



# **Submission**

**Select Committee on Work and Care Inquiry**

**Inclusion Australia**

**September 2022**

## About Inclusion Australia

Inclusion Australia is the national Disability Representative Organisation representing the rights and interests of Australians with intellectual disability and their families.

We have state members in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia:

- Council for Intellectual Disability (CID)
- Parent to Parent (P2P)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Association of Tasmania (Speak Out)
- Victorian Advocacy League for Individuals with Disability (VALID), and
- Developmental Disability WA (DDWA)

Inclusion Australia was founded in 1954 and was previously known as the National Council on Intellectual Disability (NCID). Our mission is to work to make sure people with intellectual disability have the same opportunities as people without disability.

Inclusion Australia works in systemic advocacy, projects, information and communication activities that advance the rights and interests of people with intellectual disability.

Supported Decision Making is one of Inclusion Australia's highest priorities. Our work in this area includes an Information, Linkages and Capacity Building (ILC) funded project called *Make Decisions Real*. This is a 3-year national project that aims to improve supported decision making for people with an intellectual disability and their decision supporters through co-designed resources and peer-led workshops.

To the Select Committee on Work and Care

Thank you for the opportunity to make a short submission to the inquiry into work and care in Australia.

People with an intellectual disability and their families have a wide range of expertise with our care systems and are keen to share them with the Committee.

Inclusion Australia is the national peak body for intellectual disability. We are the trusted and authentic national voice for people with an intellectual disability and their families.

Previously called the National Council on Intellectual Disability (NCID) we have been advocating for the rights of people with an intellectual disability since our formation in 1954.

We provide expertise and advice to Federal Government and other organisations to drive systemic change in Australia.

We work closely with people with an intellectual disability and families through the Our Voice committee and our state member organisations. Our Voice is an official committee of the Inclusion Australia Board, and provides advice to the Board on issues that are important to people with intellectual disability. This includes strategic decisions and policymaking. All members of Our Voice are people with an intellectual disability.

Together, we use our collective expertise to advocate for greater inclusion of people with an intellectual disability in all levels of Australian society.

In this submission, we will address the terms of reference b, d, and h.

Please get in touch if there is further information we can provide.

Yours sincerely,



Catherine McAlpine

Chief Executive Officer

## **b: The impact of combining various types of work and care (including of children, the aged, those with disability) upon the well-being of workers, carers and those they care for**

### **System complexity**

People with an intellectual disability and their families tell Inclusion Australia every day about the huge administrative load they face in trying to get the support they need.

People with an intellectual disability and their families are navigating multiple state, territory and federal government systems and agencies, which often have multiple and conflicting eligibility criteria and program rules. These include:

- Disability Employment Services (DES)
- Centrelink and the Disability Support Pension (DSP)
- National Disability Insurance Scheme (NDIS)
- Education systems
- Housing
- Health and Medicare

Research for Inclusion Australia from Swinburne University finds this complexity is a barrier for people with an intellectual disability and their families, including to employment.<sup>1</sup>

There is consistent reference in the research from multiple countries, and in Australia, to the problem of the complexity of the employment and education systems<sup>2</sup>. This creates difficulties for people with disability, their families and also for service providers in navigating this complex landscape, for which there is “currently no guide”<sup>3</sup>. International research has highlighted concerns, echoed by Australian research<sup>4</sup>, in regard to:

the difficulty students and their parents face navigating services across different programs during the transition to adult life, limited coordination across agencies, and a lack of information about the full range of service options available to young adults with disabilities<sup>5</sup>.

This complexity can lead to the polished pathway.

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<sup>1</sup> Erin Wilson and Robert Campaign, “Fostering employment for people with intellectual disability: the evidence to date,” 2020, Centre for Social Impact, Swinburne University of Technology, <https://www.everyonecanwork.org.au/resources/evidence/>.

<sup>2</sup> ACIL Allen Consulting, “National Disability Coordination Officer Program Evaluation,” 2017, [https://docs.education.gov.au/system/files/doc/other/ndco\\_evaluation\\_final\\_report.pdf](https://docs.education.gov.au/system/files/doc/other/ndco_evaluation_final_report.pdf); K.-R. Foley et al., “Functioning and Post-School Transition Outcomes for Young People with Down Syndrome,” *Child: Care, Health and Development*, January 7, 2013, <https://doi.org/10.1111/cch.12019>.

<sup>3</sup> ACIL Allen Consulting, “National Disability Coordination Officer Program Evaluation,” 2017, [https://docs.education.gov.au/system/files/doc/other/ndco\\_evaluation\\_final\\_report.pdf](https://docs.education.gov.au/system/files/doc/other/ndco_evaluation_final_report.pdf).

<sup>4</sup> As above

<sup>5</sup> Allison Cohen Hall et al., “Building an Evidence-Based, Holistic Approach to Advancing Integrated Employment,” *Research and Practice for Persons with Severe Disabilities* 43, no. 3 (July 19, 2018): 207–18, <https://doi.org/10.1177/1540796918787503>.

## The polished pathway

People with an intellectual disability and their families often experience what we call the polished pathway into a lifetime of exclusion from the community. The complexity of the support system, and the pressures on families to manage the enormous competing time pressures of work and care, can make real choice and inclusion very difficult.

For the families of people with an intellectual disability, the polished pathway is one that starts with small decisions in childhood. Families make what feel like 'safe' parental choices during those early tricky school years when everything feels overwhelming and tiring. Families are not told about the long-term implications of these 'choices', and are often presented with only one real choice.

Families are told in early childhood intervention: "Your child will never cope in mainstream school, and they will never cope with her", so they "choose" special school.

Over the next few years, the advantages of this separate system, like dedicated transport and specialised holiday programs makes it easier to stay, as they take the administrative and care work from families.

In high school generally the only employment information students with an intellectual disability and their families are given is about Australian Disability Enterprises (or ADEs), a form of separate work with very low pay. Career planning supports for students with disability are limited. Fewer than one in five students with disability represented in a 2019 survey by peak body CYDA reported receiving assistance in understanding their strengths and skills for the post-school transition.<sup>6</sup> Independent information about a wide range of available choices and supports is typically not available, and navigating those choices and supports is very difficult.

Work experience opportunities are not provided in the same way as for non-disabled students in mainstream schools.<sup>7</sup> Instead, for many students with disability, in Year 10, the special school helpfully arranges group work experience at a local ADE – a fun time that includes organised group transport and a picnic. Students with an intellectual disability are not offered work experience or after schoolwork in mainstream employment in the same way as other students.

During Year 12, the school holds an expo for all the local ADE and day program providers.

People with an intellectual disability and their families find out that signing up means a smooth transition from school.

These exclusionary support options, that ease the complex administrative burden on families, also can protect the employment of families. This must not be the choice any longer.

This pathway is an incremental journey. The problem is it leads to people with an intellectual disability in poorly paid, segregated, and congregated 'work'. It is shaped by low community expectations and supported by interlinking systems.

The connections between these systems, from early childhood intervention to Centrelink, from the NDIS to DES, and especially from school to work, are so smooth that families don't even see they are heading towards this predetermined destination until the last minute.

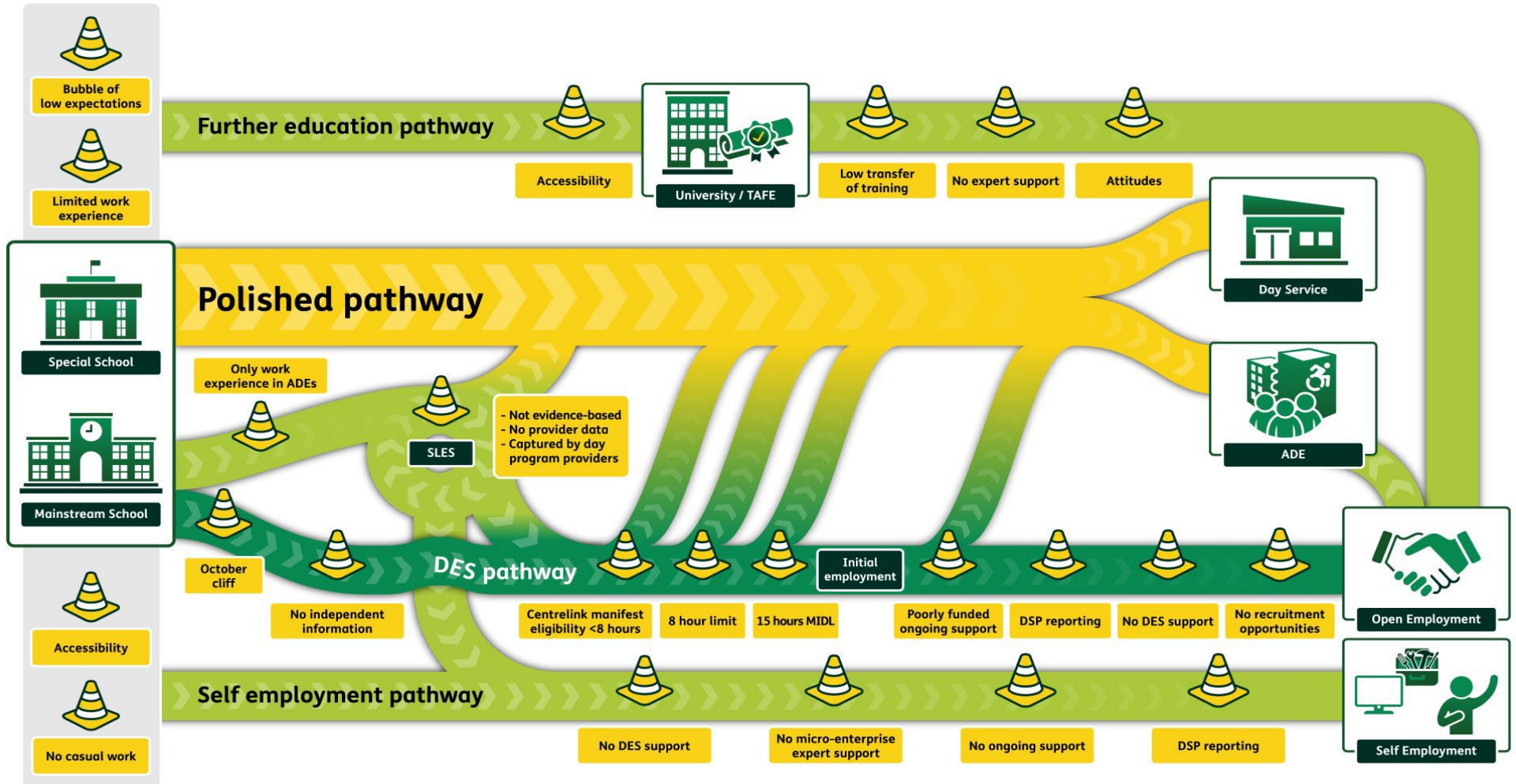
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<sup>6</sup> CYDA, "Submission to the review of senior secondary pathways into work, further education and training", 2020, <https://www.cyda.org.au/resources/details/64/the-review-of-senior-secondary-pathways-into-work-further-education-and-training>.

<sup>7</sup> As above.

For people with an intellectual disability, once they are in these support systems, they don't leave. They will not enter mainstream employment or live in the community or have the same kinds of choices and experiences as other people with disability or non-disabled people.

The polished pathway is illustrated in the diagram on the next page.





## **d: The adequacy of current work and care supports, systems, legislation and other relevant policies across Australian workplaces and society**

### **The National Disability Insurance Scheme**

People with an intellectual disability and their families will likely use disability support services for their entire lives, giving them considerable expertise about how these support systems function and how to improve them. They make up about a third of people with disability who use NDIS supports, including Supported Independent Living funding.

The National Disability Insurance Scheme is the biggest service system for people with an intellectual disability, and also influences other systems that people engage with. As such, we want to see the NDIS to operate with a high level of respect for people with an intellectual disability and their families.

### **Supported decision making**

People with an intellectual disability often do not have a say about the disability supports that they use. For many people with an intellectual disability, someone else makes decisions for them, including under formal mechanisms like guardianship or as a nominee under the NDIS. This is known as substitute decision making.

Inclusion Australia, along with many other disability advocacy organisations, supports the right of people with an intellectual disability to have a say about what happens to them. People with disabilities have rights to make their own decisions. This is covered by Article 3, Article 4 and Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>8</sup>. This is known as supported decision making (SDM).

Australia has signed the UNCRPD and the Australian Law Reform Commission (ALRC) has suggested ways<sup>9</sup> to make these rights part of Australian law.

In 2021, the National Disability Insurance Agency (NDIA) undertook a consultation process to explore how they could implement supported decision making across the Agency and Scheme.

People with intellectual disability commented that it was good to see the NDIA wants to have support for decision making in participants' NDIS plans. They thought the NDIA made some good points about the rights of decision makers. People with intellectual disability liked that the consultation talked about people with disability making their own decisions and having support

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<sup>8</sup> "Convention on the Rights of Persons with Disabilities," OHCHR, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>.

<sup>9</sup> ALRC, "Towards Supported Decision-Making in Australia," September 18 2014, <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/1-executive-summary-2/towards-supported-decision-making-in-australia/>.



when they need it. They liked that decision supporters would have information about how to support decision making.

People also have the right to change their mind. One supporter has shared a story with us about people with intellectual disability changing their mind and having that used against them as proof that they are unable to make decisions. NDIS supports are often so rigid that NDIS participants cannot change their mind about the most mundane decisions in life. As one supporter put it:

“A lot goes on in a year... I might not want a shower in the morning anymore, I might want a shower at night, or I might want two showers a day! It’s ridiculous that you can’t get that.”

People with an intellectual disability with complex communication support needs require ongoing capacity building opportunities to develop the different ways that they communicate – through their natural language as well as through the use of alternative and augmentative communication strategies. It is essential too, that people with complex communication support needs, regardless of their age, receive ongoing capacity building to develop the skills of their paid and informal support people in observing, recognising, understanding and supporting the continued development of the person’s expressive communication.

Researchers have recommended that “Some form of mandated supported decision making and an explicit onus on NDIS staff to enquire into the nature of the decision support would help to set expectations about the quality of informal support, build the capacity of decision supporters for a rights-based approach, and provide criteria to assist in accountability of their practice. Such measures will be important in increasing the chances of adults with intellectual disabilities in realising the Scheme objectives of greater choice and control.”<sup>10</sup>

To date, we are not confident that the NDIA understands this, or is willing to put in place the key requirements to ensure that a person with an intellectual disability’s right to make decisions about their lives is upheld.

## **NDIS complexity**

People with an intellectual disability and their families tell Inclusion Australia that the NDIS is overly complex and difficult to navigate. The administration load to manage NDIS plans is very high, and for people with an intellectual disability, often falls on families. Research has confirmed this, finding that “individuals need considerable skills and networks to successfully negotiate the scheme’s complex administrative processes”<sup>11</sup>.

The NDIS often works in a silo, with people with an intellectual disability and their families left trying to work out which system funds what support, such as in the education, health or housing systems. Different parts of the NDIS - local area coordinators, support coordinators, plan managers, planners -

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<sup>10</sup> Christine Bigby, “Dedifferentiation and People with Intellectual Disabilities in the Australian National Disability Insurance Scheme: Bringing Research, Politics and Policy Together,” *Journal of Intellectual & Developmental Disability* 45, no. 4 (June 24, 2020): 309–19, <https://doi.org/10.3109/13668250.2020.1776852>.

<sup>11</sup> Gemma Carey, Eleanor Malbon, and James Blackwell, “Administering Inequality? The National Disability Insurance Scheme and Administrative Burdens on Individuals,” *Australian Journal of Public Administration* 80, no. 4 (August 10, 2021): 854–72, <https://doi.org/10.1111/1467-8500.12508>.

can give contradictory information, and very little is available in Easy Read or other accessible formats.

There is very little independent information for people with an intellectual disability and their families about what choices and decisions they can make, what is good evidence-based support and how to engage with service providers.

This is a particular issue for people with an intellectual disability who don't have any family or other informal supports and may rely on a single disability service provider for all their supports. This group of people with an intellectual disability can have their capacity for decision making taken away and need the NDIS to fund independent individual advocacy and support.

Families of people with an intellectual disability are important advocates in the lives of people with an intellectual disability and can strongly support their person to make decisions about their lives. But it is not easy to find suitable resources for families, that designed by peers and evidence based.

Inclusion Australia prepared a comprehensive submission about the NDIS approach to supported decision making for the NDIA, and we recommend this to the Committee for their consideration.<sup>12</sup>

## Services for One

Inclusion Australia has completed a project, called New Solutions, that focused on the experiences of people with an intellectual disability with complex support needs, and their families.<sup>13</sup>

People with complex behaviour support needs often have limited options for housing and support. Many have also had negative experiences in disability services and with government agencies.

Some families of people with complex behaviour support needs have set up a service-for-one for their family member.

Services-for-one include those that are directly employing staff and are responsible for their own business processes. It does not include employing staff through a service provider.

In 2018, the NDIS Commission announced that any NDIS-funded service using regulated restrictive practices must register with the NDIS Commission.

Families were concerned that it would be difficult to meet these new requirements.

We worked with families and auditing specialists to develop plain language information to help families understand and navigate the NDIS registration process. We ran a trial NDIS registration audit of a service for one to better understand the auditing experience for families running a service-for-one. We also developed guidance for auditors to use when auditing a service-for-one.

Families of people with an intellectual disability with complex support needs say that "where families have stepped in and established a "service for one" arrangement, the outcomes in terms of

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<sup>12</sup> "Submission to the NDIA on Support for Decision Making – Inclusion Australia," <https://www.inclusionaustralia.org.au/submission/submission-to-the-ndia-on-support-for-decision-making/>.

<sup>13</sup> See: <https://www.inclusionaustralia.org.au/services-for-one-project/>.

the increased quality of life and reduction of restrictive practices are mind-blowing compared to outcomes for individuals with comparable support needs/presentation in group-based settings.”<sup>14</sup>

This group of people with an intellectual disability and their families are navigating systems that are not suited to their needs, and are extremely complex. At the same time, they are often developing highly innovative forms of support. There needs to be much more systemic understanding and support for these novel care systems both in the NDIS and the wider community.

Family members who are part of the New Solutions Community of Practice that Inclusion Australia runs say that flexibility in their employment is vital to manage these complex support systems. They also talked about needing somewhere quiet to work, such as a library. Families told Inclusion Australia that “I have a dream that I can buy a van that is kitted out with a table and somewhere to sit and so forth...[a] camper van that could be an office as well. That is my absolute dream. ...I'd literally be just travelling to the next road where there's a beautiful view.”

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<sup>14</sup> Disability Royal Commission, “Statement of Dariane McLean,” Public Hearing 6, September 9, 2020, <https://disability.royalcommission.gov.au/system/files/2020-09/STAT.0158.0001.0001.pdf>.

## **h: Consideration of differences in experience of disabled people, workers who support them, and those who undertake informal caring roles**

### **Parenting and risk**

People with an intellectual disability can and do provide care and support to their own families, including as parents. But parenting with an intellectual disability is often viewed as a 'risk', regardless of any evidence of risk, and are far more likely to have their children removed by the child protection system<sup>15</sup>. New research about NSW has found that "mothers with intellectual disability and their children in NSW are currently not receiving services that are targeted toward their specific needs."<sup>16</sup>

The Disability Royal Commission held a public hearing into "First Nations parents with disability [who] are particularly at risk of having their children removed and placed in care."<sup>17</sup> The hearing heard that inadequate data was kept about First Nations parents with an intellectual disability, who are at the intersection of two groups targeted by the child protection system - First Nations parents and parents with an intellectual disability.

Article 23 of the UNCPRD says that "in no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents."<sup>18</sup> Australia's 2019 review of our compliance with the CRPD found that "parents with disabilities having their child more likely removed, often on the basis of disability and by the lack of support in their exercise of parental responsibilities for their children" and recommended that there be "no separation of children from parents on the basis of the disability of either the child or one or both of the parents".<sup>19</sup>

The National Disability Insurance Scheme does not provide parenting support, and neither does any other state or territory system. Research has found that "if a mother with intellectual disability is assessed as requiring support with living skills, an NDIS funded support worker may teach her to buy and prepare her own meals and do the laundry. But the same worker is often not permitted to teach her how to sterilise her baby's bottles or wash nappies.

If the first support a mother with intellectual disability receives follows a mandatory report to child protection, it is likely to be too little and too late<sup>20</sup>."

In 2019, the Independent Advisory Committee to the NDIS recommended that the NDIA:

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<sup>15</sup> David McConnell, "Parents Labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities," *Journal of Applied Research in Intellectual Disabilities* 21, no. 4 (July 1, 2008): 296–307, <https://doi.org/10.1111/j.1468-3148.2008.00435.x>.

<sup>16</sup> S Collings et al., "Supporting the Woman, Supporting the Mother: Final Report" (University of Sydney, August 2022), <https://rcf-parenting-disability.sydney.edu.au/wp-content/uploads/2022/08/Final-Report-for-the-Supporting-the-Woman-Supporting-the-Mother-study.pdf>.

<sup>17</sup> Disability Royal Commission, "Transcript Day 1 - Public Hearing 8, Brisbane," n.d., accessed September 22, 2022.

<sup>18</sup> <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

<sup>19</sup> UN CRPD Committee, "Concluding Observations: UN Report on Australia's Review of the Convention on the Rights of Persons with Disability," 2019, <https://www.afdo.org.au/wp-content/uploads/2019/09/UN-Outcomes-Report-on-Australia.pdf>.

<sup>20</sup> Gabrielle Hindmarsh, "People with Intellectual Disability Can Be Parents and Caregivers Too – but the NDIS Doesn't Support Them," *The Conversation*, August 16, 2022, <https://theconversation.com/people-with-intellectual-disability-can-be-parents-and-caregivers-too-but-the-ndis-doesnt-support-them-186742>.

- strengthens NDIS practice to intervene early, build capacity and negotiate with mainstream services on behalf of participant parents
- provides reasonable and necessary support that is:
  - person centred, family focused acknowledging the central role of participants to children in their care
  - can be used to develop support networks around the participant
- makes representation to ensure:
  - child protection agencies make an urgent referral to the NDIS for a plan review of participants who are notified
  - mainstream agencies make adjustments to fulfil their responsibilities to NDIS participants.<sup>21</sup>

It is unclear if any of these recommendations have been implemented to date by the NDIA. Instead, the NDIS Guidelines make it clear that supports for parents to care for their children are not included, even when they are not available through the child protection system, or any other system<sup>22</sup>.

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<sup>21</sup> “NDIS Support for Participants Who Are Parents,” ed. Belinda Epstein-Frisch, Independent Advisory Committee of the NDIS, 2019, <https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5f1a5e5f446e9f2897911caf/1598501122938/NDIS+support+for+participants+who+are+parents+%28September+2019%29+Paper.pdf>.

<sup>22</sup> <https://ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/mainstream-and-community-supports/who-responsible-supports-you-need/child-protection-and-family-support>

## Recommendations

- That the NDIA work to significantly reduce the complexity of using NDIS supports for people with an intellectual disability and their families.
- That independent, evidence-based information is available to people with an intellectual disability and their families about NDIS planning, supports and services.
- That the NDIA implement a supported decision-making framework across the Agency, and the Scheme, for all people with disability, particularly people with an intellectual disability.
- That the recommendations outlined in Inclusion Australia's submission to the supported decision-making framework are implemented.
- That the NDIA clarify supports for parents with an intellectual disability, and provides supports as needed, particularly to reduce the involvement of child protection agencies.

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