

Council for Intellectual Disability

POSITION STATEMENT ON THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

January 2019

Our goal

People with intellectual disability get the support they need to live fully included lives of their choosing.

Where things stand

“The NDIS helps you to take some risks and give it a go.”

“Too much red tape, too many steps, too many papers, too many workers who don’t know what they are doing.”

(CID members with intellectual disability)

Prior to the NDIS, the availability and quality of disability supports varied enormously. Some people had good support. Others had no or inadequate support. There was little choice.

The NDIS has the potential to give people with intellectual disability choice and control and the supports they need. The lives of many people have been improved by the NDIS.

However, there have been major problems with NDIS implementation which have caused great frustration and potential harm to people with intellectual disability:

- Inadequate focus on people with intellectual disability in the design and initial rollout of the scheme, despite them being approximately 60% of scheme participants.ⁱ
- No organised strategy for outreach and engagement with people with intellectual disability who are not aware of the scheme and how it could improve their lives.
- Rushed, inconsistent and poor quality planning for many people.

- Unwieldy and slow review and appeal processes.
- Discouragement of families from pursuing self management of plans.
- Unresolved demarcation issues between the NDIS and mainstream services.

These problems arose from factors including:

- The speed of the transition process in NSW with 78,000 people moving into the NDIS in two years.ⁱⁱ
- Inadequate National Disability Insurance Agency (NDIA) processes.
- Inadequate skills right through the NDIS and provider workforce.
- The Federal Government staff cap on the NDIA.
- The NSW Government exiting from service provision including from its role as crisis and last resort service provider.
- The NSW Government exit strategy being focused on tendering out large blocks of services rather than individual choice and control.
- The NSW Government plan to stop funding disability advocacy.

MICHAEL (not his real name) had poor experiences in the past with disability services. However, he had a good relationship with the Intellectual Disability Rights Service (IDRS). His trusted IDRS worker persuaded Michael to give the NDIS a go and supported him through the NDIS processes and to choose and later change service providers. Michael's life is now much better and he has much less trouble with the police.

MARIA (not her real name) has complex needs and lived in an Ageing Disability and Home Care (ADHC) group home. ADHC provided coordinated behaviour support and other therapy services. The group home was transferred to a non government organisation. Maria's mother says that there were then a lot of problems with staff changes, inadequate NDIS funding and poorly coordinated therapy services. The mother rang CID who explained her options to make complaints and seek a review of the inadequate NDIS plan.

What's the solution?

CID's advocacy has focused on:

- The NDIA setting up proper consultative mechanisms with people with intellectual disability, their families and other advocates.
- Making NDIS systems responsive to the wants and needs of people with intellectual disability including people with complex support needs.
- The NDIS and mainstream agencies taking responsibility for outreach and engagement with people with intellectual disability who live on society's fringe.
- Sorting out demarcation issues so that people with intellectual disability do not face gaps between the roles of the NDIS and mainstream services.
- Holding the NSW Government to account for its flawed process for exiting from service provision.
- The design and set up of the NDIS quality and safeguarding framework.
- Ongoing funding for disability advocacy in NSW.

What CID has done

Some of our key activities have included:

- Our Hard to Swallow campaign for the NDIA to reverse its position that it was not responsible for funding therapy for people with swallowing problems, 2018 www.cid.org.au/our-campaigns/hard-to-swallow
- NSW Roundtable on the NDIS and people with complex behaviour support needs, 2017 www.cid.org.au/resource/pathway-through-complexity
- National Roundtable on the NDIS quality and safeguarding framework, 2015 www.cid.org.au/resource/ndis-quality-safeguards-2015
- Participants or just policed? Guide to the role of the NDIS with people with intellectual disability who have contact with the criminal justice system, 2013 www.cid.org.au/resource/participants-or-just-policed/
- Position statement on the NDIS and people with intellectual disability living on society's fringe, 2014 www.cid.org.au/resource/ndis-pwid-fringe

In our advocacy, we have worked closely with intellectual disability professionals and researchers, and other advocacy organisations.

What CID has achieved

CID's advocacy has been central to:

- The establishment of the Intellectual Disability Reference Group of the NDIA.
- An increased focus by the NDIA on people with intellectual disability.
- NSW Health maintaining the roles of the majority of health services previously funded by ADHC.
- The NDIA accepting responsibility for funding swallowing therapy.
- The NSW Government's continued funding of its intellectual disability Community Justice Program.
- The NSW Government continuing advocacy funding until at least 2020.

CID's My Choice Matters project has also provided resources and increased opportunities for people with intellectual disability to choose their own supports and control their lives and so be ready for the NDIS.

13,000 people have attended our NDIS workshops right across NSW.

CID's Info Service has provided information and referrals to people with intellectual disability and their supporters about the NDIS, other services and people's rights.

ⁱ In 2017, the primary disability of 36% of participants was intellectual disability and, for a further 29%, it was autism. National Disability Insurance Agency, COAG Disability Reform Council Quarterly Report June 2017 www.ndis.gov.au/medias/documents/hb4/h40/8804368711710/COAG-DRC-Quarterly-Report-June-2017-Q4.pdf

ⁱⁱ Bilateral Agreement between the Commonwealth and NSW, Transition to a National Disability Insurance Scheme www.ndis.nsw.gov.au/wp-content/uploads/2015/07/Bilateral-Agreement-between-the-Commonwealth-and-New-South-Wales-2.pdf