

The Barriers to Accessing the National Disability Insurance Scheme in Regional and Remote Queensland for Children with Cognitive Disabilities and Their Families

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Introduction

In Queensland between 2019 and 2020, there was an average of 187 children aged between 10 and 17 in custody each day, with the majority of these children being First Nations children.¹ 15% of the children in custody had a suspected or diagnosed cognitive disability, and 8% had diagnosed or suspected foetal alcohol spectrum disorder (FASD).² Considering the high rate of imprisonment of children with cognitive disabilities, many of these children being First Nations people, it is important to consider how this number can be reduced.

This paper will discuss the barriers faced by children with cognitive disabilities when accessing the NDIS to gain disability support, with a particular focus on the experiences of children and their families living in regional and remote areas of Queensland (RRAQ). As many of the children living in these areas are First Nations, there will also be consideration of the specific barriers faced by these children and their families. Suggestions will then be given relating to how these barriers can be addressed. These suggestions will be provided with the goal of ensuring children in RRAQ are able to enjoy their child rights as set out in the United Nations Convention on the Rights of the Child, and of reducing the likelihood of children with cognitive disabilities from coming into contact with the YJS. A brief overview of two organisations working to address the barriers experienced by children and families living in RRAQ will then be given as an example of how barriers can be successfully overcome.

¹ Department of Children, Youth Justice and Multicultural Affairs, *Youth Justice Annual Summary Statistics: 2015-16 to 2019-20*, (Brisbane, Australia: Queensland Government, 2020), <https://www.cyjma.qld.gov.au/resources/dcsyw/youth-justice/resources/yj-annual-summary-stats-custody.pdf>.

² Department of Children, Youth Justice and Multicultural Affairs, *Youth Justice Census Summary* (Queensland, Australia: Queensland Government, 2021), <https://www.cyjma.qld.gov.au/resources/dcsyw/youth-justice/resources/census-summary-statewide.pdf>.

Cognitive Disability

The term cognitive disability includes disorders that relate to the impairment of an individual's mental processes of 'knowing', including communication, memory, processing of information, learning, decision-making and attention.³ Cognitive disability specifically includes intellectual disability, learning difficulties, autism spectrum disorder, FASD, and acquired brain injury (ABI).⁴ It is not uncommon for an individual with cognitive disability to experience multiple disorders under the umbrella of cognitive disability.

Although often not included in literature referring to cognitive disability, it is important to include FASD when discussing cognitive disability in an Australian context due to the high rates of diagnosis, especially for First Nations children.⁵ Further it must be recognised that the measurement of one's capacity to process, gain and share knowledge is constructed around western knowledge systems and may therefore cause unreliable diagnosis of First Nations people.⁶

For First Nations Australians, disability, including cognitive disability, is viewed differently. A person's health is viewed holistically, and refers to the well-being of the entire community, rather than one individual, as explained in *Ways Forward – A National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health*:

This holistic concept does not merely refer to the "whole body" but in fact is steeped in the harmonising inter-relations which constitute cultural well-being. These inter-related factors can be categorised largely as spiritual, environmental, political, social, economic, mental and physical.

³ Tom Calma, *Preventing Crime and Promoting Rights for Indigenous Young People with Cognitive Disabilities and Mental Health Issues*, (Sydney, Australia: Australian Human Rights Commission, 2008), p3, https://humanrights.gov.au/sites/default/files/content/social_justice/publications/preventing_crime/cog_disr.pdf.

⁴ Calma, "Preventing Crime and Promoting Rights", p3.

⁵ Elizabeth Elliott et al., "Fetal alcohol syndrome: a prospective national surveillance study", *Archives of Disease in Childhood* 93, no. 9 (2008): 732-737, <https://doi.org/10.1136/adc.2007.120220>.

⁶ Calma, "Preventing Crime and Promoting Rights", p3.

Crucially, it must be understood that when harmony of these interrelations is disrupted, Aboriginal ill health will persist.⁷

Cognitive Disability as a Risk Factor for Youth Justice Supervision

It has been found that a high percentage of youth in the youth justice system (YJS) in Queensland have a diagnosed or suspected cognitive disability. As aforementioned, in 2021 15% of youth in the YJS were found to have a diagnosed or suspected cognitive disability, and 8% were found to have diagnosed or suspected FASD.⁸ This is significantly higher than the general population, where approximately 7.4% of youth aged zero to fourteen years are thought to have a cognitive disability.⁹ People with cognitive disabilities also report earlier contact with the YJS than those without cognitive disability.¹⁰ Further, the intersection of cognitive disability and First Nations heritage further increases the chance of early and ongoing YJS involvement.¹¹ It is evident though that children who are provided with adequate disability support are less likely to be involved with the YJS.¹² It is therefore important to consider why children with cognitive disabilities may not be receiving the support they require, and how access to support can be improved.

United Nations Convention on the Rights of the Child

When discussing access to the NDIS for children with cognitive disabilities, it is important to consider that Australia has a duty to ensure that children enjoy their rights as set out by the United

⁷ Pat Swan and Beverley Raphael, *Ways forward: national consultancy report on Aboriginal and Torres Strait Islander mental health*, (Canberra, Australia: National Aboriginal Community Controlled Health Organisation, 1995), p19, <https://vgl.sdp.sirsidynix.net.au/client/search/asset/1293955>.

⁸ Department of Children, Youth Justice and Multicultural Affairs, *Youth Justice Census Summary*.

⁹ Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia, Summary of Findings*, last updated October 24, 2019, <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#children-with-disability>.

¹⁰ Eileen Baldry, Leanne Dowse and Melissa Clarence, *People with mental and cognitive disabilities: pathways into prison*, (Sydney, Australia: University of New South Wales, 2012), p15, <https://www.mhdc.unsw.edu.au/sites/www.mhdc.unsw.edu.au/files/u18/pdf/MHDCDbackgroundOutlaws%20Conf1.pdf>.

¹¹ Baldry, Dowse and Clarence, *Pathways into prison*, p15.

¹² Baldry, Dowse and Clarence, *Pathways into prison*, p15.

Nations Convention on the Rights of the Child (UNCRC).¹³ Two articles of the UNCRC are particularly relevant to the discussion around the barriers to accessing the NDIS for children and families living in regional and remote areas of Queensland (RRAQ).

These are:

- Article 2 – Non-discrimination
- Article 23 – The Rights of Children with Disability

The National Disability Insurance Scheme

The NDIS, established in 2013, was designed to address the gaps in disability care within Australia.¹⁴ Ultimately, the goal of the NDIS is to provide lifelong financial support to those with disability in Australia, thus ensuring their enjoyment of maximum independence.¹⁵ The NDIS is implemented by the National Disability Insurance Agency (NDIA), which allocates funds for individualised supports, and gives information to service providers regarding NDIS policies.¹⁶

For children with disabilities, there are two streams under which support is received from the NDIS, dependent on age.¹⁷ The Early Childhood Approach (ECA) is the NDIS service for children aged under seven.¹⁸ For children over the age of seven, disability support is provided through the general NDIS stream.¹⁹

¹³ United Nations Convention on the Rights of the Child, November 20, 1989, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#Article-23>

¹⁴ Tamara May et al., “Brief history and user’s guide to the Australian National Disability Insurance Scheme”, *Journal of Paediatrics and Child Health* 54, (2018): 115-120, <https://doi.org/10.1111/jpc.13748>.

¹⁵ May et al., “Brief history to the NDIS”, 115-120.

¹⁶ “National Disability Insurance Agency”, National Disability Insurance Agency, September 8, 2020, <https://www.ndis.gov.au/understanding/what-ndis/whos-delivering-ndis/national-disability-insurance-agency>.

¹⁷ May et al., “Brief history to the NDIS”, 115-120.

¹⁸ “Am I Eligible”, National Disability Insurance Agency, August 9, 2022, <https://www.ndis.gov.au/applying-access-ndis/am-i-eligible>.

¹⁹ “Am I Eligible”, National Disability Insurance Agency.



Figure 1. Regional and Remote Areas of Queensland as defined by the Australian Bureau of Statistics. Reproduced from <https://www.health.qld.gov.au/mass/subsidy-schemes/rural-remote>.

Regional and Remote Areas of Queensland

As shown in Figure 1, a large portion of Queensland is considered regional or remote with approximately 37.2% of children living in a regional or remote area, and approximately 14.5% of these children being First Nations.²⁰

Barriers to Accessing NDIS Services

Children with cognitive disabilities and their families living in RRAQ face numerous barriers in accessing NDIS services, including:

- A lack of physical service provider offices
- A lack of knowledge of the benefits of NDIS plans, and how to obtain them
- A lack of disability support and health services
- A lack of culturally appropriate services for First Nations peoples
- First Nations families' fear of government involvement

²⁰ Australian Bureau of Statistics, *Regional Population*, last updated July 26, 2022, <https://www.abs.gov.au/statistics/people/population/regional-population/latest-release>.

A Lack of Physical Service Provider Offices in Regional and Remote Areas

A commonly mentioned barrier experienced by children and their families in RRAQ is the lack of physical NDIS offices in these areas.²¹ As seen in Figure 2, the majority of RRAQ are considered “thin” markets, which the NDIA has defined as having “a gap between the needs of participants and the services available in the market”.²² Families of children with cognitive disabilities who live in these areas are often required to travel significant distances to access a provider. These families may not have reliable transport, or the financial ability to travel to these offices. The advice for families living in areas that are not serviced by the NDIS is to complete the application process online or call the NDIS for support.²³ This advice is inadequate for many families, who may not have regular access to the internet or a telephone, may not be digitally literate, and whose primary language may not be English.²⁴

²¹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, (2020), *Public Hearing Report 4: Health care and services for people with cognitive disability*, <https://disability.royalcommission.gov.au/system/files/2020-10/Report%20-%20Public%20hearing%204%20-%20Healthcare%20for%20people%20with%20cognitive%20disability.pdf>; “Rural and Remote Strategy”, National Disability Insurance Agency, July 30, 2021, <https://www.ndis.gov.au/about-us/strategies/rural-and-remote-strategy>; “Aboriginal and Torres Strait Islander Engagement Strategy”, National Disability Insurance Agency, July 7, 2022, <https://www.ndis.gov.au/about-us/strategies/aboriginal-and-torres-strait-islander-strategy>.

²² Queensland Productivity Commission, *The NDIS market in Queensland* (Brisbane Australia: 2021), p.xxi, <https://s3.treasury.qld.gov.au/files/NDIS-final-report-volume-1.pdf>.

²³ “Queensland”, National Disability Insurance Agency, August 3, 2022, <https://www.ndis.gov.au/understanding/ndis-each-state/queensland>.

²⁴ Children and Young People with Disability Australia, *Improving the NDIS for children and young people with disability and their families* (Australia: 2019), p12, https://www.cyda.org.au/images/pdf/improving_the_ndis_for_children_and_young_people_with_disabilities_and_their_families.pdf; Queensland Productivity Commission, *NDIS Queensland*, p.416.

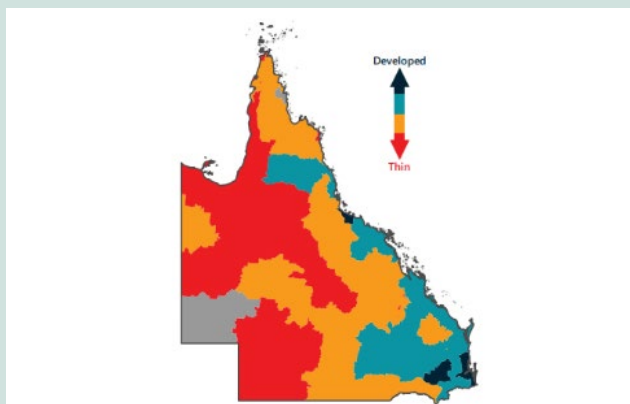


Figure 2. Developed and thin markets by Queensland LGA. Reproduced from <https://s3.treasury.qld.gov.au/files/NDIS-final-report-volume-1.pdf>.

A Lack of Knowledge of The Benefits of NDIS Plans, and How to Obtain Them

Lack of knowledge about the benefits of having a NDIS plan is a significant barrier to accessing the NDIS Australia-wide, not just in RRAQ. The use of NDIS-specific jargon by service providers causes confusion for families, children and medical professionals.²⁵ This can lead to a minimised or incorrect understanding of NDIS plans. This barrier is more pronounced for First Nations families and migrant

²⁵ Angeline Ferdinand et al., *Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities* (Melbourne, Australia: University of Melbourne Centre for Health Policy, 2019), https://www.lowitja.org.au/content/Document/PDF/NDIS_Evaluation_M_Kelاهر_v2.pdf; Edward Johnson, Michelle Lincoln and Stephen Cumming, “Principles of disability support in rural and remote Australia: Lessons from parents and carers”, *Health and Social Care in the Community* 28, no. 6 (2020): 2208-2217, <https://doi.org/10.1111/hsc.13033>; “Aboriginal and Torres Strait Islander Engagement Strategy”, National Disability Insurance Agency.; Joint Standing Committee on the National Disability Insurance Scheme, *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition* (Canberra, Australia: 2017), https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report.

families.²⁶ Much of the information about the benefits of becoming a participant of the NDIS is in English which may not be the primary language for many First Nations or migrant families.²⁷

For those who understand the NDIS and believe that a NDIS plan could benefit their child, understanding how to obtain these plans is another issue. As aforementioned, there is a lack of physical NDIS provider offices in RRAQ, leaving communities without an obvious place to go to gain knowledge about the NDIS. Families who have a regular GP for their child are often still unable to understand how to obtain a NDIS plan, as many GPs also find navigating the application process difficult.²⁸

Once gaining a plan, there is a limited understanding of how to use NDIS plans.²⁹ In remote Queensland specifically, plan utilisation is significantly lower than in other areas, with only 66% of participants living in remote Queensland, and 55% living in very remote Queensland utilising their plans.³⁰ As RRAQ families of children with cognitive disabilities are unable to attend a physical NDIS office, it is difficult to access resources to increase their understanding of how and where their children's plans can be used.

A Lack of Disability Support and Health Services in Regional and Remote Areas

In RRAQ, there are a lack of specialist health providers for children with disabilities, including children with cognitive disabilities.³¹ This further exacerbates the difficulty that families have when

²⁶ Ferdinand et al., *Understanding disability*; Karen Soldatic et al., "Intellectual disability and complex intersections: marginalisation under the National Disability Insurance Scheme", *Research and Practice in Intellectual and Developmental Disabilities* 1, no.1, (2014): 6-16, <https://doi.org/10.1080/23297018.2014.906050>.

²⁷ "Aboriginal and Torres Strait Islander Engagement Strategy", National Disability Insurance Agency.

²⁸ Joint Standing Committee on the National Disability Insurance Scheme, *Provision of NDIS services*.

²⁹ Queensland Government, *NDIS Act 2013 Review* (Brisbane, Australia: 2019), <https://engage.dss.gov.au/wp-content/uploads/2019/11/Queensland-Government-Submission-Review-of-the-NDIS-Act-and-Participant-Service-Guarantee1.pdf>.

³⁰ National Disability Insurance Agency, *NDIS Quarterly Report to disability ministers* (Australia: 2022), <https://www.ndis.gov.au/about-us/publications/quarterly-reports>.

³¹ Johnson, Lincoln and Cumming, "Principles of disability support", 2208-2217.; Ferdinand et al., *Understanding disability*.

utilising their children's NDIS plans. Any disability services in the area may not be appropriate for children, people with cognitive disabilities, or First Nations peoples. Many services operate on a sessional basis, which may not be suitable for families with work or cultural commitments, can cause a long wait time, and are less beneficial for the child than regular support.³² Further, some communities in RRAQ do not have any relevant services in which they can utilise their NDIS plans, and therefore families must travel or consider relocating in order to gain support for their children. This is difficult as many of the families in these communities do not have regular public transport systems, access to their own vehicles, or the ability to pay for travel costs and accommodation required to receive disability support.³³ Also, moving from RRAQ to gain better access to disability support for children is often not possible or wise for the families of children with cognitive disabilities, as this will isolate the children (and parents) from their families, community, and culture.³⁴

A Lack of Culturally Appropriate Services for First Nations Peoples

The existence of physical NDIS offices in RRAQ is integral to the access of First Nations families of children with cognitive disabilities. Face-to-face communication regarding the NDIS is extremely important to ensure that First Nations people receive appropriate and accurate information about how a NDIS plan could benefit them and their child, as well as to build trust between the families and the provider.³⁵ For many families, English is not their first language and thus the complicated use of language and jargon by the NDIA is also a barrier to access.³⁶ Community engagement strategies

³² Johnson, Lincoln and Cumming, "Principles of disability support", 2208-2217.; Ali Lakhani et al., "Disability support services in Queensland, Australia: Identifying service gaps through spatial analysis", *Applied Geography* 110, (2019): <https://doi.org/10.1016/j.apgeog.2019.102045>.

³³ "Aboriginal and Torres Strait Islander Engagement Strategy", National Disability Insurance Agency.

³⁴ "Aboriginal and Torres Strait Islander Engagement Strategy", National Disability Insurance Agency.

³⁵ Ferdinand et al., *Understanding disability*.; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing Report 4*.; Swan and Raphael, "Ways Forward".

³⁶ "Aboriginal and Torres Strait Islander Engagement Strategy", National Disability Insurance Agency.

currently being utilised by the NDIA are also culturally insensitive, as NDIS workers seem to arrive in communities without prior planning, advertising, and communication, causing confusion and apprehension in engaging with the workers.³⁷

For First Nations children with an established NDIS plan, cultural requirements are not included within their price guide, meaning money is often having to be taken from different areas of their plan to ensure they can attend cultural activities.³⁸ For families and children who need to travel to access disability services, or for children who have moved into supported living off-Country, no funding is provided to assist in return to Country.³⁹ The omission in the NDIS price guide of specific funding to allow First Nations peoples to be culturally involved is insensitive and inappropriate and adds another layer of inaccessibility for First Nations children.

Moreover, the view of cognitive disability held by many First Nations peoples is thought to result in an under-identification of children with cognitive disabilities. It is seen as the responsibility of family members to give extra assistance to children relating to any behaviour that may indicate cognitive disability.⁴⁰ First Nations peoples often view disability as an “integrated part of the human experience, or unique to the individual living with the disability”⁴¹ and as such the need for external generalised support in the form of a NDIS plan, rather than individualised support given by family and community may seem unnecessary, especially if the benefits are not tailored towards First Nations children.

First Nations Families’ Fear of Government Involvement

Lack of trust of the NDIA as a Government entity is a significant barrier in accessing the NDIS for First Nations families.⁴² The historical and ongoing removal of children from First Nations families

³⁷ Ferdinand et al., Understanding disability.

³⁸ Ferdinand et al., Understanding disability.

³⁹ Ferdinand et al., Understanding disability.

⁴⁰ Calma, “Preventing Crime and Promoting Rights”, p3.; Ferdinand et al., Understanding disability.

⁴¹ Ferdinand et al., Understanding disability.

⁴² Ferdinand et al., Understanding disability.; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, (2022), Public Hearing 25: The Operation of the NDIS for First Nations people with disability in remote and very remote communities,

justifiably causes reluctance in engaging with government-run services and organisations such as the NDIS. First Nations children are removed from their families at a significantly higher rate than non-Indigenous children,⁴³ and First Nations children with a disability are more likely to be removed from their families than First Nations children without a disability.⁴⁴ Although still significantly higher than the rate for non-Indigenous children, the rate of removal of First Nations children without disability has decreased since the era of the Stolen Generations.⁴⁵ For First Nations children with a disability, this is not the case.⁴⁶ Although adopting culturally sensitive practices within the NDIA will assist in overcoming this barrier, the removal of First Nations children with disabilities needs to be more broadly considered and addressed by the government.⁴⁷

Suggestions for Addressing the Barriers to Accessing the NDIS

Expansion of the NDIS Early Childhood Approach and Early Intervention Program

Currently, the ECA stream of the NDIS includes children below the age of 7, and provides support for children with developmental concerns, delay and disability, as well as their families.⁴⁸ ECA does not require children to have a diagnosis and supports children who have developmental concerns

<https://disability.royalcommission.gov.au/rounds/public-hearing-25-operation-ndis-first-nations-people-disability-remote-and-very-remote-communities>; Anne Stephens et al., “Will the National Disability Insurance Scheme Improve the Lives of those Most in Need? Effective Service Delivery for People with Acquired Brain Injury and other Disabilities in Remote Aboriginal and Torres Strait Islander Communities”, *Australian Journal of Public Administration* 73, no. 2, (2014): 260-270, <https://doi.org/10.1111/1467-8500.12073>.

⁴³ First Peoples Disability Network Australia, *Intersectional Dimensions on the Right to Health for Indigenous Peoples*, (Australia: 2016), <https://www.ohchr.org/sites/default/files/Documents/Issues/IPeoples/EMRIP/Health/FirstPeoplesDisabilityNetworkAustralia.pdf>.

⁴⁴ Ferdinand et al., Understanding disability.

⁴⁵ Ferdinand et al., Understanding disability.

⁴⁶ Ferdinand et al., Understanding disability.

⁴⁷ Stephens et al., “Will the National Disability Insurance Scheme Improve the Lives of those Most in Need?”, 260-270.

⁴⁸ National Disability Insurance Agency, *Early childhood approach*, June 20, 2022, <https://ourguidelines.ndis.gov.au/media/1662/download?attachment>.

that may not develop into a diagnosis of cognitive disability.⁴⁹ The NDIA follows the Best Practice Guidelines for Early Childhood Intervention in ECA, which states that early intervention should follow a family-based approach and offer individualised support that considers a child and family's preferences and cultural beliefs.⁵⁰ Due to this, support includes connecting children with health and disability services to improve their ability to participate in activities and the community, assisting families by providing resources and techniques to best support their child's developmental needs, helping families with applications for mainstream NDIS plans if applicable, and connecting children and families with appropriate playgroups, parent support groups, childcare and schools.⁵¹ Currently, there are no early childhood partners providing ECA in remote Queensland,⁵² despite the Queensland Government identifying the establishment of ECA services in these areas as critical in 2017.⁵³

The early intervention program (EI) is a program under the NDIS that provides support for people who have a recognised impairment, but do not meet the disability requirements of a NDIS plan.⁵⁴ ECA is included under EI, but EI also supports people older than 7. If a child is aged 7 or older, and is not considered eligible for a NDIS plan, they may be eligible for support under EI, but a diagnosis is required and support through this scheme is given with the intention of reducing the need for future NDIS supports.⁵⁵ This leaves many children with diagnosed or suspected cognitive disabilities either without

⁴⁹ National Disability Insurance Agency, *Early Childhood Approach*.

⁵⁰ Early Childhood Intervention Australia, *Best Practice in Early Childhood Intervention*, (Sydney, Australia: 2016), <https://www.flipsnack.com/earlychildhoodintervention/ecia-national-guidelines-best-practice-in-eci.html>.

⁵¹ Joint Standing Committee on the National Disability Insurance Scheme, *Provision of Services under the NDIS Early Childhood Early Intervention Approach*, (Brisbane, Australia: 2017), https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/EarlyChildhood.

⁵² National Disability Insurance Agency, *Early Childhood Approach*.

⁵³ Joint Standing Committee on the National Disability Insurance Scheme, *Provision of NDIS Services*.

⁵⁴ "Do you need early intervention?", National Disability Insurance Agency, June 30, 2022, <https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/do-you-need-early-intervention>.

⁵⁵ "Do you need early intervention?", National Disability Insurance Agency.

further support after age 7 or transferred to the main NDIS stream that does not follow early intervention best practice guidelines. This means support for parents and families is no longer provided.

The benefits of early intervention are generally well known and considered by the NDIA as outlined in the approved Best Practice Guidelines. Evidence regarding the prevention of contact with the YJS and CJS, is also generally well known and studied. Early intervention has been shown to reduce risk factors for youth offending such as poor educational attainment, hyperactivity and impulsivity, and low intelligence that may be associated with cognitive disability.⁵⁶ Further, early intervention can assist in increasing protective factors such as social competence, school achievement, problem solving skills, supportive family and attachment to community.⁵⁷ It should also be understood that early intervention does not mean intervention in the early years, but rather early in the pathway,⁵⁸ as children may not show signs of cognitive disability until an older age (for example, in the latter years of primary education or in the transition to secondary education)⁵⁹.

Expanding ECA and EI programs to an age older than 7 will allow families and children to receive evidence-based support that will address the risk factors associated with cognitive disability and prevent or reduce a child's contact with the YJS. If the ECA age limit was increased to support children through significant life transition phases, such as the transition from primary to high school and from childhood to adulthood, the likelihood of them being criminalised for disability-related behaviours would decrease.⁶⁰ Also, establishing early childhood partners in RRAQ must be a priority, as currently these children and their families are not receiving any benefits of ECA. Children with cognitive

⁵⁶ Calma, "Preventing Crime and Promoting Rights", p3.; Nick Tilley and Aiden Sidebottom, *Handbook of Crime Prevention and Community Safety*, (Cullompton, England: Taylor and Francis Group, 2017), <https://ebookcentral-proquest-com.libraryproxy.griffith.edu.au/lib/griffith/detail.action?docID=4831576#>.

⁵⁷ Calma, "Preventing Crime and Promoting Rights", p3.

⁵⁸ Calma, "Preventing Crime and Promoting Rights", p3.; Tilley and Sidebottom, *Crime Prevention Handbook*.

⁵⁹ Royal Australasian College of Physicians, *Early Intervention for Children with Developmental Disabilities*, (Brisbane, Australia: 2013), <https://www.racp.edu.au/docs/default-source/advocacy-library/early-intervention-for-children-with-developmental-disabilities.pdf>.

⁶⁰ Calma, "Preventing Crime and Promoting Rights", p3.

disabilities living in RRAQ are not being afforded their rights, specifically under Article 23 and Article 2 of the UNCRC,⁶¹ as they cannot access the disability supports that will allow them to live full and decent lives due to the location in which they live.

A First Nations-Led Approach to the NDIS

To address the barriers to accessing the NDIS for First Nations children and their families, the implementation of the NDIS must be changed to be culturally appropriate. The engagement strategies, disability supports and services, NDIS price guides, and NDIS plan creation and management for First Nations children must be established and controlled by First Nations peoples. The First Peoples Disability Network Australia has specifically outlined ten priorities to address disability inequality in First Nations communities and has highlighted the need for an Aboriginal Community Controlled Disability Service Sector that would provide disability supports for First Nations communities under the NDIS.⁶² This should include the training of a First Nations workforce that will oversee all NDIS matters relating to First Nations peoples.

An Aboriginal Community Controlled Disability Service Sector would ensure that First Nations children with disabilities, including cognitive disabilities, are supported in a way that is best for them. Face-to-face, planned engagement strategies run by First Nations employees would allow prospective NDIS participants to gain a full understanding of how a NDIS plan may benefit themselves and their children, and will allow hesitancy due to mistrust and fear to be addressed. Further, information could be given in ways appropriate to different First Nations language groups. Allowing First Nations peoples to have control over NDIS price guides for First Nations children and adults with disabilities will also ensure that important considerations such as funding for return to Country are considered, as well as understanding the disability support needs of First Nations children with cognitive disabilities from a First Nations view of health and disability.

⁶¹ United Nations Convention on the Rights of the Child, November 20, 1989, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#Article-23>

⁶² First Peoples Disability Network Australia, “Ten priorities to address disability inequality”, infographic, 2018, <https://fpdn.org.au/wp-content/uploads/2018/10/FPDN-ten-priorities-2018.pdf>.

Although the NDIA have created an Aboriginal and Torres Strait Islander Engagement Strategy in which they are interacting with First Nations peoples,⁶³ it must be guaranteed that First Nations peoples are directly involved in the implementation of the NDIS. As it currently stands, the barriers to accessing the NDIS for First Nations children and families living in RRAQ are preventing children with cognitive disabilities from receiving appropriate disability support. The establishment of an Aboriginal Community Controlled Disability Service Sector could address the intersectional discrimination experienced by disabled First Nations children living in RRAQ and help them enjoy their rights as stated in Article 23.⁶⁴

Moving Away from the Idea of Disability Care as a Market-Based System

The provision of the NDIS is a market-based system referred to by the NDIA as the ‘disability marketplace’.⁶⁵ The move away from a welfare-focussed system to a market-based system was made with the intent to give participants greater choice in disability support providers.⁶⁶ While this has been successful in metropolitan areas, the less densely populated RRAQ has been neglected due to the subsequent low disability population.⁶⁷ For the disability marketplace, this smaller population means less customers and has resulted in ‘thin markets’ in RRAQ (see figure 2). The right of disabled children to special care should not be dependent on the number of other disabled children living in their geographical region. These children should be equitably enjoying their rights. NDIS provider offices, and specialised disability support services need to be located within RRAQ regardless of the market

⁶³ “Aboriginal and Torres Strait Islander Engagement Strategy”, National Disability Insurance Agency.

⁶⁴ United Nations Convention on the Rights of the Child, November 20, 1989, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child#Article-23>

⁶⁵ National Disability Insurance Agency, *NDIS Market Approach: Statement of Opportunity and Intent*, (2016), <https://www.ndis.gov.au/media/448/download?attachment>.

⁶⁶ National Disability Insurance Agency, *NDIS Market Approach*.

⁶⁷ Queensland Productivity Commission, “The NDIS market in Queensland”.; The Public Advocate, *Inquiry into the NDIS market in Queensland: Submission to the Queensland Productivity Commission*, (Brisbane, Australia: 2020), https://www.justice.qld.gov.au/_data/assets/pdf_file/0009/697689/qpc-ndis-market-submission-public-advocate.pdf.

opportunity, so these children are afforded the same benefits as those living in metropolitan Queensland.

Moreover, Queensland has seen a steady decrease in not-for-profit disability provider organisations since the state’s NDIS roll-out, dropping from approximately 90% of the market in 2017 to 53% of the market in 2020.⁶⁸ For-profit organisations are therefore becoming increasingly more common. For-profit providers must balance other priorities than just providing the best care for the child. The rights of children with disabilities should be the priority of the NDIS and of disability care. The market-based system is another reason why children and families living in RRAQ do not have the choice of providers that was intended.⁶⁹ This is depriving children of their right to non-discrimination and their rights as children with disability. The market-based system needs to be reconsidered to ensure NDIS and disability support services are in RRAQ, despite the low populations and lower possibility of profit.

Success Stories

XtremeCare and the *Pormpur Paanthu Aboriginal Corporation* are two organisations in RRAQ that are exemplifying the benefits of culturally safe practice for First Nations peoples and providing a great example of how early intervention can be implemented.

XtremeCARE

XtremeCARE is a First Nations-owned business providing NDIS services with the aim of delivering culturally appropriate support to First Nations people with a disability. They currently engage with over 150 participants throughout Queensland, including South-East Queensland, the Torres Strait, Cape York and Gulf Regions.⁷⁰ XtremeCARE first help First Nations people become aware of the NDIS and

⁶⁸ Queensland Productivity Commission, “The NDIS market in Queensland”.

⁶⁹ Queensland Productivity Commission, “The NDIS market in Queensland”.; The Public Advocate, *Inquiry into the NDIS market*.

⁷⁰ “Indigenous-owned business providing culturally appropriate services under the NDIS”, Department of Social Services, 2022, <https://blcw.dss.gov.au/articles/indigenous-owned-business-providing-culturally-appropriate-services-under-the-ndis/>.

its benefits, before helping them apply for and manage their plans.⁷¹ The business employs First Nations staff from within the areas they service, which ensures staff have a thorough understanding of the unique characteristics of RRAQ, engage in a culturally safe manner, and understand the First Nations view of disability.⁷² This allows families to understand the ways in which NDIS plans can benefit their children, as everything is explained in a way that is personalised and can be easily understood.

Pormpur Paanthu Aboriginal Corporation

Pormpur Paanthu Aboriginal Corporation is a community-controlled organisation providing evidence-based services for First Nations families in Pormpuraaw, which is located on western Cape York Peninsula.⁷³ The corporation operates as a hub, in which many services can be accessed by families and individuals. Particularly, the organisation runs a childcare hub for families with children aged up to twelve, that promotes early childhood development and engages other local services to ensure wrap-around support. The childcare hub provides personal support for children with suspected or diagnosed disability, through providing needs assessments and management of support plans, as well as support for families and carers of these children.⁷⁴

⁷¹ Neena Bhandari, “Many rural and remote Indigenous communities “don’t know about the NDIS” and its role in disability care”, May 27, 2022, <https://hireup.com.au/news/many-rural-and-remote-indigenous-communities-dont/>.

⁷² “Indigenous-owned business providing culturally appropriate services under the NDIS”, Department of Social Services.; “About XtremeCARE Australia”, XtremeCARE Australia, 2022, <https://www.xtremecareaustralia.com.au/about-xtremecare-australia/>.

⁷³ “About”, Pormpur Paanthu, 2022, <http://pormpurpaanthu.com.au/about/>.

⁷⁴ “About”, Pormpur Paanthu.

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