and service practices and work towards raising and promoting community awareness and education of disability issues.’¹

In its 2017 Report on the Delivery of outcomes under the National Disability Strategy 2010 – 2020 to build inclusive and accessible communities, the Senate Standing Committee on Community Affairs specifically recommends (Recommendation 6, 4.53) that the NDS be revised, with an extended timeframe; that this be devised in consultation with people with disability **and include consideration of the critical role of advocacy in this process.**²

Again, in June 2018 the Australian Human Rights Commission Report ‘A future without Violence’ states that ‘both independent individual and systemic advocacy play a critical role in ensuring independent oversight of institutional settings and contribute significantly to preventing and addressing violence against people with disability in these contexts.’

¹ National Disability Strategy 2010 -2020, p17

² Senate Standing Committee on Community Affairs Report on the Delivery of outcomes under the National Disability Strategy 2010 – 2020 to build inclusive and accessible communities, November 2017, p. xi

The AHRC also acknowledged that ‘advocacy organisations sit outside the Safeguarding Framework in order to ensure that they are able to maintain their independence as their role may involve challenging the NDIS’ and that ‘Commonwealth, state and territory systems must take steps to ensure that independent individual and systemic advocacy organisations have the necessary powers and are adequately funded to undertake their work within the Safeguarding Framework.’³

In February 2018 the NSW Ombudsman, Michael Barnes advised that “there is a vital continuing role for community advocates who work with and support people with disability who require decision-making support, and who advocate for them in relation to broader, systemic issues across a range of life domains.”

The Disability Discrimination Commissioner, Mr Alastair McEwin also advised “We need advocacy organisations more than ever... advocacy organisations play a critical role in telling people their rights and then helping them to enforce them.”

Leaders with disability themselves also understand the need for advocacy. Paralympian and past NDIS Independent Advisory Council member Kurt Fearnley states “The Minister is kidding himself. No advocacy will mean a flawed NDIS. We’re creating a funding model. We aren’t solving disability.”

Independent disability advocacy, information and peak representative organisations play a much greater role than just assisting people to access the NDIS, though the need for advocacy has increased across all our organisations due to the implementation of the NDIS. Organisations such as ours assist people on broader issues such as access to education, justice, finances, abuse and discrimination, health, accessing the physical environment, housing and employment.

In addition, we support the NSW government to improve systems as a whole, working alongside them on many of their departmental advisory committees and boards, providing expert advice on best practice principles for people with disability and access to people with disability themselves for regular consultations and testing of new infrastructure. We also provide input through face to face consultations and many written submissions (such as this one) in response to Parliamentary inquiries and State and Commonwealth policy and regulation reviews.

It is also through local advocacy organisations that many systemic issues are identified and addressed, often saving government significant time and cost. For example the Physical Disability Council of NSW, the peak representational body for people with a physical disability, regularly consults with its members. As a result of these consultations, where systemic issues come to light, such as in the case of the inability of many of our members to be examined in GP surgeries (as wheelchair users couldn’t actually lift themselves up onto the examination tables, or suffering the indignity of being examined on the floor) PDCN has addressed problems for all people with disability in one process, working with the Royal Australian College of General Practitioners to mandate height adjustable beds in all NSW GP clinics.

³ AHRC report ‘A future without Violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings’ June 2018, p.71

Actioning change once at a systemic level saves time and many individual people having to work their way through the system to find the right place/department to lodge a complaint or address their issue and is extremely cost effective on both government and NFP resources.

However, as it currently stands, the State government has advised it will no longer fund any state based disability advocacy, information or peak representation from June 2020 (having only recently given an extension of funding to the sector until this time, indicating this is to assist in the delayed full roll out of the NDIS in NSW.)

This decision means the loss of **all supports** for the 90% of people with disability without NDIS funding, and any support required by the further 10% of people with disability funded by the NDIS, but for whom their advocacy issue falls outside of their 'day to day needs' and will not be dealt with by the NDIS.

The loss of funding for state based organisations in 2020 will mean the immediate closure of many services (such as Disability Advocacy's Central West office, Ability Advocacy in the Northern Rivers, all of IDEAS advocacy services throughout the state; Citizen Advocacy Western Sydney; Action Advocacy, the Physical Disability Council of NSW to name a few;) and significant losses of staff and capacity to all other organisation's services.

This loss of funding will affect thousands of people with disability, leaving them with even less access to what is an already overloaded advocacy sector at the present time.

(i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services

For those people with disability in NSW whom were receiving supports under the Community Care and Supports Program (CCSP) prior to the implementation of the NDIS and whom are not automatically eligible for the NDIS the loss of their supports is already beginning to result in greater strain on other mainstream services. In one known case an individual whom had been deemed ineligible for the NDIS and whom had lost their in home assistance with meals and care, was unable to care for themselves adequately, resulting in the need for hospitalisation. This will not be an isolated incident and puts far greater costs on the health (and other) systems as they deal with the 'fall out' of the removal of all other disability services and supports by the NSW government.

Whilst it has not happened to date due to an extension of funding for some services until 2019 or mid 2020, many other funded community services such as the Justice Support Service assisting people with an intellectual disability whom find themselves caught up (rightly or wrongly) in the criminal justice system will also come to an end, leaving very vulnerable individuals trying to navigate and understand their rights within the system post this point in time.

Alliance members Intellectual Disability Rights Service (IDRS) are already reporting increased difficulty in the ability to get timely supports in place to meet bail applications, or an NDIS plan or services enacted - meaning more people with intellectual disability are finding themselves

remanded into custody or remaining behind bars for longer whilst the necessary supports can be obtained. This again is placing additional strain on our justice system and putting people with disability at significant risk.

As the NDIS rolls out there has also been a marked increase in the amount of work that Alliance organisations are having to undertake, on top of their normal workloads. This work relates specifically to the NDIS, and for many of the organisations within the Alliance is not within their funding remit.

For example, the Physical Disability Council of NSW (PDCN) reports that over the past 3 years, in line with the implementation of the NDIS, its requests for assistance through phone and online enquiries have increased by 25 – 30%, with (depending on the year) between 14% and now 19% of these enquiries specifically related to the NDIS.

In the case of People with Disability Australia (PWD) disability services and the NDIS was also their top recorded advocacy issue, taking up more than 29% of advocacy work.⁴ Their overall advocacy workload has also increased by 20% in the last financial year.

IDEAS (Information on Disability Education and Awareness Services) arguably NSW's largest and most recognised disability information service dealt with 715,191 requests for information (between its phone, in-person, sms, live chat and website services) and again the most common enquiry type was the NDIS.⁵

For all of our organisations, this additional work is over and above that already being undertaken, and when unfunded means that often needs are unmet, or enquirers must be forwarded to other community or government services, many of whom also do not have the capacity to manage demand.

For PDCN, many people referred onto external individual advocacy services report back to the organisation, frustrated and angry, as those referred services have all indicated that they do not have the ability to take on additional clients, being already beyond capacity and holding many months wait lists for services. The stress this puts on both the individual needing assistance, and community advocacy organisation staff whom are rightfully concerned about often very vulnerable members and not meeting their needs is considerable, as is trying to make already under funded budgets cope with the additional work requirements brought about by the implementation of the NDIS.

(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales

In order to continue to improve the provision and accessibility of disability services in NSW **for all people with disability in NSW** the Alliance believe that it is imperative that oversight mechanisms such as the National Disability Agreement (NDA) and The National Disability Strategy (NDS) continued to be implemented by the NSW government alongside of the NDIS

⁴ PWD Annual Report 2016/17

⁵ IDEAS Annual Report 2016/17

and are regularly monitored to ensure implementation occurs as per timelines set. In addition, we would recommend that targets within these guidelines are clearly set and mandated, in order to address any shortfall.

These policy frameworks are designed to look beyond specialist disability services and support systems, to provide leadership for a community wide shift in attitudes and drive improved performance, as well as coordinated and comprehensive planning between all levels of government, across all portfolios, community and mainstream services.

However, in progress reports to date, and in the 2017 report from the Senate Standing Committee on Community Affairs into the delivery of outcomes under the National Disability Strategy 2010 – 2020 the Committee noted that “implementation of the Strategy has been poor, with progress reports presenting a more optimistic view of progress than what evidence on the ground suggests.”⁶

Along these lines, implementation of NSW Government department and local government Disability Inclusion Action Plans, and clear set targets, again with mandated timeframes for implementation would also go a long way to continuing progress to a fully inclusive society in NSW.

Retention of the NSW Disability Ombudsman, and its imperative role in the oversight of disability services, particularly large residential setting and group homes through its community visitor program, and other disability services that will fall outside of the NDIS Quality and Safeguarding Commission’s jurisdiction is also an important oversight mechanism that needs to remain in place to ensure all people with disability are afforded the same protections those within the NDIS will be given by the Quality and Safeguarding Commission.

Overall Recommendations:

- 1: That the NSW government provides ongoing funding for disability advocacy, information and peak representation groups to at least \$20M per annum for the foreseeable future, ensuring all people in NSW have access to advocacy support, with the increase (from approx. \$13M currently) to allow organisations to meet the increased demand.**
- 2: That the NSW government reinstate their commitment to the implementation of the National Disability Strategy and set mandated targets in order to meet performance outcomes and improve access and inclusion for people with disability in NSW community.**
- 3: That the NSW government ensure other services and oversight mechanisms (such as the Community Care and Support Program and the NSW Disability Ombudsman) remain in place, particularly where their role/activities covers the 90% of people with disability in NSW whom are ineligible for the NDIS.**

⁶ Senate Standing Committee on Community Affairs Report on the Delivery of outcomes under the National Disability Strategy 2010 – 2020 to build inclusive and accessible communities, Nov. 2017, Chapter 3, p29