

**Office of the Public Advocate  
South Australia**



**Disability Advocate Report  
Children and Young People and the National Disability Insurance Scheme**

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## 1. INTRODUCTION

This paper intends to explore the key issues and challenges faced by children and young people with disability and their carers when navigating the National Disability Insurance Scheme (NDIS). For the purposes of this report “children and young people” refers to the age range of 0 -18 years.

Issues for children and young people are complex as there can be a range of factors that impact on them accessing and utilising the NDIS. These can include, but are not limited to, living in out-of-home care (including kinship care arrangements), living in regional and remote areas, being incarcerated or being from Aboriginal and Torres Strait Islander or Culturally and Linguistically Diverse (CALD) backgrounds. These factors alone can significantly impact on a young person’s experience, and whether they are ‘getting a good deal’ from the NDIS.

One common factor for all children and young people is that they are reliant on others, such as a parent or guardian, to assist them to access the Scheme. The skills and abilities of these people to advocate and navigate the system on their behalf can make a huge difference to the outcomes for the young person. It is recognised that the NDIS can be challenging for the most skilled people to navigate and additional factors in a young person’s life can compound this.

## 2. MEETINGS

To inform this paper we have endeavoured to meet with as many people as we can to discuss the issues for children and young people and the people who support them. Some of the people we met with were from or affiliated with:

- The Department for Child Protection (DCP)
- The Education Department of SA
- The Commissioner for Aboriginal Children and Young People
- The Commissioner for Children and Young People
- The Guardian for Children and Young People (as both Guardian and Training Centre Visitor)
- Children and Young People with Disability Australia (CYDA)
- The Department of Human Services, Youth Justice Services
- Department of Human Services, Exceptional Needs Unit (ENU)
- Relationships Australia, South Australia
- Kudos (Early Childhood Early Intervention (ECEI) Partner in the Community, PITC).

Those with whom we have met have been generous with their time and in sharing resources and information.

## 3. STATISTICS

Before delving too far into the issues, it is helpful to understand how many children and young people are currently engaged with the NDIS. The following statistics are from the most recent National Disability Insurance Agency (NDIA) quarterly report from 31 March 2021.

Nationally, there are 244,958 children under the age of 18 (including Early Childhood Early Intervention (ECEI)) who have met access requirements for the Scheme (participants). The breakdown of this cohort is 121,885 who are 0- to 6-year-old, 91,466 are 7- to 14-year-old and 31,702 are 15- to 18-year-old.

In South Australia there are 40,107 NDIS participants across all age ranges. There are currently 5,489 active ECEI participants (the pathway for children aged 0-6 years) and 15,448 7-18-year-old active participants. There were 1,545 new participants across all ages in this reported quarter. Of these new participants 918 are children under the age of 18 years.

The Bilateral estimates<sup>i</sup> for South Australia at the commencement of the scheme estimated that 32,284 people would access the NDIS at full scheme. From these statistics alone it is evident that more people (including children) than anticipated have accessed and are receiving supports through the NDIS.

It is worth noting that not all children who have an ECEI plan go on to have a NDIS plan. The ECEI pathway allows for support for the family to connect their child with a developmental delay or disability to community and mainstream supports. This connection may be sufficient and require no further involvement from the NDIS. When required, the Partner in The Community, Kudos, will undertake the planning process for NDIS participants aged 0-6.

To put things in perspective, of the total South Australian population of children, 4.06% of 0-6 age, 7.18% of 7-14 and 4.47% of 15-18 have a NDIS plan.

#### **4. THE NDIS TRIAL IN SOUTH AUSTRALIA**

South Australia was at the forefront of working towards children accessing the NDIS with the commencement of the NDIS trial for children aged 0-14 years state-wide on 1 July 2013. On 1 January 2017 this was extended to young people aged 15-17 followed by the roll out by regions to adults.

#### **5. EXISTING STATE CHILDREN SERVICES**

The state-run Child and Youth Disability Service which previously provided case management services and early intervention support for this cohort evolved to become registered NDIS provider Kudos. This saw many experienced allied health professionals transitioning from state government to work in this service. Kudos is the NDIS PITC for the ECEI approach and covers the majority of South Australia (with the exceptions of Port Lincoln and Ceduna). Where Kudos does not have coverage in the state these children and their families are supported by the local NDIA office.

#### **6. CONSULTATION PAPERS**

In November 2020 the NDIA released two consultation papers related to young children and their families; the *Early Childhood Early Intervention (ECEI) Implementation Reset*<sup>ii</sup> and the *Supporting young children and their families early, to reach their full potential*<sup>iii</sup> papers. The papers sought feedback on 23 recommendations to reset the ECEI approach. As part of the consultation the NDIS engaged with a range of stakeholders and called for submissions, which closed on 23 February 2021. This feedback informed the March 2021 NDIA paper *You said, we heard - supporting young children and their families early, to reach their full potential*<sup>iv</sup>. This feedback is being considered by the NDIA and it is expected that the ECEI reset will commence towards the end of this year.

There are a range of complexities for children and young people. We have endeavoured to address these in the following sections.

## 7. CHILDREN 0-7 YEARS

The current age range for the ECEI pathway is 0-7 years. We have heard that, at times, a child may not have a disability diagnosis by the age of seven, and that this may impact on them getting a NDIS package and result in a disruption in services. It was noted that these delays in diagnosis may be attributable to waitlists for therapists to assess the child or could also relate to a lack of case management follow up to assist families to make the transition when it is needed.

ECEI Implementation reset paper recommendation 14 proposed raising the age limit for the ECEI.

*'Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age, to help children and families receive family centred support throughout the transition to primary school.'*

This recommendation was supported in the consultation feedback and is supported by the Disability Advocate as it not only provides consistent support through the transition to school but also allows further time for the relevant disability assessments and diagnosis to occur.

## 8. YOUNG PEOPLE IN CHILD PROTECTION

The Department for Child Protection (DCP) works to keep South Australia's children safe by protecting them from abuse and harm and provides alternative care for children and young people when living at home is no longer an option. When this occurs, a child may come under the guardianship of the Chief Executive of the Department for Child Protection. It is at this point DCP becomes the lead agency in the young person's life.

We recognise the work of the DCP and the commitment of its staff to the protection of the rights and safety of children and young people. DCP work with some of the most complex, vulnerable, and traumatised young people in the state. Sadly, the need for their services is ever increasing. We know that a higher proportion of young people in DCP than in the general population have a disability or disability-related need. These young people are also more likely to become involved in the justice system.

DCP has undertaken a significant amount of work to ensure that children and young people entering the child protection system access the NDIS where appropriate. The Department should be commended for the diligent and systematic approach to testing whether the children and young people in their care are eligible to access the NDIS. Once eligibility has been determined and a service plan negotiated, DCP work to ensure that each client maximises their use of the NDIS to achieve independence and improved quality of life.

Concerns were raised with us that the DCP approach to the NDIS seemed to focus more on the new intake of young people in DCP rather than the existing DCP clients and older DCP clients. However, it is our understanding that these groups are also being addressed now that the NDIS has achieved full Scheme.

Below is a brief summary of some of the issues raised by DCP with us:

- Market thin-ness presents a challenge in a range of areas such as being able to access services of therapists, behaviours support specialists and the like
- Market thin-ness in regional and remote areas where there is a lack of suitable supports and services results at time in children coming to the attention of DCP who would not normally
- Accessing NDIS Plans in a timely manner remains an issue although there has been some improvement more recently

- DCP are still awaiting the signing of the Memorandum of understanding (MOU) for Information Sharing between the NDIA and state government agencies. This will allow for access to more timely NDIS data
- The State has negotiated a MOU with the NDIA around young people in voluntary out of home care (VOOHC) arrangements. These young people are not clients of DCP but cannot remain living in the family home due to their disability
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The Exceptional Needs Unit spoke of the challenges for young people with disability who are in voluntary out of home care placements. Young people entering these placements do not require a child protection response but are unable to remain living in the family home for a range of reasons.

The NDIS system does not specifically meet the needs of these young people for a range of reasons.

Respite in the NDIS is more restrictive than in the previous State system. Parents are not able to access Short Term Accommodation (STA), which is the new respite with the flexibility and number of days they need.

The NDIA does not fund Specialist Disability Accommodation (SDA) for participants under the age of 18.

The Government of South Australia provides board and care subsidy under the VOOHC MOU, but where the VOOHC is not with another family, the availability of suitable housing remains an issue. There is also the risk of a young person becoming homeless or having to return to a stressed family home, losing both their support and housing when the service provider provides a bundled-up service and can no longer support the young person due to their behaviours.

## **9. TRANSITION FROM CHILDHOOD TO ADULTHOOD**

There are a range of challenges for young people as they approach 18 years of age and are involved with multiple agencies. A lack of planning and coordination of services and support can unnecessarily compound anxiety and see an increase in challenging behaviours for some young people. Better engagement with the NDIS prior to exiting child specific services will assist in a smoother transition.

Relationships Australia currently provide post care services and we note that work is underway to engage their services at 16.5 years when the young person first enters the post care pathway within DCP instead of 18 years. This change will go some way to providing a smoother and less traumatic transition for the young person in care.

The post care support service is a service funded by the DCP and provides support for children and young people who have lived in out-of-home care for more than six months. They provide collaborative case management and support around independent living skills. The case management provided is comprehensive and covers NDIS, housing and support to connect to services. The service is not time limited. Relationships Australia have offices in Salisbury and Marion.

Relationships Australia has found that young people do re-engage with them sporadically but find that it is usually around their 20's or when they are in a crisis and end up in receipt of a service where their disability is not well accommodated, such as Corrections or the Department of Human Services, Exceptional Needs Unit (ENU). They may never have gotten onto the NDIS.

A mandatory NDIS assessment undertaken in the last year of their time with DCP would assist these young people in their access request for the NDIS. We recommend that these

assessments be undertaken, and planning must occur from 16.5 years of age. There needs to be a clear process to ensure that, where needed, arrangements are made for adult guardianship. We discuss assessment further in the next section of this report.

The DCP has developed a process to ensure that young people exiting the Guardianship of the Chief Executive of DCP who may need ongoing guardianship due to mental incapacity are identified. At this point, an application for the appointment of a guardian can be progressed through the South Australian Civil and Administrative Tribunal (SACAT). We have heard that for some young people exiting DCP the state services are not talking to each other and although this planning reportedly occurs it was still raised as something that could be done better.

There is room for improvement around pre-planning for future needs. No specific examples were provided but this is an area the Disability Advocate would like to revisit to ensure the State is doing all it can to safeguard these young people.

It is worth noting that anyone can progress an application via SACAT, but the Disability Advocate has heard that there is a general reluctance for various agencies to undertake this process. This has been noted by the NDIA, the Adult Safeguarding Unit (ASU) and OPA alike.

## **10. ASSESSMENTS/ INDEPENDENT ASSESSMENTS**

We heard that for some young people exiting DCP who are not already on the NDIS that they do not have the required assessments to assist them in the access process. Assessments are often old and no longer current. Assessments ideally would be of most benefit to the young person whilst they are still in the care of DCP as they are still the guardian for the young person.

Post care services report that often when young people re-engage with services, they do not have the financial means to afford the assessments required for the NDIS. As the post care services are voluntary, they cannot compel a young person to engage in the NDIS process. Young people often only re-engage with these services when they are at crisis point.

The Independent Assessments have been raised as a potential way to assist with meeting this need but concerns were expressed about adding yet another face to the myriad of people who have already been involved in the young person's life.

General concerns were raised about Independent Assessments which, until recently, were due to be rolled out for NDIS participants. The concerns were that they are undertaken by people who do not know the child or young person. There is also the issue for children and young people with augmentative and alternative communication and the assessor would rely on information from others. The assessor also does not see the child in their home environment.

DCP reported on market thin-ness and the impact this has on finding suitably qualified therapists to undertake assessments. This matter would be compounded by the introduction of Independent Assessments as it would draw therapists out of an already thin market. It also explains why some young people do not have current assessments and why DCP requests other departments, where possible, to undertake these assessments i.e., Youth Justice Services.

Other areas observed that, in DCP, the focus appears to be on the younger children and newer admissions rather than the older children. This may be related to the capacity to address the need in this area.

Youth Justice Services looks to undertake some assessments whilst a young person is under its supervision but acknowledge the need to do more assessments as they get older. They also noted the challenges of finding suitably skilled staff, particularly in regional areas.

## 11. MARKET THIN-NESS

Finding suitably qualified staff remains a challenge across the state in a number of professions. This was reported in the National Disability Services (NDS) State of the Disability Sector Report 2020<sup>vi</sup> and an issue that the Australian Department of Social Services (DSS) is endeavouring to address through the NDIS National Workforce Plan 2021-2025<sup>vii</sup>.

*The care and support sector is one of Australia's largest and fastest growing sectors, with around 3,750 unfilled vacancies now and an additional 83,000 NDIS workers expected to be required by 2024.*

*DSS NDIS National Workforce Plan: 2021- 2025<sup>viii</sup>.*

DCP and Youth Justice Services both report difficulties accessing services. DCP are finding that therapists are closing their books to new referrals, respite services are difficult to obtain, and Positive Behaviour Support Planning is difficult to access. When the market fails for children in the child protection space the only option is to use residential care which changes the prospects of children coming out as well functioning adults. It is noted that there are also state-run family preservation and reunification programs along with foster care arrangements, but the absence of good therapies and positive behaviour support planning can be problems in residential care as well.

Market thin-ness significantly impacts on families and children when they cannot access supports and services. This may result in children coming to the attention of DCP who would not normally do so, if supports and services were available to the child's family. An example provided was a single parent in a regional centre with three children under 18 who all have a diagnosis of autism, various other disabilities and have NDIS plans. If this parent cannot care for these children for some reason (such as a hospitalisation) and as there are not suitable respite services in the region these children potentially come to the attention of DCP.

Market thin-ness is particularly an issue in regional and remote areas as the above example demonstrates. The Commissioner for Aboriginal Children and Young People talked about families in Ceduna, Oodnadatta and Cleve who cannot get services for children with Autism even if there is money in the plan. People must leave country to get services.

Children and families in some regional areas are reliant on the NDIA planners rather than specialist children services such as Kudos, as they do not cover some regional locations.

Although the cost of Independent Assessment is covered by the NDIS and may assist with those who find the cost of assessments prohibitive, the advent of Independent Assessments will also put pressure on the sector which is already experiencing a shortage of suitably qualified therapists.

## 12. TIMELINESS OF GETTING INFORMATION AND PLANS FROM THE NDIS

DCP reported challenges in obtaining the NDIS plan for a child or young person under guardianship. Delays in obtaining a copy of a plan can result in delays in a young person getting the disability-related services they need. The DCP have now been successful in establishing an escalation pathway and connections directly with the NDIA to expedite this

process. This has improved significantly since the commencement of the Scheme but at times can still be problematic.

The role of the NDIA Justice Liaison Officer (JLO) has improved the ability for Youth Justice Services to obtain the required information or plans in a timelier manner. The JLO role commenced in early 2020 and currently works at the Adelaide Youth Training Centre (Kurlana Tapa) on a regular basis. It should be noted that there is only one JLO who covers both adult Corrections and Youth Justice Services in South Australia.

DHS continues to negotiate a Memorandum of Understanding (MOU) for information sharing between the NDIA and State Government agencies. This MOU and the departmental schedules that sit under it will allow for more timely access to data about relevant clients. These negotiations commenced in November 2019 and have been long and protracted. Several agencies are keenly awaiting an outcome of negotiations.

### **13. INTERPLAY BETWEEN DISABILITY AND TRAUMA**

Most people we spoke with raised the issue of disability and trauma. The NDIA seems to want to separate out the two, only funding disability-related needs and not considering the impact of trauma on the functional abilities of the young person. This is not taking a comprehensive approach to the child but rather, separating them into segments.

The Youth Justice Assessment and Intervention Service (YJAIS) provided good examples of their experience of this. Below are some quotes from their staff:

*There were several children and young people we were looking at doing assessments for. They do not have disability diagnosis but require additional support and it gets back to the bigger issue of trauma-related issues and how they are considered in the broader scheme they (the young person) do not get a diagnosis but they still have additional support needs.*

*We've been warned away from using too much language that relates to functional impairments or disability needs related to trauma. We've been advised to link it directly to disability rather than trauma as it muddies the water a bit. From our perspective, we can't really separate a young person's disability from their trauma but from an NDIS perspective they want to compartmentalise.*

Maintaining a focus on the functional capacity of the young person and ensuring it is related back to the disability and having therapists who are highly skilled in tailoring reports seems to go some way to address this but it is an area for further discussion. We are concerned that this debate is revisiting some of the pointless demarcations of the past – traumatic versus substance abuse induced brain injury, developmental delay and intellectual disability, mental health and psychosocial disability. Loss of function and inability to participate in society is a disability, however it comes about.

### **14. YOUTH JUSTICE SERVICES**

Youth Justice Services, within the Department for Human Services (DHS) has statutory responsibility for the supervision of children and young people subject to a range of criminal justice mandates.

Youth Justice Services reports that often disability is only identified when the young person comes under its supervision, as often the school or medical services do not identify the needs of these young people. They may have an existing diagnosis which isn't followed up. This can also sometimes be the case for young people under guardianship with DCP.

In 2019, Youth Justice Services undertook a project to screen all of the young people in the then Adelaide Youth Training Centre (AYTC) for indicators of disability related needs. The project was the Youth Justice Kurlana Tapa Disability Screening Assessment Project<sup>ix</sup>. The initial survey came back with up to 95% of young people having a disability-related need.

Several people we met with recognised this project and the good work of the Youth Justice Assessment and Intervention Services (YJAIS) in working to assist young people to access the NDIS and connect with appropriate services.

The Disability Screening Assessment builds on the Banksia Hill project<sup>x</sup> which was undertaken by Telethon Kids in Banksia Hill Detention Centre in Western Australia during 2015-2016. This project had similar findings but also looked at Foetal Alcohol Syndrome Disorder (FASD) and its prevalence. Of the 100 young people fully assessed 36 had a diagnosis of FASD where previously only two of these young people had a formal diagnosis.

Youth Justice Services raised concerns that FASD is a diagnosis that does not meet NDIS criteria unless there is documented evidence of maternal alcohol use during pregnancy. Even if that diagnosis is met, it is not itself NDIS eligible unless intellectual impairment is included. This is concerning considering it is lifelong and can benefit from early intervention and support.

Key challenges for Youth Justice Services have been reported to include:

- Lack of skill, training and experience in the current disability service provider market.
- Support providers are not pro-active in liaising with the children to prevent them re-entering the corrections system. This requires specialist skills in how to interact with those who don't have family members advocating for them.
- Cultural barriers and a lack of capacity of service providers to work through situations and issues with families.
- On occasions service providers are not picking up as much responsibility as they should be for the young person.
- Services are sometimes not integrated enough, particularly in the regional areas when a young person leaves custody.
- There is an over representation of Aboriginal and Torres Strait Islander young people in Youth Justice Services. Those coming from remote communities may have sufficient money in their NDIS package, but services are thin on the ground and often poorly coordinated. This results in a revolving door with them re-entering the justice system.
- There is inconsistent approach across providers and there is a lack of access to services and specialist knowledge of the needs of Aboriginal children, with disability and involvement with the Youth Justice Services.
- Lack of recognition of trauma related disabilities and FASD if not linked to an intellectual disability.
- More proactive case management/support is necessary.
- For those involved in multiple systems the agreed pathways for communication are not always in synchrony. Youth Justice Services suggest a fast track process, planning for transition to occur at the point of entry, clarification of the Applied Principles Tables of Support (APTOS).

Often there is a sufficient funding package but finding a consistent provider with the skills to work with multiple complexities who is familiar with the justice system is challenging. Reluctant service engagement is also a challenge for Youth Justice Services. This speaks to the market thin-ness and the marketisation of the disability sector. It should be noted that this is also often an issue for clients of the Office of the Public Advocate where service providers do not have the skills or are reluctant to engage with such cohorts.

It was reported that in the past, before the NDIS, there were teams that provided wrap around services for vulnerable children. The team knew all of the intricacies of the family and would

be able to make decisions as a team about what the child needed. With the NDIS this does not exist. There are many stakeholders across different services and the system is now reliant on families being able to articulate the needs of their child. This does not work well for many young people under the supervision of Youth Justice Services.

A particular challenge with rural young people is that the YJAIS is well placed to help inform the access request processes and are seeing good funding packages as a result but there is often a lack of services/ supports when they return to their community. There is a disjunction between the Supported Independent Living (SIL) and the Home and Living Supports process and they have trouble obtaining this information from the NDIS.

There is often a delay in young people getting the services they need in the community when they are released from custody. They are often released into environments that are less than conducive to meeting their needs. This can be compounded by late access requests for the NDIS when people are 17 or 17.5 years of age and nearing the point that DCP are about to withdraw services. It hampers Youth Justice Services' ability to assist with a positive transition from custody to community with services into adulthood. The State Plan is in place to address this. Youth Justice Services have a deliverable regarding supporting the young person in the first 48 hours post release.

Youth Justice Services reported that sometimes DCP ask YJAIS to undertake assessments on young people whilst under the supervision of Youth Justice Services. It is unclear to Youth Justice what assessments are being done in house in DCP or by private providers that are funded by DCP.

Youth Justice Services involvement is also limited to a mandate of the Youth Court, so it is not best placed for long-term continuity when working with a young person. It advocates for greater ongoing care but recognise there is a long way to go with that and it is not a task for Youth Justice Services in isolation.

## **15. THE USE OF RESTRICTIVE PRACTICES ON CHILDREN AND YOUNG PEOPLE**

The use of Restrictive Practices (RP) with children and young people is of concern. The under-reporting of the use of RP for children and young people is an issue. The NDIS Commission reports that, currently, children and young people with disability are under-represented in the data reported to the NDIS Commission in relation to the use of regulated restrictive practices. As of 30 June 2020, only 12.2% of behaviour support plans lodged with the NDIS Commission in the 2019/2020 financial year related to a participant aged under 18 years.

The NDIS Quality and Safeguards Commission recently released the Practice Guide for Regulated Restrictive Practices with Children and Young People with Disability (March 2021)<sup>xi</sup>. This provides clear guidance around the use of Regulated Restrictive practices and examples of the balance with standard parental practices to keep children safe. It should be noted that this guide applies to service providers and not parents.

## **16. EDUCATION**

The Department for Education provides a range of integrated education, training, and child development services to benefit children, young people and families. The Department works to improve children's and young people's education, safety and developmental outcomes from birth through their transition to adulthood<sup>xii</sup>.

Some of the issues identified by the Department for Education include:

- Challenges in balancing educational needs with visiting services for children and managing these onsite visits or time away from the education environment
- The disbandment of the state group coordinated by DHS for information sharing about the NDIS
- The lack of ability to obtain data about which students have an NDIS Plan
- The late identification of disability or disability related needs of students which may be due to parental hesitancy to recognise there is a developmental delay.

It is no surprise that for the Department for Education the focus is on education and not so much on NDIS supports. Finding the balance between NDIS supports such as therapies and time taken away from a child's education is challenging for many schools. There is policy tension between services being delivered in school hours either in the school or the child having to leave the school site to attend therapy. There may be three to four providers trying to access a school child during school hours which causes constant disruptions. Special schools have always managed this, but mainstream schools don't always manage it easily. Department for Education policy requires supervision of the NDIS service provider whilst on school grounds. The Department recognises that more work needs to go into educating teachers on the NDIS.

The disbandment of the 'state group' headed up by DHS has had an impact on the Department for Education's ability to work more closely with the NDIS. DHS has recently recommenced a similar state group called the South Australia Disability Reform Interdepartmental Committee (SADRIC) which meets three-monthly. This may go some way to assist in the concerns of the Department.

The Department for Education does not currently have systematic information about students who have disability or an NDIS plan but noted the value of this to at least avoid duplication of supports. There is also sometimes a reluctance for parents to acknowledge that their child may require some form of early intervention or assessment. This, in turn, can result in delays in getting early intervention supports that a child may require. One of the recommendations for the ECEI was to extend the age from seven to nine years to allow for the transition to school.

Within the Department for Education, the in-kind arrangements for school transport and health care continue until December 2023. However, there is consideration to moving in-kind programs back to the State. Agreement on a nationally consistent approach to transport has not been able to be reached. South Australia has contributed \$12M for in-kind transport, with \$300 million dollars contributed nationally.

The Commissioner for Children and Young People raised concerns in *The Blame Game* report 2020<sup>xiii</sup> relating to the impact of exclusions from school, noting that those most likely to be impacted are already facing significant challenges outside of school. One such challenge identified in the report was living with disability.

There are legislative protections in place such as the Commonwealth *Disability Discrimination Act 1992* and the *Disability Standards for Education 2005*, but exclusionary practices impact on children with disability disproportionately. The Commissioner quoted the report tabled by the South Australian Legislative Council in 2017 on access to the South Australian education system for students with disability Which found that while students with disability made up 9% of the student population, they accounted for more than 23% of all suspensions.

She also noted that there is a failure in education to leverage the money available at the school leaving end of a child's education. Young people are leaving school with a disability and there is no coherent system response to transition to employment. There could be ways

to capture money from the NDIS to bring it to schools but there is a reluctance from schools to do this.

The Commissioner for Children and Young People also noted that there are no recorded numbers of children excluded from schools in the Catholic and private school system. This makes it difficult to know what is happening in special schools, special classes in schools and mainstream schools.

## 17. DATA COLLECTION

The people we spoke to talked about the challenges in getting good data across departments. For example, DCP appears to only collect data on children with an NDIS plan and the various stages of access whereas the Department for Education report on disability and trauma and may not know if a child is an NDIS participant. This may indicate that there are children and young people with DCP who are in need of additional support around disability or trauma related needs but do not have a diagnosis or meet NDIS eligibility and are not getting this support.

Access to good data about children and young people with disability in state care is not just an issue for South Australia but across all jurisdictions.

The Department for Education does not have access to NDIA data, and even if they did there is the additional challenge of determining which children are in the government and non-government education sectors.

## 18. ADVOCACY FOR CHILDREN

The NDIS is premised on the assumption that children have a parent or DCP support that works in their best interest. This is not always the case. There are parents who lack the knowledge or skills to access the NDIS system and then to follow up on further actions required for their child. This may be due to a range of reasons including mental health, disability of parent, substance misuse or just the sheer complexity of the system.

*The NDIS is a system founded on parents doing the best for their kids, but a lot of our kids' parents aren't able to for a whole range of reasons. There's a gap in that locus parentis role e.g. in courts and admin tribunal's young people can often have their own legal advocate. They will benefit from that in NDIS. I know NDIS aren't there to replace child protection but this is in a grey area where there is no active abuse of their child but they also aren't in the position to best advocate for their children.*

Youth Justice Services

There are also questions about when a child is under State care, who is their *nominee* and who sets up services for them?

We heard that there is a lack of advocacy for children who do not have parents who can advocate for them. An advocate within the NDIS would be of great benefit for those who do not fall within DCP, to help them identify what their needs are.

## 19. ABORIGINAL CHILDREN AND YOUNG PEOPLE

The NDIS Quarterly data does not provide specific detail about the number of Aboriginal and Torres Strait Islander children with a NDIS plan. The best information available from the March 2021 data is that in South Australia there are 2176 Aboriginal people with a NDIS plan, of these 101 were new in the last quarter. These numbers make up 6.5% of all NDIS plans in South Australia. It is disappointing that this information is not recognised in the data

as young Aboriginal people with disabilities are some of the most vulnerable young people. We also know that Aboriginal children and young people are overrepresented in both child protection and youth justice settings just as children with disability are.

Some of the unique barriers for Aboriginal children and their families have been discussed in the Disability Advocate report on *Aboriginal and Torres Strait Islander People and the NDIS*<sup>xiv</sup>. The examples below are more specific to children and young people.

The NDIS is not set up to engage appropriately with Aboriginal children and their families. There is no capacity to develop a relationship and take time to get to know the young person, their family and community which are all essential to the support of the young person.

Aboriginal families require an assertive process to assist people entering the scheme. Families need someone to walk beside them through the process. The Commissioner for Aboriginal Children and Young People is particularly concerned about hard to engage, poorly connected families and people who are not engaging.

The NDIS Act does not acknowledge or recognise private arrangements for foster care placements and kinship care arrangement. It is essential to recognise kinship care arrangements for the purpose of being able to provide information to and receive information from the NDIS. By this relationship not being formally recognised there are significant barriers for those who care for young Aboriginal children who have a disability. An example was provided where the carer could speak to Centrelink on behalf of the young people in her care under a kinship care arrangement but was not able to speak to the NDIS.

Thin markets were also an issue for Aboriginal children which prevented them accessing support coordination or services. There are a limited number of providers who provide culturally appropriate services. Services in regional and remote areas are also limited and hard to source.

It would be helpful if the NDIA and DCP had a system that would talk to each other and advise the NDIA that the carer can speak on behalf of the child.

## 20. DISCUSSION

The words of the Commissioner for Children and Young People ring true.

*South Australia must prioritise action and effort towards investing and supporting children living with a disability given that the state has more children living with a disability and more children who are active NDIS participants. On top of this, the number of children living in poverty is higher than the national average. When more than 50% of all NDIS participants in SA are children and young people and almost 30% of students in SA public schools receive adjustments for disability then it's time to prioritise their interests and wellbeing, placing them higher on our collective agendas. Putting it simply we must look beyond care and protection and invest in contributions, participation and futures*

*Helen Connolly, Commissioner for Children and Young People*

There is significant grist for the mill in this report and as noted by Helen Connolly, children make up such a large proportion of people accessing the NDIS. We support her sentiment that we need to get it right for children and young people to empower and position them to become valuable and active members of their community and enjoy all of the benefits life has to offer.

## 21. KEY POINTS

The following are key points drawn out of this report:

- Recommendation 14 of the ECEI Implementation reset paper about increasing the age limit for children supported under the ECEI is supported by the Disability Advocate. It not only provides consistent support through the transition to school but also allows further time for the relevant disability assessments and diagnosis to occur.
- A higher proportion of young people in DCP than in the general population have a disability or disability-related need. These young people are also more likely to become involved in the Youth Justice system.
- There is room for improvement around pre-planning for future needs and supported accommodation for young people as they approach adulthood.
- Market thin-ness impacts on finding suitably qualified therapists to undertake assessments. This matter may be compounded by the introduction of Independent Assessments which will draw therapists out of an already thin market.
- A lack of appropriate services/ supports particularly in regional South Australia can result in children who would not normally come to the attention of DCP also
- Market thin-ness is particularly an issue in regional and remote areas
- There is only one Justice Liaison Officer who covers both adult Corrections and Youth Justice Services in South Australia.
- We are concerned that this debate is revisiting some of the pointless demarcations of the past – traumatic versus substance abuse induced brain injury, developmental delay and intellectual disability, mental health and psychosocial disability. Loss of function and inability to participate in society is a disability, however it comes about.
- FASD alone as a diagnosis does not meet NDIS criteria unless there is documented evidence of maternal alcohol use during pregnancy. Even if that diagnosis is met, the young person may still not meet NDIS eligibility unless they have an intellectual impairment.
- There are many stakeholders across different services and the system is now reliant on families being able to articulate the needs of their child. This does not work well for many young people under the supervision of Youth Justice Services.
- While students with disability made up 9% of the student population, they accounted for more than 23% of all suspensions.
- The NDIS is not set up to engage appropriately with Aboriginal children and their families. There is no capacity to develop a relationship and take time to get to know the young person, their family and community which are all essential to the support of the young person.
- Kinship carers can speak to Centrelink on behalf of the young people in their care but was not able to speak to the NDIS.
- There are a limited number of providers who provide culturally appropriate services. Services in regional and remote areas

## 22. GLOSSARY

<b>ACRONYM</b>	<b>FULL TITLE</b>
APTOS	Applied Principles Tables of Support
ASU	Adult Safeguarding Unit
AYTC	Adelaide Youth Training Centre
CALD	Culturally and Linguistically Diverse
CYDA	Children and Young People with Disability Australia
DCP	Department for Child Protection
DHS	Department of Human Services
ECEI	Early Childhood Early Intervention
EHO	Exploring Housing Options
ENU	Exceptional Needs Unit
FASD	Foetal Alcohol Syndrome Disorder
JLO	Justice Liaison Officer
MOU	Memorandum of Understanding
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
OPA	Office of the Public Advocate
PITC	Partner in the Community
SACAT	South Australian Civil and Administrative Tribunal
SADRIC	South Australia Disability Reform Interdepartmental Committee
SDA	Specialist Disability Accommodation
SIL	Supported Independent Living
VOOHC	Voluntary Out of Home Care
YJAIS	Youth Justice Assessment and Intervention Service

## REFERENCES

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- <sup>i</sup> Bilateral estimates <https://www.bing.com/search?q=NDIS+Bilateray+estimates&src=IE-SearchBox&FORM=IESR3A>
- <sup>ii</sup> National Disability Insurance Agency - Early Childhood Early Intervention (ECEI) Implementation Reset [Supporting young children and their families early, to reach their full potential | NDIS](#)
- <sup>iii</sup> National Disability Insurance Agency - Supporting young children and their families early, to reach their full potential [Supporting young children and their families early, to reach their full potential | NDIS](#)
- <sup>iv</sup> National Disability Insurance Agency - You said, we heard: supporting young children and their families early, to reach their full potential [Supporting young children and their families early, to reach their full potential | NDIS](#)
- <sup>v</sup> National Disability Insurance Agency - Early Childhood Early Intervention (ECEI) Implementation Reset [Supporting young children and their families early, to reach their full potential | NDIS](#)
- <sup>vi</sup> National Disability Services – State of the Disability Sector Report 2020 [https://www.nds.org.au/images/State\\_of\\_the\\_Disability\\_Sector\\_Reports/SoTDS\\_2020.pdf](https://www.nds.org.au/images/State_of_the_Disability_Sector_Reports/SoTDS_2020.pdf)
- <sup>vii</sup> Department of Social Services - NDIS National Workforce Plan: 2021 -2025 – June 2021 <https://www.dss.gov.au/disability-and-carers-publications-articles/ndis-national-workforce-plan-2021-2025>
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- <sup>ix</sup> Youth Justice Disability Screening Assessment Project <https://dhs.sa.gov.au/services/youth-justice/disability-screening-assessment-project>
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- <sup>xii</sup> The Education Department of South Australia <https://www.sa.gov.au/topics/about-sa/government/departments/~:text=Department%20for%20Education%20The%20Department%20for%20Education%20provides,outcomes%20from%20birth%20through%20their%20transition%20to%20adulthood.>
- <sup>xiii</sup> The Blame Game report by the Commissioner for Children and Young People [The Blame Game \(education.sa.gov.au\)](#) or [2020 inquiries and reports \(education.sa.gov.au\)](#)
- <sup>xiv</sup> Disability Advocate Report on Aboriginal and Torres Strait Islander People with Disability and the NDIS