

Council for Intellectual Disability POSITION STATEMENT ON THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS) 2022

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 was intended to include:

- Tier 3 Funded plans for people with higher support needs ("participants")
- Tier 2 Assistance for all people with disability to increase their capacity and access mainstream and community support.
- Tier 1 Insurance and minimising the impact of disability right across the community.

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. These include:

- Inadequate focus on people with intellectual disability in the design and initial rollout of the scheme.
- 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.
- Lack of adequate and quality support for people with complex needs.
- The lack of any disability support for people who are not eligible to receive NDIS funded plans.
- · Rushed, inconsistent and poor quality planning for many people.
- · Arbitrary and inadequately explained cuts to individual funding.
- · Unwieldy and slow review and appeal processes.
- · Inadequate advocacy support for participants challenging NDIA decisions.
- Unresolved demarcation issues between the NDIS and mainstream services.
 For example, the NDIS takes a narrow view of its responsibilities to people who have committed serious criminal offences.

These problems arose from factors including:

- The role of local area coordinators being focused on participant plans rather than their intended role of supporting other people with disability to access mainstream and community supports.
- The speed of the transition process in NSW with 78,000 people moving into the NDIS in two years.
- · Inadequate NDIS processes.
- Inadequate skills right through the NDIS and provider workforce.
- The Federal Government staff cap on the NDIS and desire to curb its budget.
- The NSW Government exiting from service provision including from its role as crisis and last resort service provider.
- The NSW Government exit strategy having been focused on tendering out large blocks of services rather than individual choice and control.

Below are two real-life stories that show the potential benefits and the pitfalls of the NDIS.

MICHAEL (not his real name) had poor experiences in the past with disability services and got into a lot of trouble with the police. 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 been in much less trouble.

GINA (not her real name) has complex communication and behaviour support needs and lives in a group home. With staff changes and difficulty finding a skilled behaviour support practitioner, staff are now using restrictive practices with Gina as they struggle to meet her support needs. Despite strong advocacy by Gina's mother, the quality of service provision has not improved. After a plan review, the NDIS has cut Gina's funding by 20%. Gina's mother has applied for a review of this decision but in the meantime Gina is leading a less happy and more restricted life.

What's the solution?

CID's advocacy has focused on:

- The NDIS 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 making its resources available in Easy Read.
- 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 implementation of the NDIS Quality and Safeguarding Framework.
- The need to rejuvenate the intended Tier 2 of the NDIS including devoting the role of local area coordinators to work with people who are not eligible for funded plans.

What CID has done

Some of our key activities have included:

- Advocacy through the NDIS Intellectual Disability Reference Group.
 As individuals, three CID staff members are on this Group, two with intellectual disability and one without.
- Our successful <u>Hard to Swallow campaign</u> for the NDIA to reverse its position that it was not responsible for funding therapy for people with swallowing problems, 2018.
- CID Advocacy Group submission and evidence to the NSW Parliament Inquiry into Implementation of the NDIS 2018.
- NSW Roundtable on the NDIS and People with Complex Behaviour Support Needs, 2017
- National Roundtable on the NDIS quality and safeguarding framework, 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
- Position statement on the NDIS and people with intellectual disability living on society's fringe, 2014

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 the NSW disability agency ADHC.
- The NDIA accepting responsibility for funding swallowing therapy.
- The NSW Government's continued funding of its Community Safety Program to support access to the NDIS by people with intellectual disability and very serious histories of offending.
- The NSW Government continuing and expanding funding of the Justice Advocacy Service to divert people with cognitive disability from the local courts into the NDIS.

With funding from the NDIS Information, Linkage and Capacity Building Program, CID has run projects to promote supported decision making and increase access to employment and health care for people with intellectual disability.