

South Australian
Commissioner
for Children and
Young People
2022

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From Checkbox to Commitment

What children and young people
with disability said about identity,
inclusion and independence

PROJECT REPORT NO. 30 | MAY 2022



Definitions used in this report

This report has adopted both the social model of disability and the definition of disability used by the United Nations; that people with disability are “those who have long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

We refer throughout this report to children, young people, and children and young people. Unless otherwise specified, where we refer to children and young people, we are referring to those aged 0 to 18 years. Where we refer only to young people, we are referring to young people aged 12 to 25 years.

Acknowledgements

All direct quotes in this report are from children and young people with disabilities who participated in this project.

Special thanks to all those children and young people who participated in this listening project.

Thanks also to the following schools and organisations who supported the participation of children and young people in the project:

- Adelaide West Special School
- Barkuma Inc Transition Program
- Cabra Dominican College
- Can:Do 4 Kids Group
- Cara Inc.
- Carers & Disability Link – Barossa Valley
- Elizabeth Vale Primary School
- Gawler & District College
- JFA Purple Orange
- Klemzig Primary School of the Deaf
- Life Skills Hub – Elizabeth Vale
- Minda Inc.
- National Disability Children’s Services Group
- Open Access College Marden
- Our Lady of La Vang Special School
- Reynella East Primary School
- Seaford Secondary College
- SPELD Inc.
- Springbank Secondary College
- Wirreanda Secondary School

Suggested citation

Connolly, H. Commissioner for Children and Young People, South Australia (2022). *From Checkbox to Commitment: what children and young people with disability said about identity, inclusion and independence.*

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Commissioner's Foreword

As Commissioner for Children and Young People I regularly engage with South Australian children and young people to understand what is important to them. This information is captured through consultations, surveys, focus groups, summits, and individual interviews.

Having now engaged with thousands of children and young people throughout the state, including children and young people from vulnerable and marginalised groups, I can confidently say that the voices of children and young people living with disability are the hardest to hear.

Their views are rarely sought, and they are rarely chosen by adults to represent their schools, attend summits and forums, or be members of student representative councils, youth advisory committees, or other participatory structures. They are therefore one of the most marginalised groups of citizens in South Australia.

To shine a light on the experiences of children and young people living with disability and to fulfil my obligations to represent their interests, I undertook a targeted listening project during 2020/21 so that I could hear directly from this group of children and young people. This listening was done both online and face to face via more than 30 individual sessions undertaken with children and young people aged 9–22 years in a range of education and community settings.

To ensure the listening project was inclusive I worked with Auslan interpreters, alternative communication devices, Braille, writing, drawing, play, and Zoom to enable as much participation by children and young people living with disability as possible during COVID-19 restrictions.

From my experience of seeking out their views and voices, I think it is fair to say that there simply aren't enough opportunities for children and young people living with disability to participate, or be genuinely listened to.

Given my struggle to connect with diverse groups of children and young people with disability to hear their voices directly, it is reasonable to ask how our systems and decision-makers ensure they can hear from children and young people living with disability.

It appears that whilst South Australian children and young people living with disability have contact with many services and systems, they have very little say in how the majority operate. Practical support for the right of children and young people with disability to engage in decision-making processes is limited. This is despite significant evidence that engagement not only improves the design and delivery of systems and services, but also increases individual confidence and capabilities, and physical and emotional safety.

This report has been written against the backdrop of the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* – the culmination of more than a decade of inquiries into past and current system failures impacting people with disability. The Royal Commission includes ongoing concerns regarding the capacity of the National Disability Insurance Scheme to deliver on the most basic support needs of children and young people with disability and those of their families.



In October 2020, the Royal Commission interim report stated they had “no comprehensive data of experiences of children and young people.”

This is indicative of the continuing marginalisation for this group of children and young people. It leads to decision making that ignores their voices as well as the failure to recognise and resource opportunities for their participation.

By not involving children and young people with disability in decisions that affect them, the “system” reinforces a perception that children can’t, or don’t want to express their views and make their own decisions. Over time this can become a self-perpetuating cycle.

This report seeks to address some of the current knowledge gaps by reporting on what children and young people with disability have said about their lives.

Through a process that intentionally privileged their perspective and input over others in the room, children and young people with disability were able to express their views and participate in the consultation. Whilst some have argued that my focus should be on advocacy around the deficits that exist in meeting the fundamental physiological, safeguarding, and care needs of children and young people with disability, I have nevertheless embarked on a process to hear directly from children and young people about their lives.

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It is my view that systems-crises will continue until we recognise, respect, and act upon the experiences, needs, and wishes of the children these systems were created to serve.”

Children and young people with a disability have the right to have their voices heard in matters that involve them. I hope the voices shared in this report will provide insight into how they perceive their world, and the value their direct participation and input can bring to improving the systems currently being designed by individuals and the community who are committed to finding ways to better meet their needs.

I want to sincerely thank all of the children and young people from schools and agencies who engaged in these conversations. I would also like to thank the teachers, Student Support Officers, support workers, interpreters, parents, and advocates who supported their participation.

Their unique voices, and the experiences of participants will be shared with decision makers across the community, with the hope of encouraging others to further engage children and young people with disabilities in their work.

The views expressed are those reflected directly from the children and young people who participated. They include both positive and negative personal experiences and reflect their individuality and commonalities.

In hearing their voices, we are reminded that children and young people with a disability have diverse needs, capacities, resources, personalities, and experiences that we can only seek to understand and include by listening to what they have to say.



Helen Connolly

Commissioner for Children and Young People, South Australia

“

Themes of identity, inclusion, and independence are consistently raised by children and young people with disability as being key to the quality of their lives.”



Context

We use a variety of expressions to describe children's right to participate in decisions affecting them. Some of this language includes having a 'voice', 'choice', 'freedom', 'participation', 'engagement' and 'active involvement' in decision-making processes.

The right of children with disability to have a say in decisions affecting their lives is enshrined in two United Nations international rights conventions: the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disability (CRPD) – both of which Australia is a signatory.

The CRC is built on the declaration that “children are not just objects who belong to their parents and for whom decisions are made” but individuals with the right to have their interests considered and to develop healthily so they can live a full life. This includes the opportunity to have a say on all issues that affect them and for their views to be taken seriously.

The CRPD obliges state authorities to ensure and promote the realisation of human rights and freedoms, independence, and full participation of people with disability. This includes provision of accessible information and other forms of assistance, support services and facilities that people with disability want and need.

These UN Conventions provide every South Australian child with disability with the right to actively participate in decisions affecting their lives at an individual, program, and system level through participatory practices, processes, and structures.

It's a right that is extraordinarily important to children and young people, yet it is also a right they say they currently have little access to. Children with disability, particularly those with complex needs, are almost always excluded from decision-making at almost every level.

The rights of children and young people with disability are also embedded in the *Disability Inclusion Act SA (2018)* (the Inclusion Act) which emphasises that children with disability should be considered a priority group with different needs and vulnerabilities.

The Inclusion Act requires each state authority to develop a Disability Access and Inclusion Plan (DAIP) that must give effect to the objects and principles of the Act, and acknowledge that there are risks and principles specific to children with disability.

This also includes ensuring the views of children with disability are listened to, and that their developmental needs be considered. Despite the legislative requirement, many of the draft DAIPs developed by key state authorities do not adequately recognise children and young people with disability as a group that has needs and wants that are separate to and different from adults who are living with a disability. Consequently, they fall well short of what is required in terms of what is required to be a unique set of responses and engagement strategies.

The Inclusion Act emphasises that children and young people should be considered as a priority group with vulnerabilities that are separate to those of adults. This means that protections for children's rights and safety should be comprehensive and stronger than those devised for adults.

On 1 November 2019, the Department of Human Services (DHS) launched Inclusive SA, which commits state authorities to support young people living with disability to actively participate in decision-making and sets a quantitative indicator for measuring this. At the time of writing there is no identified funding, program, or process in place to ensure delivery of this outcome, nor mechanism for collecting the data associated with its measurement.

Despite the high prevalence of disability among children in South Australia, there continues to be a lack of know-how and capability in how communities can promote meaningful participation.

To move participation from a checkbox activity to a meaningful commitment, adults who genuinely recognise children as experts in their own lives are needed. Those who hold this view instinctively assist in ways that support children's free expression of their views and preferences on all matters affecting them.

To then move from meaningful to systemic, the rights of children with disability need to be articulated and enacted at the state and federal levels through legislation, agreements, frameworks, bodies, policies, and programs that cross all areas of children's lives; not only those considered to be disability specific.

This is difficult to achieve. We know the process of filtering and translation from conventions and frameworks to program, practice, and contracts within individual departments, agencies, and organisations, dilutes children's rights in favour of other priorities and agendas. For example, experience shows that rights such as voice and choice are regularly overtaken by activities that are focussed on child safety and protection.

Consequently, only a handful of the federal and state instruments relating to children's rights explicitly address the right of children and young people to participate in decision-making. Even less contain clear and measurable targets that are required to be regularly reported upon through accessible data sources that can quantify the extent to which children have access to this right.

Therefore, whilst the principle to participate exists in a technical sense in governing documents, in practice there is no reportable activity or measurable outcome being recorded and so for all intents and purposes the right of a child with disability to participate in decision-making about matters affecting them simply disappears.

In practice this means that in South Australia there are far too few organisations doing the work required to support children and young people with disability to actively participate in all levels of decision-making. Those organisations and agencies that should be elevating the voices of children with disability, including funding agencies, aren't prioritising this right sufficiently enough amongst competing demands.

“

As such, the voices of children and young people with disability are being sidelined or ignored altogether.”

This constitutes systemic bias that prioritises seeking the voices of adults with disability over those of children and young people with disability. It is crucial that these barriers to children and young people's participation be proactively addressed.

Some of the perspectives and issues raised by children and young people with disability are shared by their peers. They include education and learning, jobs, family, activities, and friends. Yet children and young people with disability also raise issues that reflect different priorities informed by their own lives and unique to their individual personal experiences. Themes of identity,

inclusion, and independence are consistently raised by children and young people with disability as being key to the quality of their lives. Their views on these important themes cannot simply be extrapolated or transposed from the experiences of others, including their parents and advocates, no matter how well intentioned.

Children and young people interact with a range of services in their everyday lives including through school, health, child protection, family support, transport and disability support services. For young people with disability, their dependence on these services is central to their quality of life. When these services or systems presume to understand their priorities, perspectives and wishes, without undertaking the work required to collect their points of view, they are not meeting internationally agreed to obligations. This is also a failure in safeguarding, as listening to children and young people and respecting their views and experiences is fundamental to their safety, wellbeing and personal development.

Furthermore, when we refuse children and young people with disability the opportunity to engage in decisions on matters impacting their lives, we deny and diminish their feelings of confidence and capability. When we assume that children and young people with disability 'can't' do something, our actions communicate this false assumption back at them. Over time this erodes confidence and capability.



Key facts and figures

There are approximately

369,900

children and young people under 18 years living in South Australia.¹



In 2018 in South Australia:

25,900

children aged 0 to 14 years and

23,800

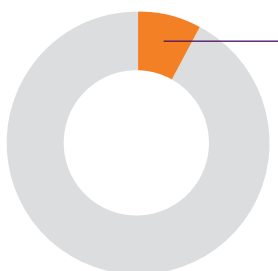
young people aged 15 to 24 years

were reported to be living with a disability.²

21,644

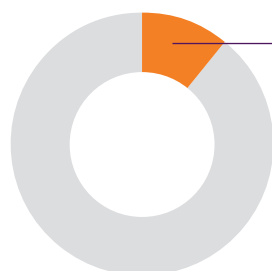
children and young people aged 0–18 years were registered as NDIS participants at 30 June 2021.³

South Australia has a **disability prevalence rate higher** than the national prevalence rate of disability.



8%

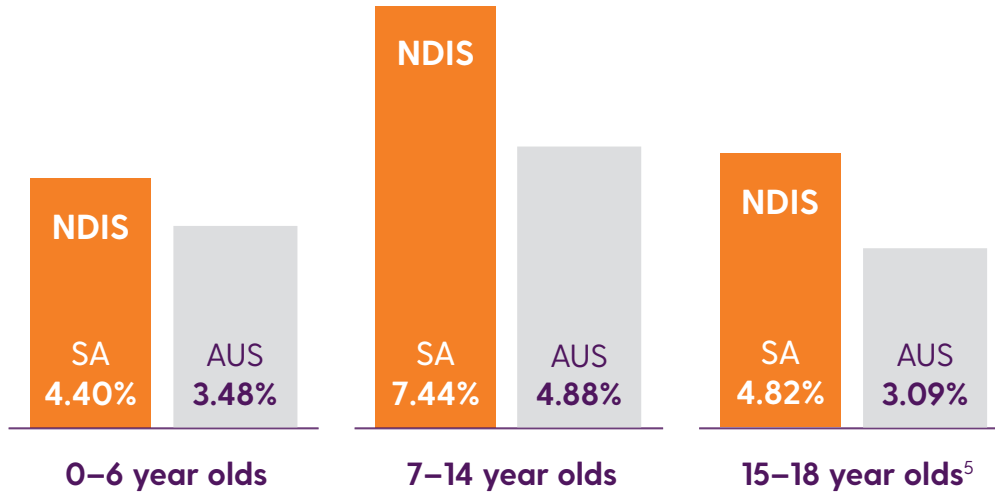
of children
0–14 years



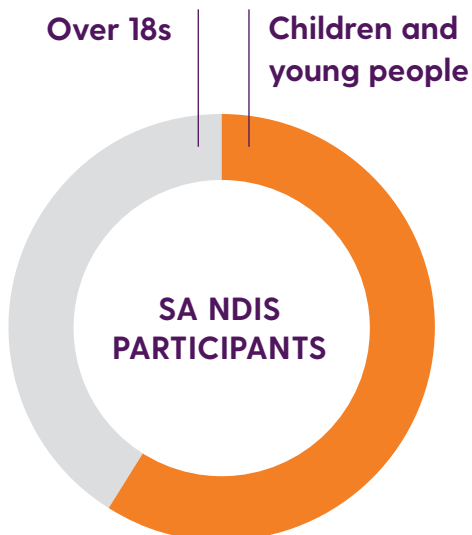
11%

of young people
15–24 years reported
to have a disability.⁴

Compared to all other states and territories, **South Australia has the highest NDIS participation rates of all children** across all three NDIS age groups 18 years and under:

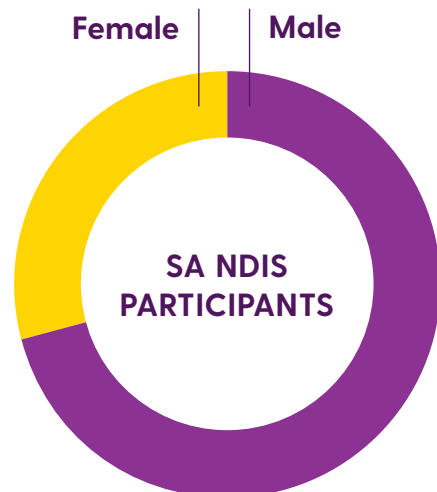


Since completion of the full rollout of the NDIS in June 2019, South Australian children and young people aged **0-18 years** have consistently made up **more than half of all NDIS participants** in the state.



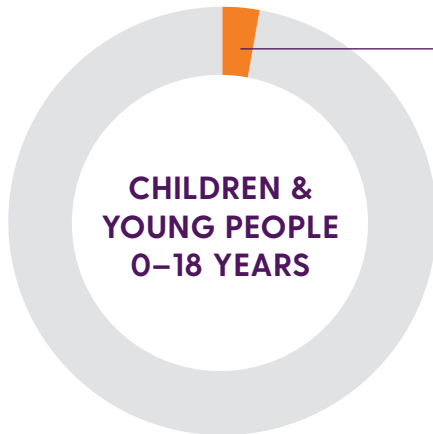
71% of NDIS participants aged 0 to 14 are **male** compared to **29%** who are **female**.⁶

Reporting from the NDIS attributes this to a higher prevalence of autism, intellectual disability and developmental delay in boys when compared to girls.



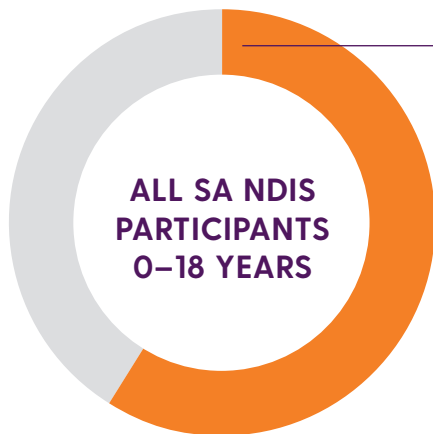
South Australia has a higher prevalence rate of autism across all age groups from 0–18 years than all other states and territories.

Children with autism make up:



3%

(approximately) of South Australia's population aged 18 years and under; and



59%

of South Australia's NDIS participants aged 18 years and under (ie 12,823 of South Australia's 21,644 NDIS participants aged 0–18 years at 30 June 2021).⁷



In 2019, South Australian government school students receiving **adjustments for disability** made up

29.6%

of total government school enrolments.⁸

Barriers to participation

Children and young people with disability have reported that they want opportunities and support to be involved in decision-making processes. We also know that the more opportunities they have to participate, the more effective their contributions become.

Whilst children and young people living with disability face all the barriers to participation that other children and young people face, there are extra physical, structural, and social biases and barriers that further limit and prevent their participation, particularly for those who are living with complex needs.

These barriers can be both attitudinal and practical and can often include children and young people with disability having their views and opinions systemically ignored and discounted. Add to this the logistical issues of limited independence that requires busy adults to prioritise children's participation, and these barriers can become self-perpetuating.

This lack of opportunity for children and young people with disability to participate in decision-making affecting their lives also excludes them from the opportunity to develop the skills, experience, and confidence they need to live their best possible future.



Attitudes

Attitudes include the thoughts, beliefs and feelings that can influence the way an adult communicates and supports a young person living with disability. The attitude of adults has a significant impact on a young person's participation. Adult attitudes related to stigma and to assumptions made about ableism can be direct barriers to participation. Young people said they are often excluded from opportunities to participate due to assumptions made by adults about their capacity to do so, and because the style or format of engagement used does not cater to their individual needs.

"I worry about being judged for my dyslexia and people not realising that I have so much more to offer." – Male, 12



Stigma

Stigma is often displayed through stereotypes that reinforce negative attitudes toward people with disability. Some adults come with preconceived expectations that a young person with a disability will be unable to participate in a meaningful way. Even when people do not mean to cause harm. These young people say that adults sometimes treat them in patronising and paternalistic ways.

"I feel included when people be human to me – when they treat me like a human." – Female, 15



Ableism

Ableism refers to expectations about typical physical and cognitive abilities. Young people experience disadvantage when their functioning capacities are seen as ‘abnormal’ and are treated differently, or they’re not given the same opportunities as others. When a teacher, or another adult assumes a child with disability cannot participate, they limit that child’s capacity for involvement, sometimes providing them with an alternative activity, that is usually of a lesser value.

“Sometimes people might think I struggle with things I don’t. And they talk to me differently.” – Female, 11



Paternalism

Paternalism supports the belief that people with disability should not make their own decisions. For children and young people this is compounded by their age. They are dependent on adults to make decisions, complete daily tasks, and plan for their future. This builds in loss of independence and perpetuates an experience of powerlessness for children and young people with disability.

“Sometimes it can feel like you are just along for the ride.” – Male, 18



Trust

Trust is crucial to ensuring children and young people with disability can participate. Many families, teachers, and carers are known to be concerned about the capacity of “others” to engage with their child or young person with disability in ways that are authentic and ethical. Consequently, adults need to feel as though participation will not distress their child or lead to negative consequences if their child has difficulty, including criticising the services being delivered by a qualified service provider. Other families question the capacity of their children or young people with disability to have views or ideas that could really influence change. Not necessarily because they don’t believe in their child, but because they don’t trust the system their child is in.

“We are all human. It doesn’t matter that we act differently or something.” – Female, 16



What we did

Throughout 2020 and 2021, the Commissioner for Children and Young People embarked on a project that enabled her to hear directly from South Australian children and young people living with disability.

Working in partnership with schools, service providers, and families, the Commissioner met with individuals and small groups of children and young people who are living with a range of physical, intellectual, and psychosocial disabilities. Over a twelve-month period, a total of 27 sessions were held with 196 children and young people aged 9–22 years in various settings across the community.

Sessions were largely conversational so that young people could feel competent and empowered to answer questions themselves. Young people talked about their families, friends, their pets, and school. Where appropriate, visual prompts and question sheets were made available with many young people expressing their appreciation for being provided with an opportunity to talk about their lives. Throughout the conversations, particular themes emerged around what young people living with disability consider to be the most important aspects of their lives. This report is a summary of what they said.



Key messages

- Children and young people living with disability suggest that beyond their disability they have many of the same issues and struggles other young people do, including bullying, relationship difficulties, mental health and sexual health challenges, and the need to plan for their future. They need services to support them with these issues.
- Children and young people living with disability seek to participate in decisions on a broad range of topics that aren't necessarily limited to youth-specific or disability-specific issues. They are interested in discussing what they have in common with their peers, rather than always highlighting the things that make them different.
- Children and young people living with disability suggest that adults including teachers, parents, coaches, and therapists respect children and young people as experts in their own lives. Adults must consult them in relation to the situations that impact on their lives; not assume that they as the adult know all the answers, or that they are always right.
- Children and young people living with disability are often excluded from community or school activities due to behaviours or circumstances which form part of their disability. It is important that mainstream community services, including emergency services and police, are trained in disability and are more proactive and innovative in how they link with these children and young people.

- Children and young people living with disability want programs and opportunities that enable them to build friendships and have social outings with peers. Loneliness and isolation are a common experience for children and young people living with disability.
- Children and young people living with disability require opportunities to participate alongside their peers. This requires an investment of time and resources, a commitment to inclusion, and more awareness of disability.
- Children and young people living with disability suggest that it would be helpful for all students at school to have a greater understanding of disability, and for more opportunities for young people in special settings to interact with “mainstream kids” on shared interests.
- Children and young people living with disability suggest more support at school in planning and preparing for post school life would be valuable, as would more work experience opportunities.

Recommendations

From the conversations with children and young people who participated in the Commissioner's Disability Listening Project, the Commissioner has made the following recommendations.

All government Disability Access and Inclusion Plans (DAIPS) should include the following sections specific to children and young people:

1

Children and young people living with disability should be informed and consulted about decisions that affect them.

2

Participation of children and young people living with disability must go beyond physical accessibility and include access to meaningful social connections, to information they can understand, and to enabling them to feel safe and respected by being valued, accepted, listened to, and taken seriously in all situations and settings.

3

Provide public sector staff with specific DAIP responsibility, child-specific disability awareness and engagement training, so they can provide more appropriate individual and systemic responses.

4

Develop and implement meaningful engagement processes for children and young people living with disability with actionable and specific goals, measures, and timeframes.

5

Develop child-focused feedback and complaint mechanisms that support children and young people living with disability to readily raise issues of concern, ensuring their issues are acted upon and/or monitored over time by a suitable oversight mechanism.

What children and young people said



Identity

The development of identity is a particularly individual experience developed over time and influenced by the views of parents and guardians, relationships with siblings, connection to community, available resources, and whether a person has physical, intellectual, cognitive, or psychosocial disabilities.

Most of the young people who participated in the sessions wanted adults to know that their experiences are not the same as adults living with or without disability, or the same as other children and young people with differing abilities.

When young people are identified by their disability first it can be confronting. They want to be identified by and valued for their age, relationships, and achievements, and to be recognised for their role as a son or daughter, brother, sister, or friend. It is these identities that take precedence over their disability.

They want to be seen and known as children and young people who have hopes, dreams and wishes for the future. They want to feel accepted, understood, and included for who they are, not because of their disability. They said they were interested in their identity being about their friends, family, pets, and in engaging in ways and on topics, similar to the peers they know living without disability.

“I have fun when I’m playing basketball. Because on the court no one knows I have dyslexia and if some do they don’t care, because it doesn’t effect my ability to play. No special modifications are need[ed]. I am just the same as everyone else.” – Male, 12

The young people who participated in this project attended a variety of education and service settings ranging from those who attend school in segregated special education units, and those who are integrated into mainstream classrooms. There were also those who are supported through inclusive settings that offer specialised support. Consequently, their experiences and expectations are diverse.

In mainstream education settings, young people with disability said they felt they were always being compared to their non-disabled peers and that this highlighted their 'difference' and 'otherness' from their "mainstream" peers. For many young people this led to feelings of disconnection and being unsupported in their struggle to develop an identity as a young person living with disability. Many of the young people who were integrated into mainstream education settings said they resented being different to their peers.

"I believe that to most people, especially in our generation, disability is negative, and that's cos people use it to single people out. It is used as an insult among young people. And what is classified as a disability? It doesn't mean we are incapable. We find ways so we don't feel different to anyone else." – Female, 16

By contrast, in more segregated settings, young people with disability said they were expected to just 'fit in with everyone else' and they said it can be challenging to celebrate and acknowledge their individuality in a positive way when this is the case.

In more specialised settings, children and young people said they are more often surrounded by peers with disabilities and who have similar daily life experiences. In these settings many said they were less likely to be treated differently.

Young people in these settings reported that their friends (disabled and abled) were more likely to speak about their disability in positive ways.

“Everyone gets along really well. There isn’t nobody who doesn’t treat you like a different person. Every person tries to feel everyone welcomes people.”
– Male, 16

In South Australia, the largest cohort of children and young people living with disability are those diagnosed with autism. Along with their peers who have learning disabilities, many young people living with autism reported that their disability is neither acknowledged, nor is it understood.

These young people were more likely to speak about bullying and feeling excluded in school and social environments, often reporting that they struggle to make and maintain friendships. They described situations of being teased and confronted at school and online, by both other students and parents. Many of these young people also spoke about feeling they had to constantly explain their actions.

Children and young people living with disability said they wished the world was more accepting of them as they are; not striving to always make them “fit in” with how everyone else does things. They seek understanding by adults about why they do things in a particular way, and they would like their peers to invite them to play and share in their interests because of who they are.

Many children and young people living with disability said they wanted to blend in and engage with other children and young people their age more. They wanted to do the same things and share in similar experiences wherever possible. When young people with disability are placed in situations where their differences are highlighted over their shared experiences or common interests, their capacity to blend with

kids their own age becomes problematic. When this happens in social situations the attitudes and actions of both adults and children can make them feel judged and inferior, knocking their confidence and sense of self.

Others felt that less was expected of them because of their disability. This included the overly sympathetic assumptions that are often being made about their ability to participate. Some young people described positive experiences where they were accepted for how they are as well as for who they are.

“When people are aware of my bad health, and are genuine in their concern at times when I’ve expressed I’m not doing okay, but they don’t see me as my illness every time and include me and invite me to things others might see as too difficult.” – Female, 17

Young people with a primary physical disability described their frustration with use of “hero” label for doing everyday activities and achievements. They described the contrast this has with the high aspirations they held for themselves which others did not. Others spoke of being self-conscious about being given alternative activities or additional supports that set them apart from their peers.

“[There needs to be] greater social understanding that disability is not a bad thing! [I want] no more ‘oh you poor thing’ when someone shares their story or exists as a visibly disabled person.” – Female, 18

“Some of my friends say they wish they were in a wheelchair, so they don’t have to walk.” – Female, 11

“

If they look pretty able
then they might say
**‘does this person really
have a disability?’**”

– Male, 13



When children and young people are unable to engage with their peers in play and social situations because of their disability, their deficits are highlighted. Young people also report that when adults attempt to make modifications so they can, it can feel ‘condescending’. Others said it can make them feel as though they are ‘dumb’ or ‘stupid’, and how this can lead them to have negative views of their disability and themselves.

Other children and young people spoke about the impact on identity that comes from being spoken to in disrespectful ways and that this is done by teachers, school support staff, parents, and peers.

“Sometimes they talk down to me, like I’m a dog.”

– Male, 13

Within some disability communities, such as the Deaf community, young children spoke positively about their connection and feeling of belonging. Deaf children spoke proudly of their differences and did not consider themselves as having a ‘disability’. Rather, their focus was on the need for more inclusive social environments. This involved change that would see the broader community communicating in Auslan, and being open to having Deaf individuals in their workplaces, homes, and communities.

“I was talking with a hearing friend and they didn’t understand. I wish they could all sign.” – Female, 13

The challenge for adults is to create inclusive, supportive spaces where young people can develop a positive disability-identity. Too many children and young people living with disability said that their school and social environments highlighted their differences and levels of ability, rather than focused on supporting them to feel included and empowered.

Inclusion

Children and young people with disability said that being included is about being heard and accepted, and about feeling that they belong in both disability-focused settings as well as within the broader community.

They understand that their meaningful inclusion needs to be facilitated and supported by adults and services. School is a crucial environment for children and young people with a disability, and teachers are key enablers who can have a real impact on a child or young person's sense of belonging and inclusion.

"I have been suspended when it's been the teacher not understanding what I need due to my disability." – Male, 13

Factors young people said that supported their inclusion and enjoyment of school included:

- flexibility in how children and young people with disability are taught
- classrooms that are set up in ways which work well for students with disability
- relevant subjects being taught
- regular break times factored in
- personal behaviour support plans put in place and followed; and
- a much better understanding of what is likely to 'trigger' individual students.

Many young people with disability talked positively about the advantage that smaller classes and personalised teaching offers them, along with a caring attitude and practical support from an adult who is clearly interested in their academic progress.

“One-on-one teaching. Receive support from teachers. Teachers know you’re learning and how each child learns best. Teachers modify learning for children who struggle with their learning. Mental health support, academic support.” – Female, 15

“You’re less defined by a certain trait and more by yourself and who you are. I can talk to a teacher like an adult. Students collaborate. You get warned.” – Male, 16

Whilst environmental considerations are important, many students said they don’t think adults really understand how important friends are to children and young people’s feelings of inclusion. They said that having friends at school is an incentive for them to attend, and is an essential part of an environment where young people feel accepted and as though they belong and fit in.

Some children and young people talked about how their school helped them make friends through buddy systems and lunchtime activities where they were encouraged to meet other students.

Many children and young people with disability had an interest in gaming, describing it as a platform where they can feel included and able to participate ‘like anyone else’ while at the same time be making friends. Many young people shared that they have more friends online than in ‘real’ life.



“
I feel included,
when people
listen to what
I have to say.”
– Female, 11

Young people identified that having friends at school and in the community and being included are the most important things in their lives. For many young people with disability, friendships are based on shared experiences, such as another person who has a similar disability or similar interests.

“I don’t have many friends, so I don’t really feel included.” – Male, 13

Young people with disability may face additional challenges in developing or maintaining friendships as a direct result of their disability (eg. difficulties with social skills). Young people with disability also report increased time pressures to attend regular appointments, and to access additional tutoring or mentoring. They also often rely upon paid supports to assist them to access the community, and this limits their capacity to “hang out” with friends.

“I only get like one night a week off.” – Male, 13

“I can only have sleepovers at my house ‘cos not everyone’s house is accessible.” – Female, 11

“I like it when they include us in everything like the main people.” – Male, 18

Many children and young people with a disability spoke about their positive experiences in special schools and special units. They said the teachers there had more time and understood them better. They also said that their physical environment was more accessible because it was smaller and meant students didn’t get lost in the school grounds. Others spoke about experiencing less bullying behaviour while in special units, and that they felt safe and better understood.

“Sometimes other kids use disability as the butt of their jokes. It’s not nice.” – Female, 13

However, other young people said they wanted to be more included in the mainstream school environment, and to be given more opportunities to mix with other students their age, particularly as they get older.

“I feel like I belong when I am part of a team where everyone’s contributions are validated and supported.” – Female, 14

Some young people attending a mainstream high school, said they often feel unwelcome and excluded from social events outside of school. Many said their learning environments were unable to adapt to their diverse and differing needs, and that they felt no-one really understood or valued them, or were prepared to work with them to become successful at certain skills. This included missing out on the privileges or rewards that other students received because they had been given more time to complete their work and were therefore not factored into consideration.

“Just because I have autism, shouldn’t mean school should be a too hard place. Teachers just tell me I’m difficult or lazy.” – Female, 17

Some young people said that teachers can contribute to the ‘otherness’ they feel, mainly due to the ways in which they interact with them.

“When I was at my old school people would think I was retarded, and teachers would over explain things to me.” – Male, 17

“The school does help me, but they didn’t make the work easier. Instead, they give me the same work as everyone else.” – Female, 16

In a school environment, young people with disability are often supported to participate in the classroom by an SSO. Depending on the school environment, young people have mixed experiences around this support. Some young people described how a lack of information about who the SSO was and why they were there, impacted their ability to benefit from the arrangement.

“They didn’t explain things to me. I didn’t know what an SSO was for.” – Male, 15

Other young people felt positive when an SSO provided them with support that didn’t involve taking over or making them feel ‘different’.

“I always had an SSO who would come into the class to work with me 1:1. I had support from that person. Not doing differently, just more support.” – Female, 19

“I think they show how they care when you are learning. The SSOs are not like ‘I’ll take over’.” – Male, 14

Young people with disability shared that they felt most included at school when they were invited to participate in activities that highlighted their interests and their strengths. Some schools had activities and ‘lunch time clubs’ that focused on interests and activities such as drawing, anime, gaming or music. Young people could share their interests without the stigma associated with being a ‘student with disability’.

“I want a girlfriend who plays Fortnite. I do chat to other people [online] but it’s actually quite dangerous. I get worried about other people.” – Male, 13

Many of the young people with disability studying in special educational settings spoke about how much they enjoyed engaging in sport and recreational activities within their broader community outside of school. They spoke about participating in activities specially designed to meet their disability needs – such as those run by Tutti Arts Inc. and Inclusive Football – and that they liked to attend social groups related to their interests, such as Minecraft and Lego.

“At Tutti I feel happy and included.” – Male, 13

Young people living with disability want to be included in social activities with their peers and want to be invited to birthday parties and playdates. They also want to be asked to hang out at lunch time. They said that for them to be included they felt their peers needed to have a better understanding of disability overall.

Young people reported that they often needed assistance to access the community. This may be through the support of the parents or family members, or even by paid mentors who play a key role in supporting them to do ‘fun things’.

Young people with physical disability told me it was difficult to access community spaces, even when they had been designed especially for them, and that physical environments that are inaccessible severely restrict where they can go and what they can do.

“The local playground is rubbish. There’s a swing out there I can’t go on... cos [the adults] can’t get me in there... It’s been hard to find a design for my wheelchair.” – Male, 14

Feeling included is important to young people. It supports them to feel valued in their schools and communities, which in turn promotes positive wellbeing and builds confidence in their ability to engage with others.

A young person's capacity for inclusion is also impacted by their family's circumstances. For those children and young people with disability who have additional care responsibilities for a parent or younger sibling, or for those with limited access to financial resources, there can be considerably more restrictions and barriers to their capacity to attend community events and be with their peers.



“

I wish people would understand what good and bad days look like for hidden disabilities.

What the signs are. Or for teachers especially to be more open to understanding chronic illness in general.”

– Female, 16

Independence

Young people want to feel as though they are being prepared for a future where they can do things for themselves and live a life separate to their parents.

This is a different journey for many young people living with disability. Young people with disability generally live their lives surrounded by adults – parents, teachers, SSOs, therapists and paid supports. For many, there are very few aspects of their lives that are not influenced by adults. The attitudes of adults who support young people with disability play a key role in their sense of achievement and their capacity to be increasing their independence.

“Having an SSO was like I was on a leash.” – Male, 17

Young people live their lives across a range of environments that include home, school, and the community. Each environment brings different challenges and opportunities that impact on their emerging independence.

*“I went to the shop alone the other day.
They didn’t understand me and I was frustrated.”
– Female, 13*

For young people with physical disabilities, the physical environment has a direct impact on their capacity to be independent. Many young people said that the requirement for adult assistance to move around the home or school grounds means they often find themselves excluded from some activities.

“I want more wheelchair access and I want more elevator access for students at my school. I also want people in politics to be more patient when talking to people with disabilities because they might have speech impairments, or they could very much not talk at all as they might have lost their voice when they were little. They might have no voice box, or they lost their voice over time.” – Female, 18

There are daily barriers faced by young people with disability in accessing environments that enable them to participate ‘normally’ in everyday social activities.

“[It is hard] when I move around on grass... when I try and push along...my wheels (walker) are too small... It’s worse when the grass is wet.” – Male, 11

When it comes to decision-making opportunities for young people to participate are dependent upon having adults who can facilitate this in an inclusive, empowering way. Adults who can do this may be parents or primary carers, or they may be teachers in a school setting.

Many young people reported having restricted access to decision-making opportunities, and that they often did not feel as though adults were interested in enabling them to participate, or supporting them to become as independent as they could be.

Some young people described the positive difference a supportive adult can make. For example, when one young person could not access the local council’s library truck because there was no wheelchair access, a teacher supported him to approach the local council to ask them to make changes. Without supportive adults like this, many young people remain frustrated by the barriers they face.

“I wish places were more accessible to have facilities closer to people. The inaccessible equipment [at playgrounds] really bugs me.” – Male, 12

Many children and young people with disability have doubts about the opportunities that will be available to them when they become adults. They have experienced limitations throughout their schooling, and therefore wonder if their disability will likely limit their capacity to reach their goals in the future.

“When I finish school I want to be a palaeontologist. I just hope that the fact I’m on the autism spectrum doesn’t impact me.” – Female, 11

Young people who were finishing school and planning post-school pathways, reported that they are not always given an opportunity to be involved in decision-making about their own future. They said sometimes teachers or parents would make decisions about their subject choices and future career or study pathways based on what those adults thought they could achieve or would be ‘best’ for them. They said this was done without any consideration of what their passions, interests, and personal goals might be, and that this approach leaves them feeling ill-prepared, disinterested and more likely to withdraw from study and work options altogether.

“Here is an area we think you’d be good in’ and completely ignore what the person is actually good at.” – Male, 21

A few young people had after school jobs in fast food, retail, or a family business. In the future, many of the young people said they wanted jobs that are familiar to them, like those in retail (Kmart, Big W) or in fast-food outlets (Hungry Jacks or McDonalds).

*“I just want a job like stacking boxes.
I want security and freedom.
Like the freedom to get married
and have kids.” – Male, 17*

Other young people expressed an interest in pursuing future employment that supported their special interest areas, including jobs in animation or beauty, or careers related to gaming and YouTube.

Young people were generally aware that they may need additional supports to get a job in the future, particularly one that reflected their interests and aspirations. They were very open to having support so that they can develop an understanding of workplace culture and expectations. However, many also described having too few opportunities to prepare for work either through volunteering opportunities or through work experience.

*“Having Down Syndrome means I need
more help to find a job.” – Male, 19*

Young people also shared their hopes for their lives beyond having a job or career. Their thinking and goals for the future reflected how much they value family, freedom, and friends. They valued the support received by those around them. In turn, they wanted their family and communities to be supported, and wanted more time to do more activities together with members of their family.

*“My mum would like for me to be independent,
but she also does a lot for me.” – Female, 19*

Developing independent living skills creates challenges for adults and service providers. It is necessary to balance risks, while also building increasing independence for young people living with disability.

“

I love feeling really **independent**, ‘cos it will **set me up for the long term.**”

– Female, 16



*“When they did it all for me, it didn’t feel good
cos I wasn’t independent.” – Male, 14*

Young people said they want to be given opportunities to do things as independently as possible. While they understood that sometimes they needed additional support, they wanted to be seen as capable and competent at the tasks they could complete. Young people told me that they want to live independently as adults, but many doubted whether it would be possible.

*“When I am 25, I want to be independent.
Maybe living with a roommate. I don’t want
to be seen as mentally younger.
Don’t want too much pressure.” – Female, 19*

*“I do need to get help sometimes cos I do have autism
and it gets in the way. I can get a bit confused
and my brain gets fogged up and I can’t think
of anything. It’s basically how my brain works.
I want to be able to work independently but I can’t.
I’m a bit nervous about year 12. I think the teachers
have high expectations and that’s kinda scary
‘cos I don’t know how I’m gonna meet that.” – Male, 16*

Despite the significant focus on NDIS for parents, service providers and policy makers, young people did not talk about NDIS as a determining factor in their independence. They sometimes spoke about mentors or paid supports assisting them to access the community, however, very few young people appear to have an active role in developing, reviewing, or utilising their NDIS plans.

How to support participation

Committing to providing inclusive and participatory environments for children and young people with disability is not merely something that is a ‘nice to do’. It is a requirement under international conventions embedded in State legislation.

Our obligations to children and young people with disability go well beyond education, therapy, support, and care. We must also uphold their participation rights and interests.

As people working with or on behalf of children and young people living with disability, we must make a commitment to addressing both the practical and attitudinal barriers that block their participation.

Adults often underestimate the competencies of children and young people with a disability and rely heavily upon parent or carer representations and assumptions. Instead we should be sourcing perspectives and experiences directly from a child or young person with disability so they have a voice and choice in proposed activities, direction and outcomes.

Community engagement initiatives tend to capture the voices of adults as being representative of the views of children and young people – either adults with disability, or parents and carers of children aged 0–18 years, or in some cases even young adults aged 18 to 30 years old.

One of the most effective ways we can protect children and young people from harm is to support them to become active and confident citizens.

This means providing opportunities for them to be heard. It means actively putting in place mechanisms and systems that view children and young people with disability as key stakeholders, for whom facilitating opportunities to have greater input into issues and matters that affect them is standard. This would help to ensure they have a voice in matters that don't directly affect them also, enabling them to operate as citizens exercising their full set of rights.

To be child-friendly and child-safe means ensuring children and young people feel they are being listened to and that when they do share their views and ideas that they are taken seriously and believed.

Informing children and young people using a service what to do if they feel unsafe or uncomfortable would assist in sending the message that their views and ideas matter and are valued. Explaining how they can provide feedback, good, bad or otherwise on the services they receive will reassure children and young people with disability that they are being taken seriously, and that the adults with whom they are interacting respect them and are interested in improving the quality of their lives through improvements in their everyday experiences.

Adults working with children and young people with disability need to:

- Start from a presumption of capability.
- Not make assumptions about the child or young person's interest or views.
- Invest in the process and take the time, attention and tools required for the child or young person with disability to participate.
- Use varied methods of engagement, technologies, spaces, mediums and formats.
- Be mindful of children and young people's diversity and support their inclusion in a holistic way.
- Create welcoming, enabling and empowering environments.
- Embrace multiple types of processes with input from children and young people to meet their diverse communication needs, preferences, and capabilities.
- Manage adult involvement in processes that are interactive providing children and young people with disability with a choice in what and how they are supported to participate.
- Share the ways in which the feedback children and young people with disability have provided has been used to improve the services being delivered.

What children and young people have said adults need to do to be more child-friendly and child-safe:

- Listen to us with interest and an open mind.
- Employ friendly staff who like us and are relatable and approachable.
- Get to know us, understand our lives, and do the right thing by us.
- Provide us with an environment that is comfortable, welcoming, with clear information.
- Let us know what to do and who to talk to if we feel unsafe or uncomfortable.
- Admit your mistake if you do something wrong.
- Find ways for us to be informed, involved and to have a say in what is happening.
- Make it easy to for us to provide feedback or to make a complaint.
- Show us respect by updating us on what is going on with our feedback.

Key reflections

The following considerations are based on the Commissioner's extensive engagement with children and young people with disability undertaken in a variety of settings across South Australia.

These key reflections have directly informed the final Inclusive SA Accessible and Inclusive Engagement and Consultation Toolkit that was developed in 2021 to meet Action 14 of Priority 6 of South Australia's State Disability Inclusion Plan 2019–2023.⁹

Safety for children and young people

Safety for children and young people with disability is much more than providing for their physical safety – it is about ensuring they feel valued, known, accepted, understood and able to express themselves, while their sensory, behavioural and physical needs are also being met.

What children and young people with disability describe as making them feel safe and included, is in many cases as basic as being treated 'like a human'. While this seems remarkably simple, their daily life experiences do not always reflect this, with many describing how small they feel when adults talk to them 'like a dog' or in a way 'that makes you feel beneath them'.

They describe the most helpful adults as those who are kind, trustworthy, fun, understanding, and who listen and respect them as individual people.

Individualised engagement

Opportunities for engagement with children and young people living with disability should be mindful of individual needs as they relate to:

- **Age**, both chronological and developmental
- **Types of disability**, including physical, intellectual and psychosocial. For example, how to account for the sensory needs of children with autism and intellectual disability, as well as the physical accessibility requirements of children and young people who have a physical disability; and
- How to engage and build trust with families, carers and other organisations or service providers to arrange appropriate scheduling, adjustments, adaptations, or risk assessments where these are required.

Authentic engagement

Authentic engagement and consultation with children and young people with disability will:

- Have a clear rationale and purpose, which is communicated from the outset;
- Be realistic about how any information gathered will be used;
- Ensure all information provided is relevant, meaningful, accessible and developmentally appropriate; and
- Make efforts to report information and key messages gathered through the engagement back to participants in a way that is meaningful and easy for them to understand including what parts were considered, used and not used, and why.

Methods of engagement

Traditional methods of engagement such as large group forums or surveys designed for a general adult audience may not necessarily be appropriate for children and young people with disability. As such, smaller groups are often preferable to enable the highest level of participation and the best possible support to meet individual needs.

Flexibility

In order to keep children and young people with disability comfortable and engaged, it is important for those facilitating and supporting their engagement to:

- Be willing, prepared and equipped to adapt approaches based on different disability-related needs, or needs related to the environment, size of the group and the ages of participants, even if this differs from original plans.
- Be able to provide young people with disability with opportunities to participate in different ways appropriate to their capabilities, whether this is through activities such as drawing, colouring, or sculpting with plasticine, or with support from communication devices, interpreters, or other technology and means.
- Use language that is child-friendly and think about the most appropriate way to frame questions beforehand.
- Keep questions broad and open-ended so that children and young people with disability can interpret and respond in ways that are comfortable for them. Open-ended questions are much more likely to engage children and young people than closed questions will, particularly those that require a technical or specific answer or response.

Identity

Like all children and young people, those living with disability view their place in the world quite differently to adults. They seek to be identified by and valued for their age, relationships and achievements – not by their disability.

Identity develops over time and many young people may not want to be defined by their disability or might even choose not to disclose their disability in many circumstances and situations. As such, opportunities for engagement should:

- Be available on a wide range of issues and experiences beyond ‘disability-specific’ or ‘age-specific issues’;
- Acknowledge that the way a young person self-identifies may impact how they engage.

Recognise and minimise barriers

The barriers facing children and young people with disability can be attitudinal as well as practical, ranging from ableism (which perpetuates low expectations about the capacity of people with disability to participate and communicate) to ‘adultism’, which ignores or discounts children’s perspectives.

Logistical barriers also require advance consideration in order to maximise participation by children and young people with disability. Such barriers can intersect with poverty and geography and can include the affordability and availability of safe and accessible transport options.

In addressing these barriers, it may be worth considering the potential need to, and benefits of partnering or collaborating with external agencies or organisations, such as youth organisations with disability expertise.

Recognising and working to break down these barriers is an important part of putting the social model of disability into practice. This means acknowledging that:

- Children and young people with disability are disabled by barriers within society, such as the attitudes of others or physical environments; and
- Disability is not a deficit of the individual, but rather a deficit of the society in which we live to meet the needs of all citizens with rights.

Respect children and young people's time

In addition to school, young people with disability attend regular appointments, undertake capacity building activities, and often access additional tutoring or mentoring. This can reduce the time they have outside of school and their capacity to access services that might support them to participate in engagement activities or social events.

Ultimately, engagement with children and young people with disability is not always about doing engagement 'differently'. It is about doing engagement safely and with authenticity, flexibility, and an understanding of the unique and diverse needs of the individual child or young person involved.

When disability and age are well considered, the engagement experiences and outcomes of children and young people with disability are likely to benefit everyone, regardless of ability.



Next steps

Removing the day-to-day barriers children and young people living with disability face requires a new approach. This approach positions children and young people living with disability as key stakeholders with their views, ideas, and opinions expressed and acted upon.

Embedding strategies and goals into DAIPs specific to children and young people is step one. This includes establishing the mechanisms and processes that ensure the voices of children and young people with disability can be heard. It requires flexibility, adaptability, innovation and behavioural change from parents and carers to educators, health professionals, therapists and service supports who interact with children and young people living with disability.

These are the adults who can facilitate tremendous positive change in relation to removing barriers to their participation that exist. Supporting children and young people living with disability to become part of decision-making will not only ensure their rights are upheld under international covenants and State legislation – but it will also, most importantly, improve the system and ensure services are tailored to their specific wants and needs.

We must also adjust service delivery based on the direct feedback of children and young people with disability.

When we place children and young people with disability at the centre and ensure their rights are protected and upheld we will go one step closer to ensuring they are supported to live their best lives.

It is within our power to make changes that enable participation beyond the basics. This also means supporting and scaffolding the participation of children and young people with disability in student leadership groups, committees, boards, and in roles within the service organisations working with children and young people with disability.



Endnotes

- 1 Child Development Council, 'Data Snapshot: Children and young people as a proportion of the total population, South Australia,' 2021. Available at <https://childrensa.sa.gov.au/wp-content/uploads/2021/09/Data-snapshot-CYP-Proportion-of-SA-Popn-2020-2021-09-22.pdf>.
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- 5 The participation rate refers to the proportion of general population that are NDIS participants. NDIS, September 2021. Quarterly Report to disability ministers. 'Table N.16 Participation rates by age at 30 September 2021', p. 593. Available at <https://www.ndis.gov.au/about-us/publications/quarterly-reports>.
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- 8 The Centre for Inclusive Education, Professor Linda Graham. Inquiry into Suspension, Exclusion and Expulsion Processes in South Australian Government Schools: Final Report. p.37. Available at <https://www.education.sa.gov.au/sites/default/files/report-of-an-independent-inquiry-into-suspensions-exclusions-and-expulsions-in-south-australian-government-schools.pdf>.
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The Commissioner's Role

The South Australian Commissioner for Children and Young People is an independent statutory position, established under the *Children and Young People (Oversight and Advocacy Bodies) Act 2016* ('the Act').

The Commissioner's role includes advocating for systemic change to policies, programs and practices that impact the rights, development and wellbeing of South Australia's children and young people.

This work is informed by the experiences and issues of children and young people themselves, with a specific focus on those who struggle to have their voices heard.

The Commissioner's strategic agenda was formulated with direct input from children and young people. In particular children and young people asked the Commissioner to facilitate their involvement in decision making and to create opportunities for them to experience authentic participation in the adult world.

The Commissioner is working with a number of partners on this agenda including ways in which children and young people can have input into the design and delivery of policies, processes and practices that relate to delivery of services aimed directly at them.

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