



**Commissioner for Children and Young People**  
Western Australia

## **Speaking Out About Autism**

The views of WA children and young people with autism

July 2020

## **Recognising Aboriginal and Torres Strait Islander people**

The Commissioner for Children and Young People WA acknowledges the unique contribution of Aboriginal people's culture and heritage to Western Australian society. For the purposes of this report, the term 'Aboriginal' encompasses Western Australia's diverse language groups and also recognises those of Torres Strait Islander descent. The use of the term 'Aboriginal' in this way is not intended to imply equivalence between Aboriginal and Torres Strait Islander cultures, though similarities do exist.

### **Disclaimer**

This report has been prepared by the Commissioner for Children and Young People and is intended to provide the views of the young people who participated in the consultation. Any errors of omission or commission are the responsibility of the Commissioner for Children and Young People.

Both terms 'autistic person' and 'person with autism' have been used throughout this report to respect the choice of language that individuals used about themselves.

### **Suggested citation**

Commissioner for Children and Young People WA 2020, *Speaking Out About Autism - the views of WA children and young people with autism*, Commissioner for Children and Young People WA, Perth.

### **Alternative formats**

On request, large print or alternative formats can be obtained from:

Commissioner for Children and Young People  
Ground Floor, 1 Alvan Street, Subiaco WA 6008  
Telephone: (08) 6213 2297  
Facsimile: (08) 6213 2220  
Freecall: 1800 072 444  
Email: [info@ccyp.wa.gov.au](mailto:info@ccyp.wa.gov.au)  
Web: [ccyp.wa.gov.au](http://ccyp.wa.gov.au)

ISBN 978-0-9925925-9-2

## Message from the Commissioner

Children and young people have individual differences and no two children are the same.

Similarly, children and young people with autism<sup>1</sup> are a diverse group and each experience different challenges with communication and social interactions, and for some, repetitive behaviours.

The health and wellbeing of children and young people with autism are important, particularly given the limited understanding of autism spectrum disorder and the lack of research into how it affects the growing number of children and young people diagnosed with autism each year.

All children and young people have the right to be heard on the issues that affect them, as outlined in the United Nations Convention on the Rights of the Child. The national discussion around the current system of autism diagnosis, intervention and support and the associated need for a National Autism Strategy, led by the Senate Select Committee on Autism, was an opportune time to seek input from autistic children and young people themselves on what they found helpful to develop their lives and any ideas they had to improve their life experiences.

My aim in preparing this report is to ensure that Western Australian children and young people are a part of this national discussion. The views of children and young people expressed throughout this consultation have been shared with the Senate Select Committee on Autism.

I would like to thank the 12 children and young people who shared their experiences and views so openly for our consultation and I also acknowledge the family members and support workers who supported them in doing so.

Children and young people with autism have the right to timely, effective services and supports and to be empowered to make their own decisions about the autism specific interventions they receive to improve their everyday lives and increase their chances of enjoying more independent and empowered lives.

### **Colin Pettit**

Commissioner for Children and Young People WA

## Role of the Commissioner

The Commissioner for Children and Young People works closely with children and young people, their families, community and government to improve the wellbeing of children and young people up to the age of 18 years across Western Australia. To do this, the Commissioner undertakes consultations, projects and research, and publishes reports and resources to positively influence legislation, policy, services and attitudes impacting children and young people.

The work of the office is guided by a set of principles as outlined in the *Commissioner for Children and Young People Act (the Act) 2006*, which state that:

- children and young people are entitled to live in a caring and nurturing environment and to be protected from harm and exploitation
- the contributions made by children and young people to the community should be recognised for their value and merit
- the views of children and young people on all matters affecting them should be given serious consideration and taken into account
- parents, families and communities have the primary role in safeguarding and promoting the wellbeing of their children and young people and should be supported in carrying out their role.

The Commissioner must have regard to the United Nations Convention on the Rights of the Child and give special consideration to children who are Aboriginal and who are vulnerable or disadvantaged for any reason.

One of the key functions of the office is to ensure that all children and young people have the opportunity to participate in the making of decisions that affect their lives, and to encourage government and non-government agencies to seek the participation of children and young people appropriate to their age and maturity.

The Commissioner also has roles in monitoring the way in which government agencies investigate or otherwise deal with a complaint made by a young person, and in monitoring and reviewing written or draft laws, policies, practices and services that affect the wellbeing of children and young people.

## The prevalence of autism in Australia

Autism is increasingly prevalent among children and young people with an estimated 160,000 children and young people currently affected by the lifelong complex developmental disorder of autism in Australia. The current overrepresentation (83%)<sup>2</sup> of children and young people aged under 25 years in prevalence data may be explained by historically inconsistent diagnostic protocols, the lack of research or inadequate records to track the disorder.<sup>3</sup> The Australian Bureau of Statistics (ABS) suggests that another reason for the lower rate of adults in autism data may be due to the lower life expectancy of people with autism.<sup>4</sup> Therefore the need to improve life outcomes for children with autism is imperative and a National Autism Strategy that coordinates a best practice approach to investment and services could support this.

Around 90 per cent of autistic people aged over five years with a National Disability Agreement (NDA) require support with interpersonal relationships and communication, and help with education.<sup>5</sup> Not all autistic people have a disability, however in 2015, 64.8 per cent

of people with autism reported that the disorder caused them profound or severe disability.<sup>6</sup> Constituting 32 per cent of all National Disability Insurance Scheme (NDIS) participants, autistic people represent the largest primary disability category while commonly experiencing other forms of disability including intellectual, psychiatric, learning or attention deficit disorder, speech, physical or neurological disability.<sup>7 8</sup>

### **Western Australian context**

In 2019 there were 8,725 Western Australians with a primary disability of autism, representing 36 per cent of NDIS participants in the state, which is four per cent higher than the national rate.<sup>9</sup> The Western Australian Autism Register<sup>10</sup> places WA in a unique position, being the only registry of autism diagnosis in the country that confidentially collects data about new diagnoses, specific autism conditions and demographical information. Children and young people are diagnosed using consistent practice called the Autistic Diagnostic Guideline<sup>11</sup> and are recorded on the WA register to collect data and expand an evidence-based understanding of autism.

While autism amongst children is common, the disorder is not well understood. Early signs of autism can be identified in babies as young as one year old who may exhibit traits such as struggling to relate or communicate with others, difficulty in reading social cues, or obsessive behaviours such as flapping hands or repeating sounds. Some children with autism may experience amplified sensitivity to stimuli such as sound, touch or sight, or they may respond in a minimal way to the sensory world.

Children and families report that a diagnosis of autism improves their lives, however, without a solid understanding of the condition, detecting the developmental disorder can be problematic as the highly nuanced conditions of autism may be overlooked. More robust research into the causes and intervention of autism is needed, and more readily available evidence-based information is required to effectively improve understanding of autism.

Families of children displaying early signs of autism can be placed under a great deal of emotional, mental and financial stress as they navigate the complex system of assessment and intervention while trying to provide the best level of care for their children. While there is limited evidence for the efficacy of early interventions for children under the age of four years, it is widely accepted that children who receive early intervention for autism symptoms, that include tailored supports and strategies, are better equipped to deal with educational transitions, the workplace and participation in community activities.<sup>12</sup> Commonly, children and young people failing to meet developmental milestones do not receive funding for targeted intervention to improve their conditions until after a diagnosis, leaving many children and families unsupported.<sup>13</sup>

Furthermore, the mental health of children and young people with autism requires close attention and they need to be adequately supported at all times to cultivate positive and enduring growth and wellbeing. Autistic children and their families need equitable access to information, advocacy and resources from pre-diagnosis and through all life stages.

## Project overview

In November 2019, the Australian Senate resolved to establish a Select Committee on Autism (the Committee) to inquire into and report on the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy.

The Commissioner commenced discussions with local stakeholders to plan a consultation with children and young people with autism about a range of issues including diagnosis, education, health and mental health, employment, social inclusion and community engagement, justice and rights, housing and their experiences with the NDIS.

The aims of the project were to:

- ensure the voices of WA children and young people with autism were considered in the submission to the Committee
- promote the views of autistic children and young people to service providers/ stakeholders and the wider community.

The consultation was promoted widely throughout March and April 2020 via the Commissioner's website, direct contact with relevant stakeholders, youth advisory networks and social media.

Hearing directly from children and young people with autism can be problematic in itself because they are often inaccessible to the standard consultation processes and may face barriers to communicating their experiences. Therefore external stakeholders with relevant expertise were involved in the consultation strategies and ethical considerations for consulting with children and young people with autism to ensure that these aligned with best practice.

Given the consultations took place during March and April 2020, at the peak of concern and restrictions relating to the COVID-19 pandemic, the Commissioner's office continually evaluated risk in line with current health authority recommendations. To minimise risk to participants and adhere to health recommendations, the consultations largely took place through video interviews.

Participants needed to be aged between eight and 25 years and have a diagnosis of autism. An information sheet outlined various ways in which children and young people could choose to be involved.

Consultation questions were open, flexible and asked for their views about belonging, their level of participation in making decisions in education and employment, and within community and support agencies they receive services from. Feedback was gathered through face-to-face and video interviews. The option to respond via an online survey was not taken up by any of the participants.

A total of twelve children and young people aged from nine to 24 years participated in the consultation. All of the participants were based in the Perth metropolitan area, four were female, and no participants identified as Aboriginal or culturally and linguistically diverse. A number of participants were recruited directly through their involvement with an autism service provider and these young people took part in group video interviews.

The participation rate was consistent with similar consultations elsewhere with equally low numbers, including 2019 research by Macquarie University<sup>14</sup> (12 family members of 16 autistic children and young people from Australian Capital Territory, Victoria, New South Wales, Queensland, the Northern Territory and the Torres Strait Islands), and the Commissioner's 2013 Springboard Youth and Autism Community Centre consultation<sup>15</sup> (17 young people with autism from the metropolitan area of WA).

## Key themes

All of the twelve children and young people who participated had positive experiences of autism and supports to help them overcome challenges, and were able to communicate with minimal assistance. The participants had various life experiences, yet reflected similar themes throughout the consultation relating to their autism conditions.

The main issues that were important to the children and young people in regards to autism were:

- being listened to, encouraged to make decisions and to contribute
- having an autism diagnosis
- having access to health and mental health services that understand autism
- inclusion and support in education
- equal access to employment and fair treatment in the workplace
- support to live an independent and successful life
- social connections and access to community activities
- having greater understanding of autism in the wider community
- support people who are respectful, well-informed and capable of taking action
- having a more effective NDIS.

### **Being listened to, encouraged to make decisions and contribute**

The feedback from participants about the consultation was that they appreciated the opportunity to have a say and to be listened to in a way that respected their individual needs and experiences.

*"Kids have to be given the opportunity to say something. It helps if more people have a say about what it's like with autism and then with more people talking about it, then that creates a larger voice." 15 year-old*

*"Yeah, adults need to listen to us more." 11 year-old*

*"If they're made to feel comfortable about speaking about how they feel, make sure they understand and make sure they can speak on their own choice." 21 year-old*

They also said they want to be asked about what they need and appreciated it when their views are taken into account.

*"Also giving them time to speak, because often they get cut off by other people talking. Yeah they need the time to speak and they need the time to be listened to." 22 year-old*

*"Give them the opportunity to say something and not just ignore them for whatever reason...like give them the opportunity and listen to their advice on how to help them...yeah encouragement." 15 year-old*

## Having an autism diagnosis

Children and young people emphasised the importance of having an autism diagnosis in terms of understanding themselves, validating their experiences and growing their confidence.

*"Before my diagnosis I thought there was something wrong with me but after my diagnosis I recognised I was just a normal person who has autism...There was nothing wrong with me, I just wasn't a neurotypical person that's all."* 22 year-old

*"Having a diagnosis helps...having a kind of clarity to sort of answer questions about the disorder. Yeah, that puts things into perspective. I think a diagnosis makes it easier because now I know what the traits mean and what traits I have...like the questions I had about why I was so weird when I made social contact."* 15 year-old

Participants experienced more constructive responses from others after diagnosis and were thankful when carers and service providers showed they understood their individual needs and acted competently to support them.

*"...when I didn't know I had autism in Year One I kept on getting in trouble because I was getting too excited...And I kept on calling out, that was the thing I got in trouble for...and teachers would just tell me off like I was not an autistic kid but now they just remind me to raise my hand."* 9 year-old

*"[An autism diagnosis] has given me quite a lot of understanding and now I know I have it, it's made it easier for me and made it easier to relate to others I guess...it solves quite a lot of questions I had about myself and cleared up some things."* 15 year-old

*"Understanding the disorder. Yeah, other people understanding it more and yourself understanding it, which helps a lot."* 15 year-old

## Having access to health and mental health services that understand autism

Being physically and mentally well was extremely important to the participants in the consultation.

*"I'm lucky, my family is healthy. We eat good food and exercise and stuff...Yeah, it's really important."* 9 year-old

Children and young people recognised that to have positive health and wellbeing, they need access to the highest level of support, as well as fair treatment from consistent, respectful and knowledgeable people. Several participants reflected that they were best helped by professionals who were fun, caring and demonstrated an understanding of autism.

*"My speech therapist...she's awesome because I used to have a lisp, like my tongue would go 'thhhhh', in front of my teeth like that and she taught me...and we played a few games as well to help and it was really fun."* 9 year-old

*"When [the medical professionals] treat you like a real person, then they help you. It's the ones who don't even care enough about you to ask what's going on, they're s\*\*t!"* 24 year-old



*"[Medical professionals should] try and make it not as awkward as possible. Like, forget the stigma around it. Knowing their traits and symptoms, like individually and maybe getting to know them a bit, and I guess make it as comfortable as possible for them."* 15 year-old

*"I have an OT...She hooked me up with another friend who's my closest buddy. She's played a part in my making friends and has helped me to find my closest friend."* 24 year-old

Participants also indicated that processes should be more accessible for young people and they need help to navigate and link in with health and mental health services.

*"In my view if you're going to ask a question, make it answerable. Especially questions on forms, if they're riddled with ambiguity it's a really difficult scenario because you have to answer a question that you don't really understand what they want from you."* 19 year-old

Mental health was an area of significance for children and young people in the consultation, who said they felt supported when professionals took their ideas and concerns seriously and helped them to adopt practical strategies to improve their conditions.

*"Most of the time it's techniques on like, social interaction and such. It definitely helps me... [My psychologist and I] have been doing a bit of mindfulness stuff, we've like discussed relaxation and stuff. Trying to calm yourself down, distancing yourself from the bothers in life and such. So that space sort of helps when you're in a social situation."* 15 year-old

*"I see a therapist. Like one day every school week. They come in to see me at school...we play some games and talk about moods...the zones [of regulation]....It's pretty helpful."* 9 year-old

*"For me personally it's about forgetting that I have autism and forgetting about the symptoms because sometimes when you...think too much about the symptoms it sort of makes your brain follow them, so most of the time I just try to forget about them and then I can function better."* 15 year-old

One young person recalled a mental health service that did not demonstrate autism awareness and therefore did not provide quality of care.

*"I had some mental health issues and it didn't get better it got worse."* 18 year-old

## **Inclusion and support in education**

Feeling safe, supported and included in education was important for all of the participants. Participants agreed that a successful learning environment included respectful educators, safe physical spaces and a culture of inclusion. They said they want to have good friends at school, have their achievements acknowledged, and be physically, socially and emotionally safe. Children and young people with autism want to be treated fairly, listened to, and to feel positive about their future.

### **Supportive adults who are respectful, understanding and helpful**

*"I had the support from the teachers...and my parents talked to the school about my condition."* 19 year-old

*"...the Learning Assistant was really helpful, she had two sons with autism and she had a whole basket full of fidget toys...because sometimes autism kids feel like they have to move around or fidget or touch somebody and some neurological kids definitely wouldn't like that, so fidget toys keep our hands to ourselves."* 9 year-old

*"[Teachers] remind me to wear my headphones so I don't have to put up with all the noise. I do have someone who helps me in my class...he helps me do my work."* 9 year-old

*"I'm in the educational support unit at my school so if I have a problem, I can just go to them and ask for help...My parents are good. My dad talks to the school about stuff, so I'm lucky I guess."* 14 year-old

*"...some of the teachers are also very considerate and they ask me what I want to do and stuff, but unfortunately that's very rare and I wish it happened a bit more."* 14 year-old

### Having individual needs recognised by understanding educators and receiving appropriate support

The majority of participants faced a range of barriers at school or university due to their autism conditions. They wanted educators to listen and pay more attention to them about what support they need, as well as to be consulted about solutions to their own problems.

*"I don't have more help. It's not easier. I don't like school. I don't get along with other kids there...I don't have an EA [Education Assistant] in my class. I want to have help but no one's listening to me."* 9 year-old

*"Sometimes they are just focused on the other students and not really on me. When I ask about it sometimes they're like, 'no I'm kinda sick of you, you badger me too much', you know? And trying just be like, 'go away' but other times they're nice and helpful."* 14 year-old

*"If they would pay a bit more attention to me...because although I don't need a lot of academic help, I'm still a student at [the special education centre]. I'd like them to spend more time I guess...I hope that I'm more recognised in school and I hope that my life isn't going to be too difficult in the social things."* 14 year-old

*"The teachers teach all the kids the same but they're not all the same."* 11 year-old

*"I want the teacher, or whoever to listen more. And even if the students could understand more about autism it would help a lot."* 14 year-old

*"[The teachers] always get annoyed because...I have to be doing something all the time. Like, I like to move around!"* 9 year-old

Participants want to feel safe to take educational risks. They know how they learn best, and want to be asked about what they need and involved in developing strategies to help them succeed academically.

*"No idea should be stupid, kids with autism get afraid to talk sometimes."* 24 year-old

*"I work best when it comes down to visual instructions like telling us how to cook and such."* 24 year-old

*"I struggle or get nervous when I'm doing tests. Like when I can't think of a certain answer...I just want to give the goodest answer but I can't seem to think what the goodest one is...it's stressful I guess."* 22 year-old

A group of young people involved with an autism support organisation said that they actively cultivated greater understanding and acceptance of autism in schools by sharing their lived experience with students and educators.

*"Just going into the community and educating kids about what it's like to have autism...we go into the schools and into their assemblies and do talks on autism awareness to educate the high schools and the primary schools about autism."* 22 year-old

### A safe physical environment that supports learning and accommodates educational needs

Children and young people agreed that they learned best in surroundings that considered their barriers to learning, responded to individual needs and enhanced learning opportunities.

*"My new school is better because it's smaller. There's less people and it's a lot more quiet. It's also a bit more easy-going than my previous school."* 15 year-old

*"I would help others by letting them have fidget toys. Kids with autism, they're very fidgety...yeah it helps them stay focused."* 9 year-old

*"I'd probably say light sensitivity for myself. So particular lighting may throw me off so I always have to carry a pair of sunnies with me everywhere I go."* 22 year-old

Many of the participants identified that the physical environment of their educational institution intensified their autism conditions, making them feel agitated, distressed and unable to concentrate.

*"It's a bit annoying having the autism. All the things that are annoying to me, like...when I'm in places like assembly...all the clapping and the talking. It's the noise. Sometimes I think my natural habitat would be a library."* 9 year-old

*"I especially hate being hot. People are annoying too...I get stressed and then I get hot and then grrrr."* 11 year-old

*"Like when I'm in the library and I'm trying to study for my double degree, when people are talking...I find it difficult to focus on the task at hand if I can hear other information coming in from other people...it's too hard, so I prefer to study at home."* 19 year-old

### Support to develop social skills within inclusive and connected educational communities

Having secure, healthy attachments and meaningful relationships at school were identified as being essential to feeling socially confident and included. Most wanted extra help to be included, to make friends and to socially interact with others.

*"I'm not really included. Sometimes I feel really lonely. Some of the students don't act like they even know I'm there."* 14 year-old

*"I play by myself because it's too hard to play with other people."* 9 year-old

*"The teacher forces us to do group work...I don't like it...some kids don't include me but I've gotten used to it."* 11 year-old

### **Equal access to employment and fair treatment in the workplace**

Participants were enthusiastic about their future employment goals. Many articulated an interest in pursuing their interests, refining their talents and achieving financial success.

*"I'd like to become an author...I'll write novels."* 9 year-old

*"I'm going to become a developer of games and become rich...I'm going to be in Silicon Valley where pretty much all the developers there are really rich."* 9 year-old

*"Yeah employment and mental health, they're really big things. They're the biggest things for me anyway."* 18 year-old

*"I'd like to be a successful lawyer and I'm also interested in genetics and neuroscience. I don't know if I'll combine the two careers but I also want to be rich as well. And really successful."* 19 year-old

*"My dreams for the future are that I just really hope to be accepted by the wider community. I'd like to go into voice acting and I'd like to showcase my talents for everyone."* 22 year-old

*"For myself, [my goal is] to get a fulltime employed job and to be able to work most days of the week."* 22 year-old

### **Support to access inclusive employment**

A few young people in the consultation were grateful to receive help to find employment, and to work for inclusive employers who understood and accommodated their autism conditions.

*"I'm very grateful to be able to work in the hospitality industry in the place where I am because they're the only café I know that actually looks after and caters for those on the spectrum."* 22 year-old

*"In my job that I just got we're an equal opportunity employer...they employ people with disabilities and the lady who runs it I believe, has like a degree like a psychologist or something, and helps those with a disability to work and to find new jobs as well...All the staff members are evaluated as equal so we get a say in what we do onsite and off-site."* 22 year-old

*"My current support is the [name]. They help with me finding a job and being in a social group."* 22 year-old

### **Barriers to employment for autistic young people**

Participants identified a range of obstacles to employment that were a consequence of their conditions of autism.

*"Well we need help with getting transport and like getting a job...because like it's hard if you can't use Transperth because it's too noisy or whatever and you can't get*

*to work any other way. So I had someone who used to drive me to my job.*"24 year-old

*"I get nervous [in interviews] or I struggle a bit I just want to sound like I'm okay, like I'm normal or whatever. It's hard because I get nervous and then I can't like, speak."*24 year-old

*"Sensory overload...It's really distressing...I can't go anywhere where it's too noisy and there's big crowds. If too many people are talking at once or there's lots of noise on the bus or somewhere, I do kind of get overstimulated."*22 year-old

### Discrimination of autistic people in the workplace and ill-informed employers

A few young people experienced harsh judgement from employers who underestimated their capabilities and strengths. They preferred to keep their autism conditions quiet or work for themselves rather than risk disrespectful treatment and face discrimination.

*"I used to work as a kitchen hand and when I disclosed my diagnosis I got demoted on the spot. So now I don't disclose my disorder, because I can get away with not disclosing it so I elect not to...I think the hospitality industry is pretty dodgy in that respect."*19 year-old

*"I guess if you run your own business then you eliminate any potential for discrimination or whatever."*19 year-old

### A lack of employment opportunities for autistic young people

Some participants experienced discouragement and expressed frustration due to a lack of employment opportunities.

*"I don't have paid employment. I've been looking for over six years but I'm still trying to find a job."*24 year-old

*"Resumes and job interviews. I just don't want that anymore, that's just not the true way of getting a job."*24 year-old

*"I don't have a job but I'm doing some art to keep myself sane."*18 year-old

### Support to live an independent and successful life

The children and young people were unanimous in saying they want empowered, autonomous lives and need support from other people to help them fulfil their goals.

*"My dream for the future is to get my licence, maybe learn to live independently, and maybe learn to cook some recipes on my own."*21 year-old

*"Most of the time I have the control over my disorder...like I think I make my own decisions and have control over my own life."*15 year-old

*"...my secondary goal is to build up the skills for living alone...I stayed in [name], I had a social worker come by and helped with my time there so that was okay. And I'm going to try again soon by living with a group of people, so we'll see how that goes."*24 year-old

## Social connections and access to community activities

Children and young people with autism want to feel connected, be empowered in community activities and events, and respected in organisations and the wider community.

### Barriers to making friends and maintaining strong connections with social groups

Overwhelmingly participants spoke about a range of barriers in social situations with peers, including peers who misunderstood their condition and were insensitive, difficulties connecting with others, and challenges in navigating friendships with their peers who did not have autism (often described by participants as 'neurotypicals').

*"...you have a more different brain than other people, like neurotypical people, so sometimes it makes it hard to be friends with certain people...in some ways being different is good because you get extra special help...but sometimes it's harder."* 9 year-old

*"Social contact is hard. Kind of makes you feel alienated at times...Like the awkwardness of not being able to connect with people and not knowing what makes other people connect with each other."* 15 year-old

*"With neurotypicals you're sometimes masking...like camouflaging, you have to act normal and that can be tiring sort of because you can't just relax and be yourself. Like I'm always trying to figure out with neurotypicals if I'm doing ok, like if I'm not info-dumping too much and annoying them."* 22 year-old

*"I get the impulse to info-dump around my neurotypical friends and that's kind of hard for me because I want to act normal but I usually get the urge to info-dump around them about my special interests and I'm not sure how well they tolerate that...I've tried having friendship circles with neurotypical people and they don't usually last very long".* 18 year-old

*"No, [peers] don't listen to me...I'd just rather do things on my own...Yeah it's frustrating."* 11 year-old

### Connecting with peers with autism

Children and young people described the value of having peer relationships with other young people with autism, and felt that they could relax and be themselves in these friendships.

*"Having a network, having the support of people who have the same condition...this group ...is really important. We've been together for about two years."* 22 year-old

*"It's better having autistic kids with autistic kids than autistic kids with normal kids...because we just cope better with autistic kids...at least I do. It's just easier to communicate and everyone understands each other...Maybe it's because we understand what each other feels."* 9 year-old

*"It's really important to talk to other people who are like me."* 19 year-old

*"I'm lucky...this group is good, and I have my friends, so yeah I'm ok."* 18 year-old

*"...what helps is having a group of friends I have now, we always invite each other out every week and go somewhere different to catch up each week and we always make sure we catch up so we can see each other."* 22 year-old

### Strategies that support children and young people to connect with others

Participants who had help to improve communication and practise social skills explained that they were calmer and interacted with others more easily.

*"I guess I'm more calm around people now. Most of the time I guess like with my little quirks and stuff with my social interactions...it's just awkward kinda...Mostly around eye contact. Keeping up a conversation, things like that."* 15 year-old

*"It helps to have quiet time. To be by myself, away from it all, just being myself, that helps to calm me down. Just being away from other people gives me time to collect my thoughts, it just helps being away from the triggers of it. Calming me down so I'm better next time in social interactions."* 15 year-old

*"I suppose it helps when you try not to let the diagnosis get into your personality...like not bothering yourself with the symptoms so much...not concentrate on the problems."* 15 year-old

*"Yeah people listen to me...I just try and make it as direct as possible. I try not to beat around the bush too much."* 15 year-old

### Access to community activities and public events

Children and young people in the consultation said they want community events and activities to be accessible for people with autism. A few participants identified events that specifically cater for people with autism but most of the participants expressed dissatisfaction with community happenings that excluded them from being involved.

*"I look forward to more community events, especially making them more accessible for people on the spectrum...the one thing I miss was like the Perth Skyworks when they had the quiet tent set up if any of my friends needed to duck into the quiet tent."* 22 year-old

*"They should make places like shopping centres more quieter."* 18 year-old

*"No way, I can't catch public transport...Too many people, too noisy!"* 19 year-old

### Having greater understanding of autism in the wider community

Throughout the consultation, children and young people said they want people in the wider community to demonstrate an understanding and acceptance of autism. To reduce the stigma they want to be included, respected and appreciated for who they are.

*"Autistic people think differently but there's nothing really wrong with us, it's just hard when the neurotypical world tries to make us like them instead of trying to help us deal with the world."* 22 year-old

*"A neurotypical person is someone who does not have autism and assumes that their view of the world is correct."* 22 year-old

*"...there needs to be more education for the general public on autism spectrum disorder to raise the profile."* 19 year-old

*"I guess...educating the community that it's okay to be different."* 18 year-old

*"There definitely needs to be more education in my church for people in my youth group in my age. It's like I'm not even there, like I'm invisible to them."* 24 year-old

*"Just like, forgetting about all the stigma. Also, just acceptance really, of the real person."* 15 year-old

### **Support people who are respectful, well-informed and capable of taking action**

Overwhelmingly participants agreed that in all aspects of their lives, they were best supported by people who had a clear understanding of autism and showed integrity.

*"It helps when people know a bit about autism, like what it's about, what the traits are so they understand more. I guess getting rid of the stigma...Understanding the disorder. Yeah, other people understanding it more and yourself understanding it, which helps a lot."* 15 year-old

*"When people have a better understanding of each other, they just get along better."* 11 year-old

*"I think talking the talk but not walking the walk, you say you'll do something but you don't end up doing it...yeah it's bad."* 19 year-old

Family and parents were most commonly identified as providing the most effective support because they had the skills and motivation required to help them.

*"I'm lucky to have my family...My mum ended up going to the [NDIS office] and sitting there until she got someone to help us, she's really stubborn like that!"* 19 year-old

*"My parents are really, really helpful."* 14 year-old

*"...my parents helped me a lot. They are extremely important."* 19 year-old

Knowledgeable and experienced support workers who appropriately responded to the individual needs of children and young people were considered highly important.

*"...my support workers are really important because with my autism support network that's really helped because I've kind of grown as a person and progressed and stuff and learned new skills with what I'm learning."* 19 year-old

*"My support workers are people that come and help me out."* 19 year-old

One young person, who volunteered to mentor other children with autism, described the experience as beneficial for everyone involved.

*"Kids need mentors. Like I mentored a couple of kids that I knew from the centre I was at. And the parents said it helped them because their kids were able to talk to someone else, not just them and not just the staff who they're used to."* 22 year-old



## Having a more effective NDIS

Children and young people recognised the importance of NDIS funding for autism specific services that provided them much needed help with their conditions. However, the majority reported negative experiences with the NDIS, including unreasonably long waiting times, confusing processes and lack of clarity around eligibility to access support.

*"It helps with things like this (autism support) and people who help me...it was just annoying that it took so long."* 18 year-old

*"So the NDIS is not very user-friendly."* 24 year-old

*"...in my experience my mum and I found it really hard to get funding because I was only a Level 1 on the DSM-5, so I didn't need that much help but we found it really hard to get hold of someone in the NDIS and when we did they kept giving us different information and it was really confusing, so yeah."* 18 year-old

*"Well I was supposed to get help from the NDIS, like I had all the diagnosis and doctors reports and that but it took more than a year to get funding."* 24 year-old

*"There seems to be a lot of misinformation from the NDIS, like for instance my friend who is also autistic was told he didn't qualify for the NDIS support anymore because he was at university. If he didn't go in there and interrogate this, he probably would've dropped out of uni because he...needed help with housing and transport because of his disorder."* 19 year-old

The experiences of the participants in this consultation cannot be considered representative of all children and young people with autism, however, their reflections provide important insights into the lives of those with autism and their views should be heard, respected and valued.

Their views highlight the need for more effective mechanisms for children and young people to give their feedback, share concerns and be involved in making decisions about their own health and mental health, education, social interactions, employment and how they choose to be involved in the wider community.

*"...doing this [consultation] helps because kids don't get asked enough about what they want."* 9 year-old

*"It helps if other people make you feel empowered...like ask you what you want and what you need...and it helps if they're empathetic, not just sympathetic. Like people that can relate to you personally either on the spectrum or understand the spectrum. I've been fortunate to have people in my life like that."* 19 year-old

*"When there's something going on in your life and you don't have any control over it, that's when things go bad...some people I know just get told what to do all the time and they don't have any control over their lives, so that sucks."* 24 year-old

## Other consultations with children and young people

### Springboard consultation

In 2013, the Commissioner consulted 17 autistic young people from WA aged 12 to 19 years from Springboard Youth and Autism Community Centre as part of the *Speaking Out About Disability* report.<sup>16</sup> Young people participated in a variety of focus groups and workshops and were asked about their lived experiences with autism. Similar to other consultations, they pointed out that they are all individuals who want to be asked about what they need and can achieve remarkable things with the right support.

*"Those with a disability are not limited, it just opens other doors of unimaginable abilities, talent and potential."* 16 year-old

Many of the most important issues for the autistic young people in 2013 were consistent with the findings from this consultation. Young people said they want:

- support to have meaningful relationships with friends
- support from understanding families
- help at school to overcome difficulties associated with autism conditions
- to be involved and accepted in social activities
- more support with mental health
- better understanding of autism in the wider community.

Other issues raised by the children and young people in the Springboard consultation included:

#### Resilience

*"Us kids with disabilities are strong. I'm a 14 year-old girl with dreams and hopes like any other 14 year-old except I was wired a different way. It doesn't make me any less of a person. I'm just different, but aren't we all unique?"* 14 year-old

#### Social networking

*"A place called [name] on the internet is where I create comics to express my opinions on the world."* 19 year-old

#### Romantic relationships

*"One thing I find difficult is trying to find someone to love."* 17 year-old

#### Funding for support services by capable professionals

*"Easier funding. We are human beings, not government toys. Stop using certain terms to refer to us. Treat us as you would other people."* 17 year-old

*"Getting special treatment, if not treated with subtlety, will make the person feel different in that way, which is not desirable."* 15 year-old

#### Autism specific community activities and events

*"By having more people [with autism] running more youth clubs."* 19 year-old

*"Autistic rugby programs and footy. Neighbourhoods for autistic kids so we don't have haters 😊."* 17 year-old

## **Aboriginal and Torres Strait Islander consultation**

In 2019, Macquarie University conducted a consultation with families of Aboriginal and Torres Strait Islander children and young people with autism, giving a voice to their experiences and identifying areas of further research and improved support.<sup>17</sup> *We Look After Our Own Mob* is informed by in-depth, semi-structured interviews with 12 families with 16 children and young people aged between two and 22 years with a range of autism conditions. Participants lived in diverse areas across Australia including the Australian Capital Territory, Victoria, New South Wales, Queensland, Northern Territory and the Torres Strait Islands.

The families of autistic children and young people in this study raised issues that complemented those raised in the Commissioner's consultations. However, they also highlighted a range of specific considerations for Aboriginal children and young people such as the need for:

- more information about autism in Aboriginal communities
- better support for parents and families
- improved access to flexible supports and services across the lifespan
- more Aboriginal personnel in health, education and disability services
- enhancing children's right to cultural identity
- culturally safe and respectful interactions with services and institutions
- more research that listens to the voice and experience of Aboriginal children in autism.

## **Autism Spectrum Australia (Aspect) consultation**

The research project conducted in 2013 by Autism Spectrum Australia (Aspect) surveyed 100 high functioning young people with autism (aged 12 to 17 years) and 65 parents across Australia about their life experiences, support needs and future aspirations.<sup>18</sup> Findings identified areas of need in education, health, employment, social and community engagement, service availability and support to pursue future prospects.

Young people with autism and their families suggested that support services could be improved by:

- asking them what they need
- increased access to facilities
- more availability of professionals
- better coordination and affordability
- improved autism training and more understanding professionals.

Autistic young people and their families called for:

- more funding to access support services
- increased educational assistance
- help with employment
- additional support to live independently
- a national autism awareness campaign.

## Final considerations

The Commissioner acknowledges the Committee's inquiry into the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy. The following points have been made through the Inquiry process.

### **The need for a National Autism Strategy**

The needs and experiences of children and young people with autism should be central to the development of a National Autism Strategy. Children and young people with autism would benefit from a national organised approach that increases the rights of all children and young people, invests in coordinated action, and adequately funds mechanisms such as:

- equitable and timely access to autism diagnosis
- a consistent best-practice diagnostic assessment protocol
- early interventions for all children
- targeted supports for priority populations of children and young people (including those who are vulnerable or disadvantaged)
- ongoing research and coordinated data tracking
- strategies to hear the views of children and young people with autism and their families.

In addition, an oversight body with functions that monitor system performance and, for example, manage workforce training, and accreditation would provide a valuable opportunity to greatly improve outcomes for autistic children and young people and their families.

This National Autism Strategy should also include a clear commitment to child safety and the need for organisations working with children and young people to adhere to and implement the National Principles for Child Safe Organisations.

### **Health and mental health**

Children and young people with autism recognised the importance of their wellbeing and having easy, equitable access to appropriate health and mental health services. They would benefit from:

- appropriate services with understanding, well-trained health and mental health professionals
- accessible information and practical support for children and young people and their families to link into health and mental health services in the community
- prioritised mental health support, including mechanisms that identify autistic children and young people experiencing mental health conditions (eg autism specific assessment).

### **Education**

Participants in the Commissioner's consultation said they need inclusive educational institutions that have autism specific training, provide safe physical spaces and mechanisms to help them develop positive relationships with peers. They want:

- caring and well-informed adults who are respectful, capable and effective
- to be consulted about individualised support to overcome educational barriers

- greater understanding of autism and more empathetic responses within their educational community
- physically, emotionally and academically safe learning environments
- help with social interactions and making friends.

### **Employment and independent living**

The rite of passage of employment and living independently are important to young people and they want help to find meaningful work and live autonomous lives through:

- supportive employment programs and workplaces that demonstrate an understanding of autism
- help to overcome individual barriers to employment
- raised autism awareness in workplaces
- practical support to live independently.

### **Social connections, participation and community understanding of autism**

Autistic children and young people said that miscommunication and the lack of understanding from others creates some of their greatest challenges. They want:

- support to develop communication and social skills to improve interactions with others
- help to be seen, heard and treated with respect within services and in the wider community
- public promotion of autism awareness.

### **A more effective National Disability Insurance Scheme (NDIS)**

NDIS funding was considered essential to accessing critical autism specific services for autistic children and young people, however, their experiences prompted suggestions for improvement such as:

- reduced waiting times to access NDIS funding and support
- more accessible information and clearer processes
- greater understanding of autism within the NDIS.

## **Ongoing role of the Commissioner**

The Commissioner works closely with the WA community to advocate for all children and young people to live in a caring and nurturing environment, protected from harm and exploitation.

Respecting the rights of children and young people with autism is the responsibility of parents, families and professionals across all sectors and levels of the Australian community.

All children and young people have a right to be safe, to belong, to be listened to and to contribute to decision-making in all areas of their lives.

The Senate Select Committee on Autism review is a positive opportunity to ensure these rights are recognised and acted upon, within the system and by all parties and professionals involved.

The Commissioner looks forward to reviewing the Senate Select Committee's report on its completion.

## Endnotes

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- <sup>1</sup> Both terms 'autistic person' and 'person with autism' are used throughout this report to respect the choice of language that individuals use about themselves.
- <sup>2</sup> Australian Institute of Health and Welfare 2017, *Autism in Australia 2017*, Cat. No: WEB 187. Canberra.
- <sup>3</sup> Australian Bureau of Statistics 2018, "Autism in Australia", *Disability, Ageing and Carers, Australia: Summary of Findings*, Canberra.
- <sup>4</sup> Ibid.
- <sup>5</sup> National Disability Insurance Scheme 2019, *COAG Disability Reform Council Quarterly Report 31 December 2019*, Q2 2019-20.
- <sup>6</sup> Australian Bureau of Statistics 2015, "A Profile of Autism in Australia", *Autism in Australia - Disability, Ageing and Carers, Australia: Summary of Findings*. ABS cat. no. 4430.0. Canberra.
- <sup>7</sup> National Disability Insurance Scheme 2019, *COAG Disability Reform Council Quarterly Report 31 December 2019*, Q2 2019-20.
- <sup>8</sup> Australian Institute of Health and Welfare 2017, *Autism in Australia 2017*, Cat. No: WEB 187. Canberra.
- <sup>9</sup> National Disability Insurance Scheme 2019, *COAG Disability Reform Council, Quarterly Report, Q2 2019-2020*.
- <sup>10</sup> Telethon Kids Institute, Autism Register Portal, available at <https://autism.telethonkids.org.au/autismregister/>
- <sup>11</sup> Cooperative Research Centre for Living with Autism (Autism CRC), *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia*, available at [https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline?gclid=EA1aIQobChMIqfns5bu66gIVUiUrCh0AtAw6EAAYASAAEgKo0PD\\_BwE](https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline?gclid=EA1aIQobChMIqfns5bu66gIVUiUrCh0AtAw6EAAYASAAEgKo0PD_BwE)
- <sup>12</sup> Magiati I et al 2012, Early comprehensive behaviourally based interventions for children with autism spectrum disorders: A summary of findings from recent reviews and meta-analyses, *Neuropsychiatry*, Vol 2 No 6. pp. 543-570.
- <sup>13</sup> Taylor L, Brown P, Eapen V et al. 2016, *Autism spectrum disorders in Australia: Are we meeting best practice standards?* Autism CRC, pp. 5-9.
- <sup>14</sup> Lilley R et al 2019, *We Look After Our Own Mob – Aboriginal and Torres Strait Islander Experiences of Autism*, Macquarie University, Sydney.
- <sup>15</sup> Commissioner for Children and Young People WA 2013, *Speaking Out About Disability - The views of Western Australian children and young people with disability*.
- <sup>16</sup> Ibid.
- <sup>17</sup> Lilley R et al 2019, *We Look After Our Own Mob – Aboriginal and Torres Strait Islander Experiences of Autism*, Macquarie University, Sydney.
- <sup>18</sup> Autism Spectrum Australia (Aspect) 2013, *We Belong Too: The Experiences, Needs and Service Requirements of Adolescents with Autism Spectrum Disorder*.