



# National Autism Strategy Submission



[www.swanautism.org.au](http://www.swanautism.org.au)

## Acknowledgements

SWAN acknowledges the traditional owners of the land on which this submission was produced, the Wardandi Noongar people. We acknowledge the deep spiritual connection to this land and extend our respects to community members and Elders past and present.

## Submission preparation

This submission was prepared by South West Autism Network Inc. In order to write this submission, we listened to the views, concerns and experiences of autistic people, their families and advocates, and the wider disability community.

## 1) About Us

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**The South West Autism Network (SWAN) is grateful to the Department of Social Services for the opportunity to provide feedback on the development and implementation of the National Autism Strategy.**

SWAN is a not for profit, charitable organisation supporting autistic individuals and their families living in the south west region of Western Australia for the past 12 years. We are a Disabled Persons and Families Organisation (DPFO), currently delivering two Information Linkages and Capacity Building (ILC) projects. We have almost 2000 registered members, with hundreds more people with disability and their families accessing support from SWAN. All staff, volunteers and Board members either have a disability, are a family member of people with disability, or both.

Our role in the community is to provide information, peer support, advocacy, and connection to mainstream and disability services, building the capacity of people with disability and their families to navigate Government and non-government systems in order to meet their needs and participate in their local communities. We support people seeking diagnosis, post-diagnosis, and across the lifespan.

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## 1) Social Inclusion

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Social inclusion is a crucial aspect of a just and equitable society. Every Australian should have the opportunity to participate fully in all aspects of life. In understanding social inclusion for autistic individuals, we must view issues through the lens of the social model of disability, which posits that disability is not an inherent trait but rather the result of societal barriers and attitudes.

### SWAN's Perspective on Segregation:

In order for meaningful social inclusion of autistic people to occur in Australian communities, desegregation in all settings is vital. This is in line with the [United Nations Convention on the Rights of Persons With Disability \(UNCRPD\)](#) (United Nations, 2007). Achieving desegregation of people with disability, including autistic people, ensures that the National Autism Strategy takes a human rights approach to social inclusion.

### SWAN's View on the Importance of Desegregation:

SWAN believes it is extremely important to recognise segregation as a key issue for autistic people. Without full inclusion in the community, we are not able to gain proximity to people who are not autistic and who may have little or no experience or understanding of autistic individuals. Conversely, the more bullied, harmed, or abused we are in mainstream society, the more likely we are to be pushed toward congregate living, workplace, or other arrangements. Limitations imposed by societal structures and norms, as well as community attitudes, hinder the full participation of autistic individuals. We are separated from the wider community by legislation, policy, and frameworks that enable segregated arrangements.

The Disabled Persons Australia Position Paper on Segregation (Disabled Persons Organisations Australia, 2020) asserts that the segregation of people with disabilities, including autistic individuals, is discriminatory and goes against the principles of the United Nations Convention on the Rights of Persons with Disability (CRPD). Segregated arrangements may include:

- Day programs
- Congregate living environments
- 'Special' schools
- Segregated employment settings

For those with higher support needs, such as individuals requiring communication support, those with co-occurring or multiple impairments, or those with a psychosocial or intellectual disability, there are few choices when it comes to individualised housing, education, or employment.

### The Impact of Segregation:

Studies show that autistic individuals are routinely denied supports and accommodations every day and that segregation leads to poorer outcomes. ( (Stokes, Drew, Leeuwen, & Ries, 2022)).

## Meaningful Social Inclusion and Education:

Meaningful social inclusion should commence within our schools. Research reveals the significant advantages of inclusive education for both disabled and non-disabled students. When autistic students are effectively integrated into schools alongside our non-disabled peers, provided with appropriate support and accommodations, social and academic outcomes are notably enhanced.

Research addressing academic and social outcomes for children with a disability has consistently found that academic and social outcomes for children in fully inclusive settings are better than in segregated or partially segregated environments. (All Means All website)

A submission by Down Syndrome Australia notes (Australian Institute of Health and Welfare, 2017) a shift towards attending special schools and away from attending special classes in mainstream schools between 2003 and 2015. Given that the Disability Royal Commission's recommendation is to phase out segregated education (over a time period which SWAN considers may be excessive), the increase in attendance in segregated schooling is of concern.

There is also mounting evidence that segregated employment settings actively target students in segregated education settings, including building supported employment facilities near special schools, providing 'work experience' or 'volunteering opportunities'. This continues a lifelong pattern of segregation and makes us 'tourists in our own communities'.

## The Importance of Inclusive Employment:

However, true social inclusion for autistic individuals must extend beyond improving educational integration. Segregated housing and employment practices, as well as the [Supported Wage System \(SWS\)](#), should be eliminated. For autistic Australians to experience genuine social inclusion, we must be visible, heard, and supported to actively participate in all aspects of community life.

There is a direct correlation between 'special schools' (non-mainstream schools) and segregated employment for people with disability, including autistic people.

A research report by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (People with Disability Australia, 2023)<sup>12</sup>. It states that when participants went to segregated schools or classes, it affected what kind of jobs they worked in and how likely they were to find a job. These participants were more likely to work in Australian Disability Enterprises (ADEs), which are businesses that train and hire people with disability<sup>13</sup>.

## Ending Wage Injustice:

Data from the National Disability Insurance Agency (NDIA) shows that the vast majority of NDIS participants who have an intellectual disability and are employed are working within segregated employment. (Australia) Specifically, 70% of participants aged 25 and over with an intellectual disability who are employed are employed within an Australian Disability Enterprise (ADE), which is a form of segregated employment, after being in the scheme for 3 years (Down Syndrome Australia, 2020). According to the National Disability Insurance Scheme (NDIS) Quarterly Report, for participants aged 15 to 64 years with autism, 23%

reported that they had a paid job at their latest reassessment, compared to 23% for the Scheme as a whole; however, in the absence of comparative data around segregation and the subminimal wage, this statistic means little when it comes to economic parity.

Every Australian deserves the right to receive a fair minimum wage, whether we have a disability or not. Regrettably, Australia still undervalues autistic employees and people with intellectual / cognitive disability by allowing employers to pay employees with a disability as little as \$2.90 per hour through the SWS.

SWAN notes that four of the Disability Royal Commissioners recommended phasing out segregated employment, including Australian Disability Enterprises, in the recent Disability Royal Commission recommendations. Commissioners also recommended raising subminimum wages to at least 50 percent of the minimum wage.

SWAN believes that autistic employees, including autistic employees with intellectual disability, should not experience wage injustice. The term 'minimum wage' should apply to all employees working in Australia.

## Inclusion and Societal Structures

A recent Australian study (Jones, Gordon, Akram, Murphy, & Sharkie, 2021) presents the findings of two comprehensive Australian studies that investigate the societal inclusion of autistic individuals. The research provides a detailed examination of the lived experiences of autistic people and the societal structures that impact their inclusion.

The first study involved primarily non-autistic participants (n=2,383), while the second study was conducted with primarily parents and carers of autistic individuals (n=1,297). The findings reveal that societal discrimination against autistic people is perceived by a majority of non-autistic adults, which aligns with the experiences reported by autistic people and their supporters.

The research highlights that societal attitudes towards autistic individuals significantly impact their inclusion. For instance, non-autistic respondents expressed concern about scenarios involving autistic adults in positions of authority or in personal relationships. This concern was more pronounced among older respondents (aged 65+).

In the context of employment, societal beliefs about the capabilities of autistic individuals were explored. Non-autistic respondents believed that autistic people are most suited to roles such as artist / musician (87.7%), supported employment (87.4%), stacking shelves in a supermarket (79.2%), and computer programmer (75.5%). However, older respondents were less likely to believe that an autistic person could hold a professional position.

The study also investigated societal attitudes towards making adjustments for autistic people in schools and workplaces. A significant proportion of respondents agreed or strongly agreed that schools (73.4%) and employers (69.4%) should make adjustments for autistic people.

The study reveals that 51.6% of respondents agreed or strongly agreed that they feel socially isolated. A significant proportion reported that they have lost friends (40.6%) or jobs (20.1%) due to their or their family member's autism, and 26.5% reported that there are family members who they no longer speak to because of their response to their or their family member's autism.

Respondents also reported experiencing negative reactions in the community, with more than half reporting that people often or sometimes stare at them (81.4%), tut or shake their heads (61.3%), or actively avoid them (63.6%). Approximately one in five reported that people often or sometimes mock or taunt them (20.2%) and get aggressive with them (19.1%).

More than half of the respondents reported avoiding certain public places such as restaurants or cafes (51.3%), concerts (48.2%), sporting events (44.3%), shops (44.3%), cinemas (39.6%), or theatres (38.6%). The main reasons for this avoidance were related to physical aspects of the environment, such as the number of people (80.4%) and the level of light or noise (67.8%). However, social barriers were also reported, such as concern about how people will respond to them (40.5%) and needing support to go to these places (35.8%).

Among the respondents who identified as autistic, 70% reported feeling socially isolated, 47% reported losing friends due to their autism, and 42% reported feeling unable to leave the house due to concern about negative reactions from others.

## **Bullying and harassment in schools and workplaces**

Bullying and harassment are significant issues that impact the lives of autistic individuals, particularly in schools and workplaces. According to Autism Spectrum Australia (Aspect (Autism Spectrum Australia, 2017)), individuals on the autism spectrum are more susceptible to bullying. This susceptibility is not limited to being victims of bullying but extends to various roles within bullying situations, including being the bully, assistant, follower, defender, outsider, and victim.

The prevalence of bullying of autistic students is alarmingly high. A study titled “Bullying Prevalence in Students With Autism Spectrum Disorder” (Campbell, et al., 2017) found that autistic students reported significantly more traditional victimisation (physical, verbal, and social) than their typically developing peers. This finding underscores the urgent need for interventions to address bullying in educational settings.

The study’s findings are a stark reminder of the challenges faced by autistic individuals in their daily lives. The experience of being bullied can have profound effects on an individual’s mental health, self-esteem, and overall well-being. It can lead to feelings of isolation, anxiety, and depression. For autistic students, these experiences can be particularly distressing and can significantly impact their academic performance and social interactions.

In addition to the emotional toll, bullying can also have serious consequences for an individual’s physical health. Victims of bullying often experience physical symptoms such as headaches, stomach-aches, and sleep problems. In severe cases, bullying can lead to self-harm or even suicide.

The issue of bullying extends beyond the school environment and into the workplace. Autistic individuals often face discrimination and harassment at work. This can take many forms, including unfair treatment by colleagues or supervisors, exclusion from social activities, or being overlooked for promotions or career advancement opportunities.

Addressing the issue of bullying requires a multi-faceted approach. Schools and workplaces need to implement policies and procedures that explicitly prohibit bullying and harassment. These policies should be clearly communicated to all students or employees and should include specific consequences for violations.

Education is another crucial component in tackling bullying. Students and employees need to be educated about autism and the challenges faced by autistic individuals. This education should aim to foster understanding and empathy towards autistic individuals and discourage negative stereotypes or misconceptions.

Support services for autistic individuals who have been victims of bullying are also essential. These services could include counselling or therapy to help individuals cope with their experiences and build resilience. Support groups can also provide a safe space for individuals to share their experiences and receive support from others who have had similar experiences.

There is a pressing need for strategies to address bullying and harassment of autistic people in schools and workplaces. This includes promoting awareness about autism, fostering understanding and acceptance in schools and workplaces, providing support services for those affected by bullying, and implementing policies that prohibit bullying and harassment.

## **Violence, Abuse, Neglect and Exploitation**

As evidenced by the Disability Royal Commission (DRC), violence, neglect, abuse, and exploitation are significant issues that impact the lives of autistic individuals in Australia. These issues not only cause immediate harm but also act as barriers to social inclusion, preventing autistic individuals from fully participating in society.

A number of submissions to the DRC have provided valuable insights into the issue and how it has impacted upon the lives of people with disability, including autistic individuals. SWAN recommends that the National Autism Strategy includes a review of not just the recommendations, but also a thorough review of the intersect of autism and violence, neglect, abuse and exploitation, as well as gender and intersectional identities.

The “Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia” report by the Centre of Research Excellence in Disability and Health (CRE-DH) provides valuable insights into these issues. (Centre of Excellence in Disability and Health (CRE-DH), 2021). This report presents a comprehensive overview of the prevalence and experience of violence against people with disabilities, including those on the autism spectrum. It highlights that people with disabilities are at a heightened risk of experiencing various forms of violence since age 15, including physical violence, sexual violence, intimate partner violence, emotional abuse, and stalking<sup>1</sup>.

Another important resource is the “Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability” report. (Clifton, 2020) This report discusses how power imbalances increase the possibility of violence against people with disabilities. It emphasises that outdated ways of thinking about disability continue to shape the meanings of disability negatively and impact the treatment of people today<sup>2</sup>.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has also published numerous reports covering public hearings, research, and policy themes. These publications provide an in-depth understanding of the nature and extent of violence, abuse, neglect, and exploitation experienced by people with disabilities in Australia.

In terms of gender, one key issue highlighted by Autism Tasmania is the vulnerability of autistic women to abuse and coercive control. Factors such as financial dependence make autistic women more susceptible to such experiences. This highlights the need for support services to have a greater understanding of autism and the unique challenges faced by this community.

And a recent study conducted in France revealed alarming statistics about abuse against autistic women (Cazalis, Reyes, Leduc, & Gourion). The study, one of the largest to date focusing specifically on this population, found that as many as nine out of ten autistic women in France have suffered sexual violence. The high prevalence of sexual violence against autistic women underscores the urgent need for interventions and support systems tailored to this vulnerable group.

There are discrete issues which have not been fully explored by the DRC. They include:

- Access to and availability of accessible counselling services for those who have experienced trauma, or who are experiencing ongoing trauma.
- The lack of legislation in Australia around hate crime and hate speech. Although there is a DRC recommendation about vilification, it does not include a recommendation to address Australia's lack of hate crime laws. We are one of the only Western countries to have this policy area remain unaddressed.
- Investigating mate crime and online exploitation, as well as exploitation of young people for financial extortion during cybercrime activities.

Mate crime is an area that should be addressed by the National Autism Strategy, as it causes trauma, is difficult to detect and impacts significantly upon the lives of victims. Here are some key points about mate crime and autism:

- Mate crime can occur when someone becomes a friend or acquaintance of an autistic individual and then purposely takes advantage of, or bullies them.
- Examples may include getting an autistic person to commit a crime, engage in risky drug or substance use behaviours, engage in sexual behaviours, lend or spend money on a person, give away their things to other people that they don't really want to give away, let others in their home to live or party, give rides, or feel pressured in any way.
- A 2015 study by the autism advocacy group, Autism Together, reported that 100% of autistic people between 16 and 25 years old have a hard time telling true friends from those who bully or abuse them. (Spectrum Life, 2015)
- Autistic individuals who are in those crucial social years from mid-teens to mid-twenties are most vulnerable. This is when their social life is most important to them.
- Many autistic individuals find it difficult to make and keep friends, a challenge they may have experienced since childhood. Friendship is not only important to most autistic people, but since it has been so hard to come by, they may be highly motivated to make or keep friends.

These issues significantly prevent autistic individuals from being included in society. They create an environment of fear and insecurity that hinders their participation in social activities. Furthermore, they contribute to the stigmatisation and marginalisation of autistic individuals.

## 2) Economic Inclusion

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The link between education and employment for autistic individuals is a critical one, with the school, post-secondary, and tertiary sectors playing pivotal roles in shaping our career trajectories.

In the school sector, autistic students often face challenges such as a lack of understanding about autism among educators and peers, and the need for reasonable adjustments to facilitate their participation. These barriers can impact our educational outcomes and subsequently our employment prospects. In fact, more than half (56%) of autistic students reported being treated unfairly to some degree. (Amaze & University, 2018)

In the post-secondary sector, limited self-advocacy skills among autistic students can hinder our ability to request necessary supports, thereby affecting our academic performance and future employability. Furthermore, late diagnosis of autism in women and girls can impact our life outcomes, particularly in relation to education and employment.

In the tertiary sector, the labour force participation rate for autistic people of working age is only 38.0%, compared to 84.1% for those without disabilities. This disparity underscores the need for greater understanding of autism among employers and more inclusive workplace practices.

According to the Australian Bureau of Statistics (ABS), an estimated 164,000 Australians had autism in 2015, a number that has been increasing over the years. However, the unemployment rate for autistic people is 31.6%, three times the rate of people with a disability and almost six times the rate of people without a disability. This suggests that being considered as having skills and qualifications, many autistic individuals remain underemployed or unemployed.

To address these issues, potential areas of action include increasing autism knowledge among educators and employers, providing extra teaching support and appropriate adjustments in schools, creating more pathways to employment for autistic people, and making transport more autism-inclusive. These measures could help improve the educational experiences and employment outcomes for autistic individuals across all sectors.

### School Education

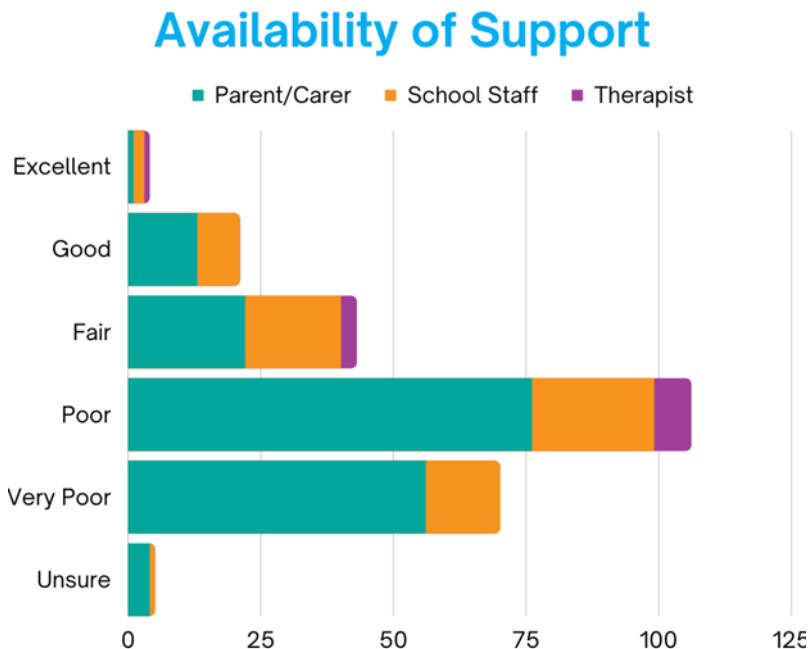
SWAN recently made a submission to the Western Australian Government about support for autistic students in WA schools. Our full submission can be found [here](#). In preparing our submission to the State Government, we received responses from 259 people, comprising autistic students, parents, school staff and therapists living throughout Western Australia in 17 days.

Early childhood, primary and secondary education play a critical role in the learning, participation and wellbeing of autistic children and their families. According to the Australian Institute of Health and Welfare (2017), in 2015 85% of autistic people aged 5 to 20 years, reported difficulty at school, with the five most common types of difficulties experienced being:

- Fitting in socially (63%)
- Learning difficulties (62%)
- Communication difficulties (52%)

- Intellectual difficulties (27%), and
- Difficulties sitting (18%)

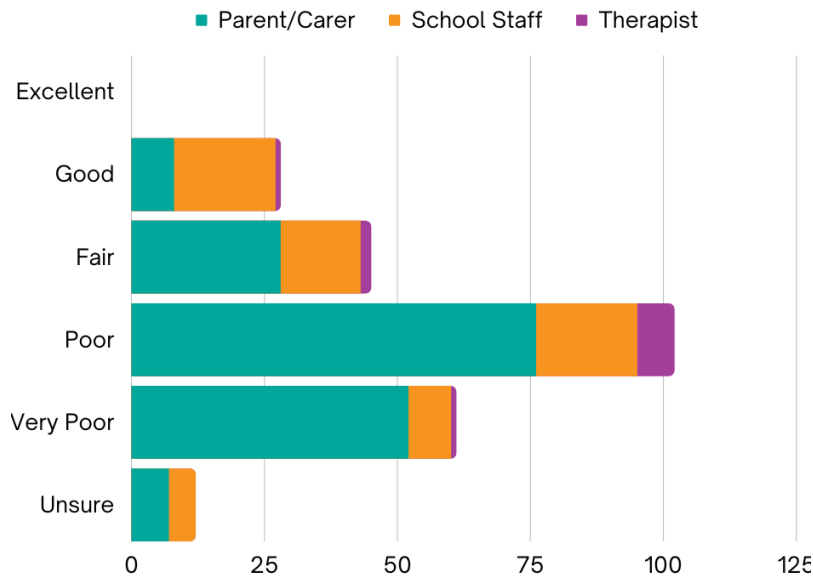
Based on the results of our most recent survey, the current availability of supports for neurodivergent students in WA schools is significantly lacking, as reflected in the graph below.



Of the 249 survey respondents who answered this question, only 10% rated availability of support for autistic students in WA as excellent or good. Alarming, 70.7% rated availability of support as poor or very poor. Without a substantial increase in Government support, funding, and investment in training for teachers and support staff, neurodivergent students are likely to fall further behind than their neurotypical peers, be at greater risk of academic decline, social isolation, and poor mental health. Longer term, there is the risk that insufficient support during school years will impact negatively on an autistic person's self-esteem and ability to gain and maintain financial independence and autonomy in adulthood; hence the necessity to provide greater support during early childhood, primary school, and adolescence.

In addition to lack of support availability, survey respondents also reported issues with the quality of support in WA schools, as shown in the graph on the next page.

## Quality of Support



Of the 248 survey respondents who answered this question, no one rated the quality of support for autistic students as excellent. 11.3% rated the quality of support as good, and concerningly, 65.7% rated the quality of support for autistic students in WA schools as poor or very poor. We note also that 40.9% of school staff responding to this question rated the quality of support as poor or very poor, and only 28.7% of school staff rated the quality of support in schools as good.

It was reported by [ABS \(2018\)](#) that in 2018, 92.3% (101,900) of young autistic people aged 5-20 years experienced some form of educational restriction, with some unable to attend school because of lack of support for their disability-related learning needs. NDIA have captured outcomes data for autistic participants aged 0-14yrs on education outcomes, comparing a baseline for their entry into the scheme with outcomes two years later. As at 31<sup>st</sup> March 2023, only 65% of autistic participants aged 0-14yrs were attending mainstream schools, compared with the baseline of 72%. Despite 2 years of NDIS funded support, 7% fewer autistic NDIS participants in that age group are now attending mainstream schools. As State-based Education Departments are responsible for support for autistic students within schools (rather than NDIS), this indicates that current school-based supports for autistic students are insufficient to meet needs. As can be seen in the table below, SWAN's extensive interactions with autistic people and families over the last 14 years emphasise the lack of support in WA schools, with enquiries regarding this issue increasing.

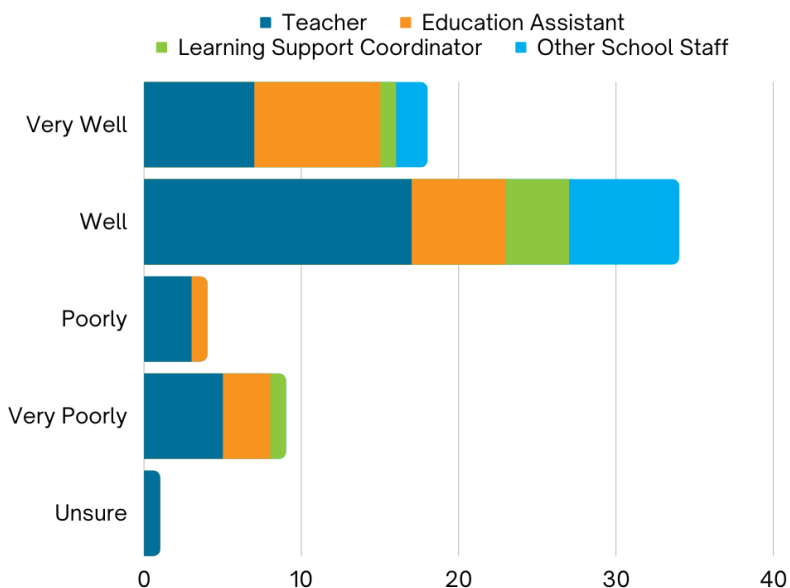
Enquiries to SWAN about issues with schooling					
2018 6mths	2019	2020	2021	2022	2023 6mths
12	149	144	488	504	378

*Note that the figures for 2018 and 2023 are both for 6 month periods only.*

[ABS \(2018\)](#) reported that two in five (40.4%) autistic students needed special tuition and 32% needed help from a counsellor or disability support person. Of great concern, it was also reported that almost half the autistic young people aged 5-20 years (45.9%) indicated they needed more support or assistance at school than what they were receiving.

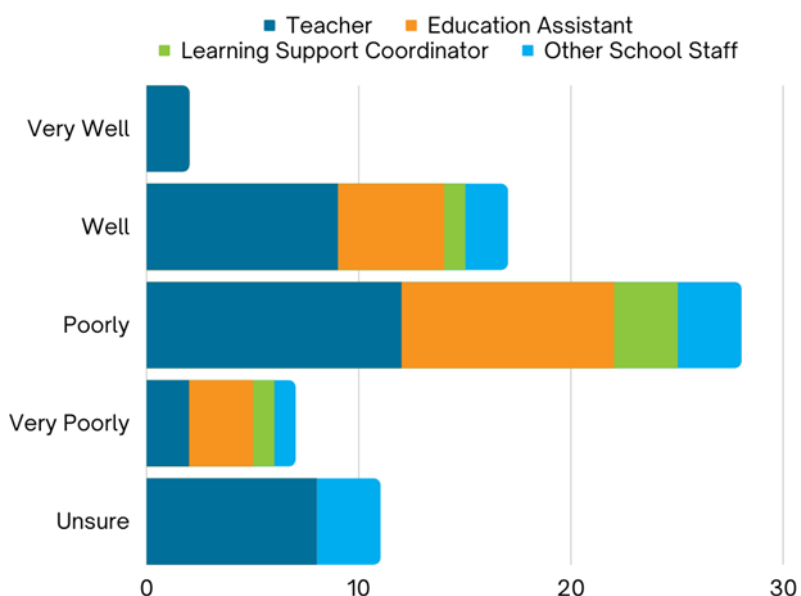
In the survey we asked school staff how well they understand autism in order to source data on general knowledge about autism among education employees, and identify knowledge gaps. Responses to this question are detailed in the graph below:

### How well do you understand autism?



Excepting the 4 staff who identified as being autistic themselves, the 18 school staff who indicated that they understand autism 'very well' also tended to suggest that school staff would benefit from fewer training topics, which may signify a lower level of understanding than self-assessment indicates. When asked to reflect on how well co-workers understand autism, school staff responded quite differently.

### How well do other staff understand autism?

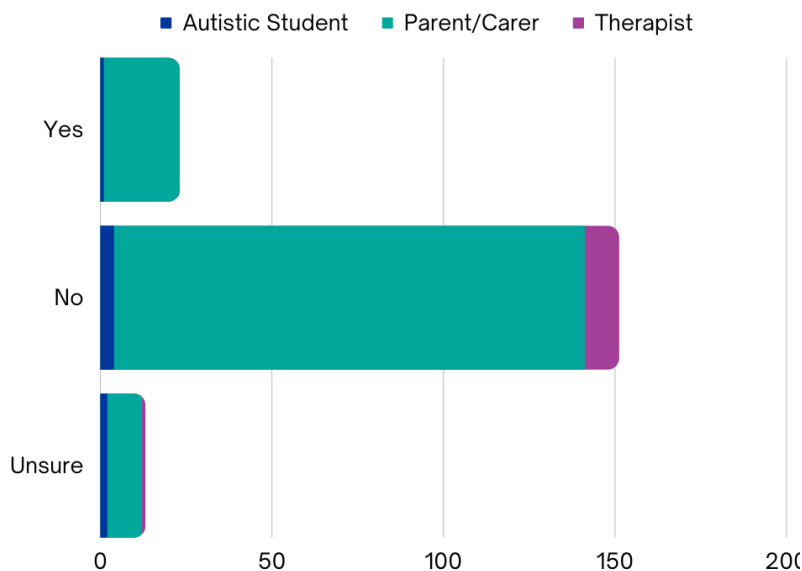


It's important to note that both graphs and their accompanying comments highlighted the fact that Professional Development (PD) training on autism is entirely optional, and is not included in the current undergraduate training for school teachers. Some staff choose to undertake PD on autism, however the quality and amount of this training varies greatly. The accompanying comments to this question indicated a high degree of variability in staff

knowledge and understanding of autism, with some school staff having undertaken extensive training, including in their own time, some having undertaken a limited amount of training, and many having undertaken no training on autism.

We also asked students, parent/carers and therapists if they felt school staff understand autism:

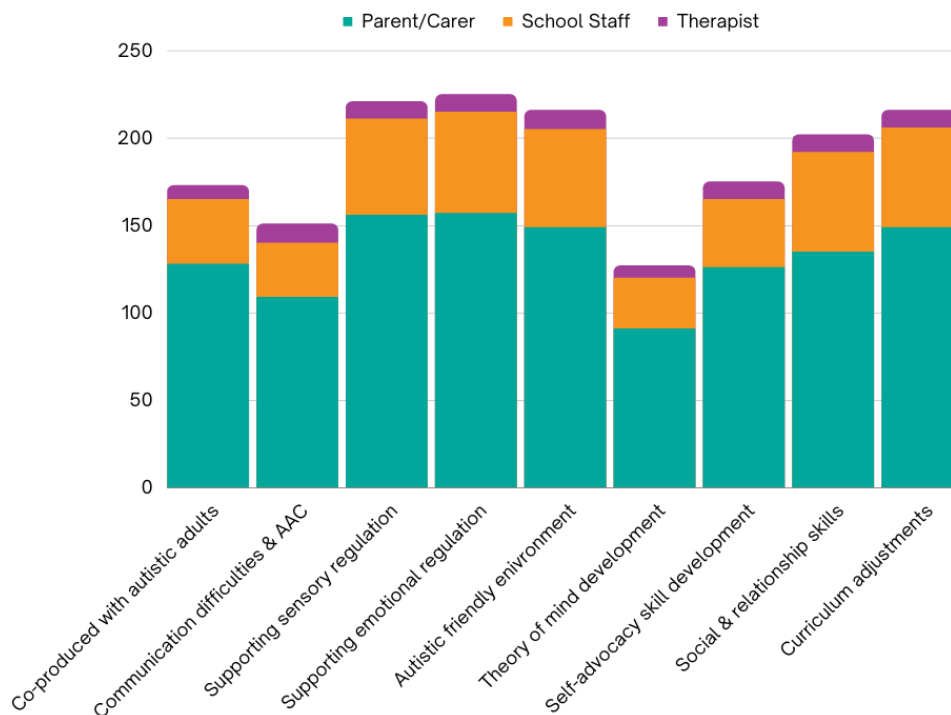
## Do school staff understand autism?



Of the 187 respondents who answered this question, 80.7% of survey respondents felt that school staff do not understand autism, while 12.3% felt that school staff do understand autism.

School staff, parent/carers and therapists were also asked what training about autism they felt would improve support for autistic students in WA schools. The results from this question can be seen in the graph on the next page.

# Training for School Staff



In addition to the above, suggestions for other training that would improve support for autistic students in WA schools included:

- Dr Ross Greene’s Collaborative and Proactive Solutions
- Double Empathy – teaching neurotypical people to accommodate autistic communication and social styles (communication and social interaction are both two-way streets)
- Executive Functioning Skills and Life Skills
- Pathological Demand Avoidance (PDA)
- Trauma Informed Practice
- Youth Mental Health First Aid

The Commonwealth funded Positive Partnerships training was also highly recommended by some school staff, however, as with all professional development training about autism, this is entirely optional.

This survey question attracted 71 (optional) comments. A common theme was concern about compliance-based methods being used in the classroom, such as Applied Behaviour Analysis (ABA), and the related harm to students’ mental health and long-term capacity for self-advocacy. Compliance-based methods of behaviour management place autistic students at risk of physical, sexual, psychological and financial abuse, and leads to Post Traumatic Stress Symptoms (PTSS) in nearly half of ABA-exposed individuals (Kupferstein, 2018), and tend to have more severe PTSS.

Due to the high volume of important comments throughout the survey, we have attached all comments as an addendum to this submission to ensure that the voice of all survey respondents is included, and strongly encourage you to thoroughly read the attached addendum. Below are two quotes from each type of survey respondent about what they believe school staff need to learn about autism.

While training about autism is vital in ensuring appropriate support for autistic students in WA is provided, the current support systems are being implemented inconsistently and with varying degrees of success. Public schools are able to access support from the School of Special Education Needs – Disability (SSEND), whereas private schools are not.

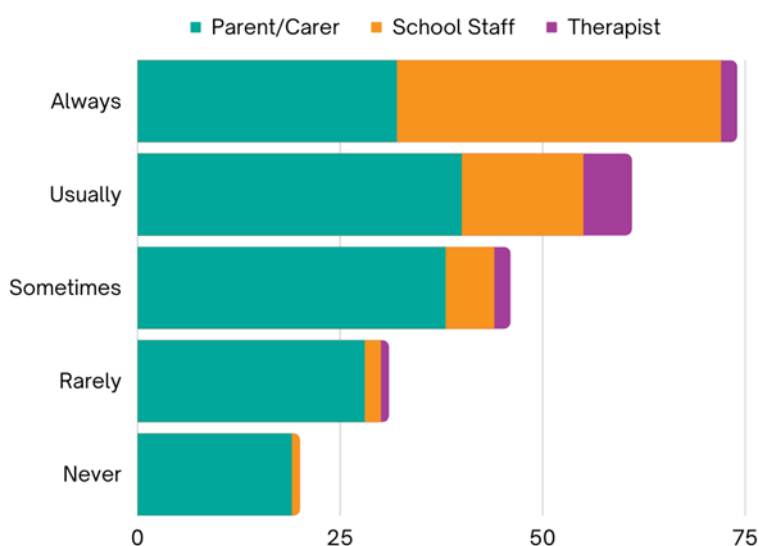
Further, individual public schools have the freedom to decide whether to invite SSEND staff into the school to support staff and students. Where schools choose not to invite SSEND to the school, there is risk that time-poor school staff are expected to undertake tasks with limited expertise that SSEND could assist with, and risk that outcomes for autistic students may be lower.

School staff also report that SSEND are under-resourced, short-staffed, and difficult to access. Some schools refuse to apply for assistance from SSEND, viewing it as a ‘waste of time and resources’ for the school – many of which are likewise under-resourced and short-staffed.

Funding for Education Assistants (EAs) is typically the most common support offered for autistic students within the WA school system. As previously noted, EA funding is not available for students without a formal diagnosis – and with wait times for autism diagnostic assessment now up to four years in duration, the impact on both student learning and school staff trying to support them is very significant. Currently, EA funding for a student with disability is frequently utilised by schools to support other students without an eligible diagnosis who are in need of additional learning support. This practice has serious implications for the students with diagnosed disability, as their learning support needs are not being met. SWAN frequently hear from parents and school staff alike, complaining that the current funding practices for learning support in schools prioritise funds and/or supports for students who may be disruptive in class or who have behavioural issues – to the academic detriment of students with disability who struggle with their learning but may not be disruptive in class.

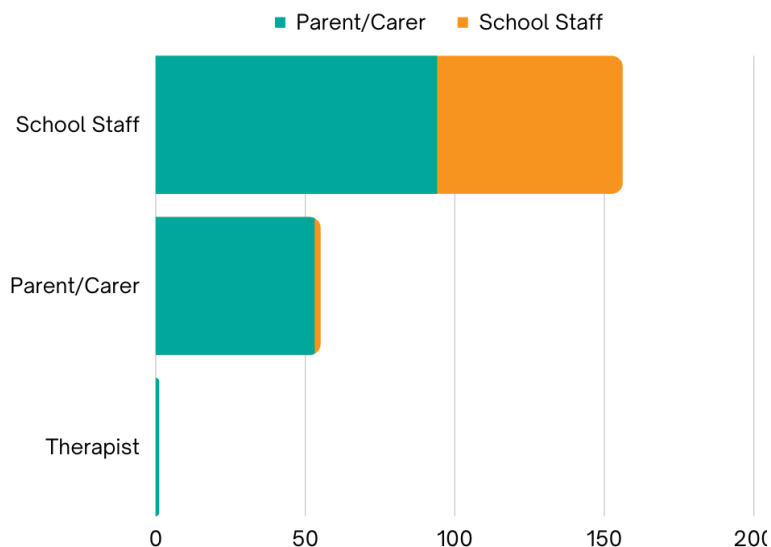
With the exception of Education Assistant (EA) support, the most common practice schools appear to implement to support students who have learning difficulties, is to introduce an Individual Education Plan (IEP), or Curriculum Adjustment Plan (CAP). We asked survey respondents how often IEP’s are developed for autistic students in WA schools. Responses are displayed in the graph below:

### How often are IEPs developed?



The 232 survey respondents who answered this question indicated that IEPs are always or usually developed for 58.2% of autistic students, with 22% indicating that IEPs are rarely or never developed for autistic students. We also asked survey respondents about who commences the IEP process, with results displayed in the graph below:

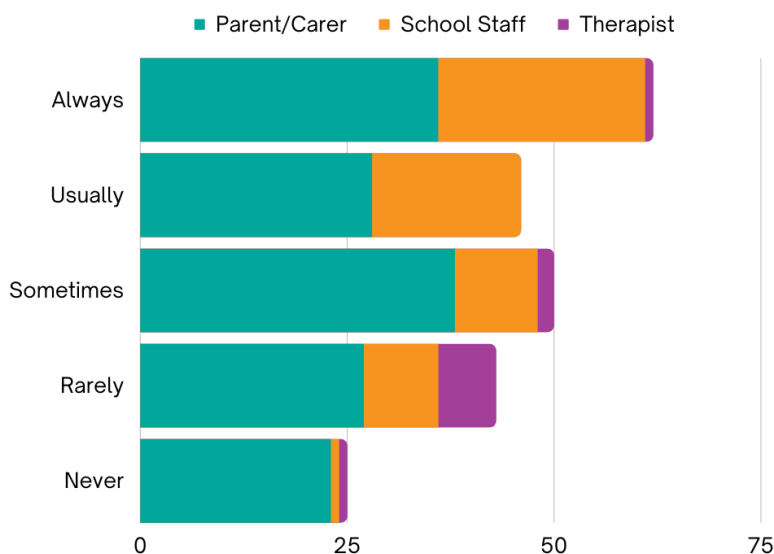
### Who starts the IEP process?



The 212 survey respondents who answered this question indicated that school staff start the IEP process 73.5% of the time, with parents / guardians starting the IEP process 25.9% of the time. We note that several parent / guardian respondents also commented that while they had indicated that school staff start the IEP process, this only occurs after the parent / guardian requests one.

We asked survey respondents how often parents / carers (and therapists) are included in the development of an IEP, with results displayed in the graph on the following page:

### How often are parents/carers (& therapists) included in IEP development?



The 226 survey respondents who answered this question indicated that parents (and therapists) are always or usually included in the IEP process 47.8% of the time, and rarely

or never 30% of the time. We note that according to the [Department of Education WA](#) an IEP *‘...is written specifically for your child to address their academic and personal needs. All staff working with your child at school will use the plan. Your input in the planning process is very important and regular reviews will be conducted to ensure the plan is current and relevant.’* The survey responses indicate that this policy is being implemented inconsistently between schools. Whilst we recognise that some parent/carers may choose not to be involved in the IEP process, all who responded to this survey indicated a desire to be included in the development of their child’s IEP, and 32.9% of parent/carers were rarely or never included in developing their child’s IEP.

In seeking feedback from people across the state, we obtained responses from people in metropolitan, rural, regional, and remote areas. The feedback was generally consistent across the board, regardless of location – reflecting a clear lack of consistency in the approach to supporting autistic students and their families from one school to the next. It is important to note, however, that the number of available supports in rural, regional, and remote areas are significantly less than what is available in the metropolitan area, with longer wait times to access these services.

Currently autistic students are subject to ‘geographic lottery’ in trying to access appropriate support in school. A student living on one side of the street may reside in the catchment for a school offering an inclusive, supportive, and flexible learning environment; while a student living across the road may reside in the catchment for a different school providing an inflexible, unsupportive, and sometimes discriminatory learning environment.

SWAN staff consistently hear teachers report that when they have implemented strategies in the classroom to address the needs of neurodivergent students, all students in the classroom benefit from these reasonable adjustments. The typical WA classroom environment is a sensory nightmare for neurodivergent students, and this was reflected in many comments from survey respondents. With fluorescent lighting, lack of air conditioning (many neurodivergent students have difficulties with temperature regulation), group seating structures, background noise, preference for verbal communication and lack of sensory and movement breaks, the classroom environment is overwhelming and triggering for neurodivergent students. This results in reduced academic achievement, shutdowns / meltdowns, and behavioural difficulties.

By ensuring that the classroom strategies utilised in all schools are neurodiversity-affirming, it’s clear that all students will benefit.

## Postsecondary and Tertiary Education

### Access to Postsecondary Education

In Australia, there is a pressing need to expand the availability of Certificate I and II options at public TAFEs. These options should be accessible to adults, not just high school students. Certificate III is often seen as the entry level, but many individuals with Intellectual Disability and/or autism need the opportunity to build skills and capacity through Certificates I and II before attempting Certificate III.

The [Priority Skills List](#) is the document that determines course availability, especially for subsidised and free courses. Unfortunately, there is no regard given to diversity or disability in this process. Consequently, students who are preliterate, who have intellectual disability and many autistic people with cognitive disability find themselves unable to access

education and training in a post secondary setting. This may be due to not being able to meet the inherent requirements of the position (including in literacy) or because of poverty.

The use of Plain English should be a minimum standard in all TAFE level reading materials and assessment papers. This will ensure that the content is accessible to all students, regardless of their cognitive abilities. Easy English should also be available for all standard TAFE level documents.

There is also a need for better training in neurodiversity and disability for lecturers as well as within support services. This will help them understand the unique needs and challenges of their students and adapt their teaching methods accordingly.

Improvements are needed in disability supports, especially for students studying externally. At the university level, there should be better training for lecturers, improved disability accommodations, more accessible student housing, and greater support for students studying remotely.

## **Systemic Barriers in Economic Systems**

Autistic individuals face unique challenges in economic systems, often encountering barriers to economic parity. These barriers are multifaceted, encompassing aspects of social security, employment, and disability support systems.

### **Disability Support Pension (DSP) Application Process**

The DSP application process in Australia has been criticised for its complexity. The eligibility criteria are often seen as restrictive, potentially excluding many autistic individuals who require support. Simplifying the application process and refining the eligibility criteria could make the DSP more accessible to autistic individuals.

### **Mutual Obligations Process**

The mutual obligations process, which outlines the responsibilities of individuals receiving social security payments, also needs simplification. The current system can be overwhelming for autistic individuals, potentially hindering their ability to meet their obligations and maintain their benefits.

### **Universal Basic Income (UBI) and Poverty**

Poverty is a significant issue for autistic individuals in Australia. 45% of those with a disability in Australia are living either near or below the poverty line. This is more than double the Organisation for Economic Co-operation and Development (OECD) average of 22%.

The concept of a UBI has gained traction in recent years. A UBI could provide a safety net for autistic individuals who are unable to work full time due to their disability. By ensuring a guaranteed income, a UBI could alleviate financial stress and provide greater economic stability.

### **Employment Accessibility**

Improving employment accessibility is crucial for enhancing economic outcomes for autistic individuals. This involves overhauling recruitment processes to be more inclusive and accommodating of autistic individuals' unique needs. The Supported Wage System (SWS), which allows employers to pay wages based on an individual's productivity, is one such initiative. Job customisation and microenterprise could also play significant roles in improving employment outcomes.

## Centrelink and NDIS Issues

There are notable issues between Centrelink and the National Disability Insurance Scheme (NDIS). Currently, Centrelink is unable to provide a letter confirming that a person isn't eligible for the Disability Employment Service (DES), while NDIS often won't fund School Leavers Employment Support (SLES) or Finding & Keeping a Job unless a person gets confirmation from Centrelink that they aren't eligible for DES.

Young people without disability expect to have the opportunity for part-time employment from the age of 14 years, typically while still attending high school. For most teenagers, part time or casual work is a rite of passage – building independence, resilience, self-reliance and employment skills. For most autistic adolescents, a part-time or casual job after school is typically an unachievable pipe-dream. Whilst the National Disability Insurance Scheme (NDIS) **can** fund Capacity - Building Employment Supports (either Finding and Keeping a Job or School Leaver Employment Supports (SLES)) for high school aged NDIS participants, this is rarely to never approved by NDIA Delegates.

According to [NDIS Data and Insights](#), of the 161,279 NDIS participants aged 7-14 years, only 12 are funded for Finding and Keeping a Job supports Australia wide. Of the 52,802 NDIS participants aged 15-18 years, only 5,171 (9.7%) are funded for Finding and Keeping a Job supports nationally. In Western Australia, of the 13,196 participants aged 7-14 years, NDIS data states <11 (NDIS does not report data of fewer than 11 participants, which means there could be zero WA participants in this age group with this type of funding). Of the 5,136 participants aged 15-18 years, only 811 participants (15.7%) are funded for Finding and Keeping a Job supports. We note that the majority of individuals in the 15-18 age group with this type of funding will be 18 years old.

During the trial phase of the NDIS vs the state-based scheme in WA, the Perth Hills NDIS trial implemented a pilot program ensuring that all school leavers with disability were given funding for [School Leavers Employment Supports \(SLES\)](#) for a minimum of one year between Year 10 and Year 12. This prior history in the Perth metropolitan area is likely to be the reason for the higher percentage of Capacity Building Employment funding in Western Australia. Currently the National Disability Insurance Agency typically denies funding for employment supports for young people still attending high school.

When looking at the NDIS Data and Insights for disability types, only 10,838 of the 214,880 participants with autism as their primary diagnosis are funded for employment supports. In Western Australia, that figure changes to only 1,669 of the 19,481 total WA participants with a primary diagnosis of autism. Unfortunately, the NDIS Data and Insights webpage no longer enables users to filter data by region or by disability type. Unfortunately, this is not the typical experience in the southwest region of WA, as well as in many other regions. It's extremely common for NDIA delegates and Local Area Coordinators (LACs) to demand evidence that a participant is ineligible for DES via Centrelink before agreeing to fund employment supports in their NDIS plan. However, as Centrelink IT systems do not permit staff to create a letter or statement advising that someone is not eligible for DES via Centrelink, so no one is able to provide the 'evidence' being demanded of them.

This lack of funded employment supports for autistic adolescents is a major barrier to achieving that notable rite of passage – an after-school job. A common enquiry SWAN receives from families of autistic high school students regards their expressed desire to have an after-school job like their peers. SWAN has often supported families to seek NDIS funded employment supports for their teens and **have never seen it approved for a student still attending high school**. Likewise, unless an NDIS participant in Year 12 is within 1-2

months of finishing school, SWAN has never seen School Leaver Employment Supports (SLES) approved in an NDIS plan for this cohort.

SWAN prioritise employment of autistic people within the organisation, and are currently running an Information, Linkages and Capacity building (ILC) project involving the employment of 16 young people with disability to codesign short films while building employment readiness skills. All employees working on the project are paid above minimum wage, regardless of their work capacity. One of our autistic staff members was forced to resign from their position with SWAN because their NDIS funded disability service provider refused to transport them to their work shifts. Another employee supported by the same organisation offered to transport them, but the service provider refused. The same service provider made another employee repeatedly late for their paid work shift at SWAN due to arranging volunteer activities which conflicted with their paid work shifts. This represents a culture of devaluing the employment of autistic and Intellectually Disabled youth, including by the NDIS funded service providers who should be supporting their economic participation.

### **Changes in DES Access**

In 2021, the law for accessing DES changed, restricting access to those receiving JobSeeker or DSP. This change has potentially excluded autistic school leavers who need additional support to access employment but are not eligible for JobSeeker, DSP or NDIS. These individuals are no longer eligible for DES support, potentially blocking them out of employment.

Full time high school students with disability are likewise barred from accessing Disability Employment Services (DES). Currently, people with disability must be receiving either [JobSeeker Allowance](#) or [Disability Support Pension](#), and be deemed to have capacity to work a minimum of 8 hours per week to be eligible for DES. School leavers in receipt of Disability Support Pension may be exempted from Job Capacity Assessments where they have an appropriate letter from a supported Education Department or Education Support School. However, for youth with disability not eligible for Disability Support Pension, there may be no access to DES until they are 22 years of age.

Addressing these barriers requires systemic changes at multiple levels. Simplifying application processes, refining eligibility criteria, considering UBI implementation, improving employment accessibility, resolving issues between Centrelink and NDIS, and revisiting changes in DES access are all critical steps towards achieving economic parity for autistic individuals.

## **Employment**

### **Challenges Faced by People with Disabilities**

People with disabilities face numerous barriers to education and employment. These barriers range from low expectations by those around people with disability and people with disability themselves; the accessibility and quality of our education; the ease to which the right support can be accessed at the right time for both people with disability and people supporting people with disability; and the interface and support of other systems.

From a disability rights perspective, this situation is unacceptable. The Australian Government acknowledges that life outcomes for autistic Australians are unacceptably poor and come at an enormous personal, social, and economic cost. The government has

initiated efforts to improve these outcomes through the development of a National Autism Strategy. Recommendations have also been made to address the issue through the Disability Royal Commission.

## Transport

Transportation is another significant issue. Public transport can be difficult for people with a disability, and is critical to being employed, especially in Australia. Factors such as accessibility, communication about changes or cancelled services and malfunctioning equipment (e.g., lifts to train platforms) can all contribute to transport disadvantage for people with a disability. For autistic people, there can be issues with attitudinal barriers, difficulty with managing schedules, a lack of support and physical barriers such as inaccessible wayfinding (directional signs).

Access to driving lessons is also a barrier, as is car ownership, for reasons such as poverty. A study suggests that 3 in 4 teenagers with Autism (who do not have an accompanying intellectual or learning difficulty) will successfully obtain their driver's licence. However, they generally take 7-9 months longer than their peers without autism to obtain their licence, and many require significantly more driving lessons and practice. While it is possible to access funding for additional driving lessons through NDIS, NDIS representatives frequently demand that autistic participants undergo an Occupational Therapist Driving Assessment. This assessment costs an average of \$2,000-\$2,300, whereas the funding in an NDIS plan for additional driving lessons typically averages \$700-\$1,400. This demand for 'evidence' of the need for additional driving lessons increases the cost of this support by 260%-385%.

Furthermore, adults on the autism spectrum often report that they regulate their own behaviours more strictly by avoiding things like highways or nighttime driving. This might suggest that a significant number of autistic people may choose not to drive or limit driving.

Additionally, around half (50.9%) of the people with autism reported that they had a mobility restriction that means they require some assistance or supervision to be able to move around (The Spectrum, 2019). This could potentially impact an ability to drive.

## Public Transport

Another study, titled "Enhancing the capacity of autistic people to use public transport" was conducted across Western Australia and New South Wales, Australia. The research aimed to address community mobility challenges experienced by young autistic adults, focusing on public transport access<sup>1</sup>.

The project was co-produced, meaning that at each step of the research, the team worked with autistic individuals, their families, and carers to ensure that any solution that arose from the research was one that was built together with the wider autistic community<sup>1</sup>.

The project produced an evidence-based piloted technology solution, OrienTrip, to assist autistic individuals to use public transportation. It was found that OrienTrip is helpful in facilitating public transport use for autistic individuals. OrienTrip can improve autistic individuals' ability and confidence to use public transport independently. However, it was also suggested that OrienTrip can be improved by making it easier to use.

Another study titled "Exploring the relationship between community mobility and quality of life, employment and completing further education for autistic adults" found that Autistic

adults self-reported less accessibility to both public transport and driving to meet their community mobility needs and were less likely to use a car or public transport. Further, autistic adults reported significantly lower self-rated quality of life, were less likely to be employed and were less likely to have completed further education.

Notably, although public transport or car access are not predictors of employment and educational outcomes, such access improves quality of life, but in different ways when compared to non-autistic adults. By contrast, public transport use is a predictor of better educational outcomes, and public transport and car use are predictors of both.

The study concluded that more nuanced attention to autistic people's individual perspectives and their experiences will help better develop ways to more intuitively define and measure both access and use in a meaningful manner. Qualitative studies are needed to explore why access does not always equate to use. The needs of autistic people should be considered by a range of policies impacting community environments, such as urban and public transport design, training of police and transit authorities and emergency response.

## Systemic and Intersecting Barriers

According to Australian Bureau of Statistics data, there are significant employment issues facing individuals with autism. There is a need for more support for transitioning from high school to adulthood.

Recruitment processes need to be overhauled to improve accessibility. The Supported Wage System (SWS), job customisation, and microenterprise could all play a role in improving employment outcomes for individuals with autism.

There are also issues between Centrelink and NDIS – Centrelink is unable to provide a letter confirming that a person isn't eligible for Disability Employment Service (DES), while NDIS often won't fund School Leavers Employment Support (SLES) or Finding & Keeping a Job unless person gets confirmation from Centrelink that they aren't eligible for DES.

In 2021, the law for accessing DES changed. Now people can only access DES if they are receiving JobSeeker or DSP. This means that autistic school leavers who need additional support to access employment but are not eligible for JobSeeker, DSP or NDIS, are not eligible for DES support, and may be blocked out of employment.

Support should be provided for employers to implement job carving models. This would allow jobs to be tailored to the abilities of individuals with autism, increasing their chances of successful employment.

As already discussed in other submissions, inclusive practices and disability confidence should be promoted. Employers should be encouraged to make necessary adjustments and provide training about autism to promote an inclusive workplace.

SWAN supports the Disability Royal Commission recommendation to ensure disability targets in the public sector in Australia, but believes targets should not be restricted to Commonwealth employment. There should be incentives granted to private sector and local government employers who set targets and develop Disability Access and Inclusion Plans, linked to tangible and measurable outcomes.

### 3) Diagnosis, Services and Supports

#### Diagnosis

There is a misconception in the community that autism is over-diagnosed in Australia, and that most autistic children require minimally funded supports through the National Disability Insurance Scheme (NDIS). In Western Australia autism is significantly under-diagnosed, as evidenced by a comparison of prevalence rates, as follows;

**Western Australia:** The proportion of people estimated to have autism is 0.5%.

**South Australia and Tasmania:** The proportion of people estimated to have autism is 1.0%

**New South Wales:** A study published in the Journal of Autism and Developmental Disorders reported that the prevalence of Autism Spectrum Disorder (ASD) in a cohort of children born in 2002–2015 in New South Wales was 1.3% by age 12.

According to [Wang et al., 2022](#), prevalence rates of autism have increased 20-30 fold in the last 40 years worldwide, with research now indicating that one in every 100 individuals will have a diagnosis of autism ([Ziedan et al., 2022](#)). In Australia, there were 205,200 autistic Australians recorded in 2018, up from 164,000 in 2015 ([Australian Bureau of Statistics \(ABS\), 2018](#)).

There are no accurate records in Australia for the number of people diagnosed with autism, as there is no compulsory state-based or national register of autism diagnoses, and not all formally diagnosed autistic people are participants in the National Disability Insurance Scheme (NDIS). The [National Disability Insurance Agency \(NDIA\)](#) reports that as at 31<sup>st</sup> March 2023, of the 592,059 active National NDIS participants, 35% (207,385) participants had a primary disability of autism, making it the most common disability for NDIS participants. Below is the [NDIS Demographic Chart Data for Autism](#):

As at 31 Mar 2023	Autism	All participants	Proportion - autism	Proportion - All participants
<b>State/Territory</b>				
NSW	60,666	177,277	29%	30%
VIC	51,827	158,480	25%	27%
QLD	46,291	125,549	22%	21%
<b>WA</b>	<b>18,848</b>	<b>50,994</b>	<b>9%</b>	<b>9%</b>
SA	20,659	51,072	10%	9%
TAS	4,309	13,049	2%	2%
NT	1,253	5,522	1%	1%
ACT	3,511	10,060	2%	2%
OT	20	51	0%	0%
Missing	<11	<11	0%	0%
Total	207,385	592,059	100%	100%
<b>Age band</b>				
<b>0 to 6</b>	<b>21,098</b>	<b>95,773</b>	<b>10%</b>	<b>16%</b>
<b>7 to 14</b>	<b>108,669</b>	<b>155,651</b>	<b>52%</b>	<b>26%</b>

<b>15 to 18</b>	<b>33,217</b>	<b>50,409</b>	<b>16%</b>	<b>9%</b>
19 to 24	23,208	48,444	11%	8%
25 to 34	12,858	51,495	6%	9%
35 to 44	4,831	46,070	2%	8%
45 to 54	2,325	54,034	1%	9%
55 to 64	951	63,988	0%	11%
65+	228	26,195	0%	4%
Total	207,385	592,059	100%	100%

Of note in the table above, only 9% (18,848) of Western Australian NDIS participants have autism as their primary diagnosis, compared with 30% for NSW, 27% for VIC and 21% for QLD. As per our [submission](#) to the State Government on Child Development Services in October 2022, access to diagnostic services in Western Australia is seriously limited. There is currently a wait time of up to 4 years for an autism diagnostic assessment in WA, with people waiting up to 2 years for a paediatrician appointment and up to a further 2 years for diagnostic assessment through the public system. This has been exacerbated by [changes to Medicare](#) effective 1<sup>st</sup> March 2023. A Medicare rebate for diagnostic assessment is now available for most disabilities via referral from a GP up to the age of 25 years, however autism has been classified as a Complex Neurodevelopmental Disorder, with Medicare rebate only available via referral from a paediatrician or psychiatrist.

We note also that as per the [Disability, Ageing and Carers Australia: Summary of Findings 2018](#), changes to the criteria used to clinically diagnose autism have been subject to some variation since first appearing in the DSM-III in 1980, with diagnostic criteria being clarified over time. This has impacted the number of individuals formally diagnosed with autism across the different age groups, reflecting the marked decrease in prevalence of diagnosed individuals in the higher age bands, as shown in the NDIS table on page 5.

The diagnosis rate can be influenced by many factors including:

- access to diagnostic services
- awareness of autism (especially in Aboriginal and CALD communities) and
- variations in diagnostic criteria over time.

Given that waitlists are so long for the public system here in Western Australia and a substantial portion of the population cannot afford the cost of a private autism assessment, prevalence rates recorded across certain demographics do not accurately reflect actual rates of autistic individuals in our state. A portion of individuals are self-identified autistic, without a formal diagnosis or formal supports and a large number of individuals (across the lifespan) will be unable to undergo a formal assessment due to financial, accessibility, or mental illness constraints.

It's clear that the prevalence of autism in WA is grossly under-diagnosed compared to other Australian states. Access to NDIS and providing funded supports in WA schools only where a formal diagnosis of autism has been confirmed by two-three clinical diagnosticians (comprising paediatrician, psychologist, and speech pathologist), is a great disservice to WA children and adolescents - restricting access to learning and development for neurodivergent students.

Due to extreme staffing shortages and stringent diagnostic processes, WA families are waiting up to two years to access a paediatrician and up to a further two years to access

formal diagnostic assessment. The more regional or remote someone lives, the more limited the access to diagnosticians and autism diagnostic assessment.

Accessing autism diagnostic assessment in WA is arduous, traumatic, and actively discouraged by too many paediatricians. Families with the financial means to pay privately for autism diagnostic assessments are able to source diagnosis and access support much faster (particularly if they do not require the Medicare rebate), but many are still delayed by the requirement for referral by paediatrician to access the [Medicare rebate](#). Almost all paediatricians who perform autism diagnostic assessment and referral in WA have closed their waitlists, and the waitlist for those with open waitlists are eye-wateringly long.

For adults, the situation is even more dire. In Western Australia, access to free autism diagnostic assessment through the public system is only available to children aged 0-17 years, and only with referral by a paediatrician. While the Autism Association of WA provide Medicare bulk-billed diagnostic assessments for 18-30 year olds, this is only available in Perth, with a wait time of 12-24 months.

Further, the assessment is typically performed over three separate appointments, requiring people in regional and remote areas to travel to Perth on three separate occasions. Alternatively, the Autism Association of WA offer TeleHealth assessments. People have reported issues with this, as the diagnostician is unable to observe body language, and may not notice that the person being assessed is stimming.

For all other adults, there is no free pathway to autism diagnostic assessment available in Western Australia. The Medicare rebate for autism diagnostic assessment was extended to cover people aged 0-24 years in April 2023, along with a range of other disability types, however only autism was listed as a 'Complex Neurodevelopmental Disorder', requiring referral by either a paediatrician or a psychiatrist to access the rebate. In Western Australia there is an extreme shortage of both paediatricians and psychiatrists making this extremely difficult and costly to access. Medicare rebate on diagnostic assessment for all other disability types is available on referral by General Practitioner (GP), making diagnosis much more accessible.

The impact of having no access to free diagnostic assessment for adults cannot be understated. There are far too many undiagnosed adults who have been trapped on JobSeeker Allowance; often for many years; struggling to understand and manage mutual obligations, unsuccessful job application after job application, hospital admissions for worsening mental health...only to finally encounter a mental health professional familiar with autism who tells them they are autistic.

SWAN are often contacted by undiagnosed adults in such circumstances, and we are in the unfortunate position of having to explain that they are not formally diagnosed, and as such, ineligible for NDIS, the Disability Support Pension, or Disability Employment Services.

We are supporting adults whose mental health has been destroyed by lack of support and understanding and are in the position of causing further harm by explaining that there is no free diagnostic assessment available, and to be diagnosed they would have to pay \$1,800 - \$2,500. This cost is completely inaccessible for JobSeeker recipients.

## National Disability Insurance Scheme (NDIS)

The introduction and rollout of the NDIS has been life-changing for autistic children, teens and adults in Australia. Prior to the NDIS, there was minimal early intervention funding for diagnosed autistic kids prior to their 6<sup>th</sup> Birthday, and typically no funded supports available until after they turned 18yrs of age and were post-school. The NDIS changed this, enabling access to funded supports throughout the lifespan for formally diagnosed autistic people who meet the NDIS eligibility criteria.

Due to difficulties accessing autism diagnostic assessment, individuals and families experiencing financial hardship are unable to access reasonable and necessary funded supports through the NDIS for autistic children for up to 4 years, unless the developmental delay was identified before their child turned 6 years of age.

Individuals and families experiencing domestic violence, homeless and severe financial hardship are rarely connected to services able to identify these needs, or difficulties relating to autism may be incorrectly assumed to be trauma-related. As per the [NDIS Demographic Chart Data for Autism](#), the proportion of WA NDIS participants with a primary diagnosis of autism is only 9%. Data for South Australia matches this statistic, whereas New South Wales (30%), Victoria (27%) and Queensland (21%) all have significantly higher proportions of NDIS participants with a primary diagnosis of autism. Tasmania (2%), Northern Territory (1%) and ACT (2%) all have a very low proportion of autistic participants.

We note also that autistic children typically receive very low funding in their NDIS plans. For 7-14 year old autistic kids, we routinely see NDIS plans with Capacity Building – Improved Daily Activities funding only, with amounts between \$4,000 and \$11,000 per year, the average being around \$5,000. For context, \$5,000 per year equates to **less than one hour of therapy per fortnight**. It's well established that autistic children benefit from multi-disciplinary therapy, requiring Psychology and Occupational Therapy as a bare minimum, with many also requiring Speech Pathology and sometimes Physiotherapy. Autism is a spectrum condition, impacting each individual differently.

*“Delivery related to supporting a child’s development of functional skills in one or more developmental domains should involve practitioners with allied health and/or education qualifications that correspond with those domains (e.g., occupational therapy for enhancing participation and engagement in childhood occupations, physiotherapy for gross motor skills, psychology for cognition and mental health, speech pathology for communication).”* ([Autism CRC 2022](#))

For many autistic kids, repetition and consistency are vital for building skills, and this simply cannot be achieved with such low funding. Under-funding supports for autistic kids impacts long-term sustainability of the NDIS – autistic adults whose support needs were not met in childhood require substantially more support throughout their lifespan.

Since early 2021, autistic NDIS participants and families have reported increasingly negative experiences when dealing with NDIS, and as advocates this is something we have directly witnessed. Prior to 2021, the NDIS plan was built around the person. Now, the NDIS tries unsuccessfully to fit the person into the plan, and we continue to see significant problems regarding this issue. Too many NDIS representatives are still treating NDIS participants, families and supporters as being deliberately deceptive and fraudulent when requesting funded supports to meet their disability needs. There is a lack of respect for participants and their supporters. Reasonable and Necessary support requests are often dismissed without being recorded, and we have witnessed NDIS representatives gaslighting autistic

participants and supporters when stating the impact of the disability on their function. The default stance within NDIA and NDIS Partners in Community seems to be the assumption that autistic participants, nominees and/or supporters are over-exaggerating or lying about their needs. Participants and families frequently report highly adversarial meetings and interactions with NDIS representatives, and SWAN is often contacted by distraught people, particularly after negative planning and reassessment meetings. Planning, Review and Reassessment meetings need to be collaborative, as per the NDIS legislation.

The culture of prioritising cost cutting over the well-being of participants, introduced in 2021, continues to impact on NDIS Participants. Concerningly, *'should represent value for money'* continues to be prioritised over all other [Reasonable and Necessary criteria](#), when all criteria should be given equal consideration by delegates. There is a lack of recognition of human rights in decision-making, as evidenced by the NDIA's frequent practice of reducing or removing supports previously funded and needed by participants, and the reliance on undisclosed algorithms lacking in co-design, knowledge and understanding of disabilities to create Typical Support Package (TSP) plans. SWAN was recently advised that the TSP for participants with a primary diagnosis of autism level 2 aged 7-14 years is \$12,000 per year – which begs the question – why are we seeing so many NDIS plans funded substantially below the TSP (as little as \$4,000 per year), and rendering them effectively unusable? The funding amounts we see in NDIS plans for autistic participants aged 7-14 years are frequently in line with the amounts proposed in the NDIA's [Autism Consultation Paper](#) in 2021. [Submissions](#) on the Autism Consultation paper were overwhelmingly critical of the propositions in the Autism Consultation Paper (including [SWAN's submission](#)), and NDIA ultimately made the decision not to proceed with their proposed changes for autistic participants ([Interventions for children on the autism spectrum consultation summary report](#)). We note, however, that the release of the NDIA's Autism Consultation Paper coincides with autistic participants receiving significantly lower funding in NDIS plans.

Frequently SWAN staff see NDIS Plans bearing no resemblance to the supports discussed in the planning or reassessment meeting. It's apparent that much of the input of participants, their supporters and existing supports (including professional therapists) is often ignored. Too often we see NDIS plans featuring goals which do not reflect the goals requested by the participant and their supporters, breaching the NDIS Act 2013. We also commonly see that the 'About Me' section of the plan is rarely updated during plan reassessments, which means that the plan does not accurately represent the person and their current circumstances – increasing the issue of inappropriate plans. Another common issue is seeing copy and pasted plans, where a different participant's name appears in parts of the NDIS plan.

NDIS Representatives continue to assume that therapist recommendations are excessive in order to increase profits. These assumptions about therapist reports are particularly ludicrous when there remains an ongoing, national shortage of allied health professionals (particularly in regional and remote Australia), and most (if not all) therapy providers have either long waiting lists or have closed their books. In the south west region of WA, the wait time to access therapy providers ranges from 8 months to more than 3 years, depending on the type of therapist being sought and the age of the person. Further, **there is still no appropriate guidance, standard or format from the NDIA to therapists on how to write and present progress reports and Functional Capacity Assessment reports to be deemed acceptable evidence for NDIS to approve the recommended supports.**

Participants and families are frequently informed that they need to provide more evidence, but no information is given to explain what that evidence looks like, or how it should be phrased. It should also be noted that whilst NDIA commonly demand therapist reports as

evidence to support all requests for funded supports, the decision-makers within NDIA are typically bureaucrats with no allied health qualifications, and are rarely able to accurately understand or interpret reports by therapists. Since 2021, NDIS has been requiring extensive and expensive reports to justify **all** requested supports, and then consistently ignoring the recommendations made in these reports. Expensive reports are also being required to justify relatively inexpensive supports, as exemplified by the requirement of an OT Driver Assessment in order to approve funding for additional driving lessons for autistic participants.

The increase in demand for Occupational Therapist reports from NDIS representatives has significantly impacted on the availability of Occupational Therapists to provide actual therapy supports for participants. This is particularly concerning when NDIS representatives are routinely denying funding for other allied health supports such as Psychology, Speech Pathology and Physiotherapy – instead funding Occupational Therapy only. Many participants have been waiting 18mths to 3 years thus far to access an Occupational Therapist.

NDIS Plans are increasingly prescriptive in nature. It's extremely common to see NDIS plans stating Capacity Building – Improved Daily Activity budgets describing \$3,879.80 (20 hours) for Speech Pathology and \$4,849.75 (25 hours) for Occupational Therapy, for example. While the plans sometimes state that this budget is flexible, participants and families are often reprimanded at plan reassessment if they claimed Psychology to support their autistic child with developing emotional regulation and social skills, rather than Occupational Therapy as decided by NDIS. This is despite substantive evidence that Psychologists are the allied health professional to support autistic children in building the necessary skills in this area; with Psychology having been well established as the primary allied health support for autistic children, youth and adults for more than 30 years. It's necessary to emphasise here that Occupational Therapy is in such high demand due to being prioritised by NDIS over all other allied health professionals, that participants struggle to access this support.

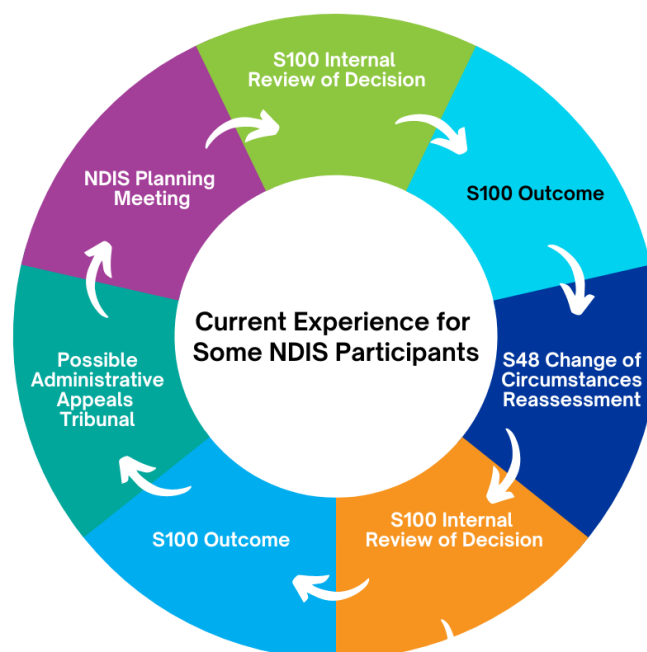
Prior to June 2021, participants and families who contacted SWAN primarily sought assistance with preparing for NDIS planning meetings and implementing their plan. Since July 2021, the most common reason people with disability and families have contacted SWAN has been to gain support to seek an Internal Review of Decision or Change of Circumstances Reassessment because they received insufficient funding in their NDIS plan to meet their needs – either due to the Typical Support Package being grossly inadequate for autistic children, or due to funding being cut. Many people experienced a 30-60% reduction in funding, and this issue is continuing to occur. A common issue we have seen at Reassessment, is a participant's 1 year plan being turned into a 2 year plan, with the funding remaining the same – that is a 50% cut to funding.

The largest funding cut we have seen was a reduction of 83%, which occurred in February 2023. The new plan was issued as a 3 year plan with only \$2,000 per year allocated in the Core and in the Capacity Building budget, for an autistic adult with co-occurring physical disabilities; the plan was essentially unusable. The 83% plan cut occurred because the NDIA delegate claimed there was no documentation in the participant's file, and they also ignored the previous NDIS plan expenditure of 97%. The participant's file contained 2 comprehensive Functional Capacity Assessments dated 2 years apart and 6 progress reports over the course of their 4 years as a NDIS participant. Despite formal complaint to NDIA and internal escalation to the NDIA's WA Participant Solutions Team, it took 4 weeks to rectify the plan.

NDIS systems and processes are overly complex, with each new amendment to processes increasing complexities, rather than simplifying or streamlining processes. Participants and families are trying to comply, but the rules and Operational Guidelines keep changing. Ask one NDIS representative, you get one answer. Ask another, and you get a different answer. Of note, a change was made to the NDIS Operational Guidelines for S100 Internal Reviews of Decisions which occurred approximately September-October 2021. NDIA removed the requirement for Internal Reviewers to contact participants or their nominees direct, and conduct the Internal Review **with** the participant.

In January 2022, we started to hear from NDIS participants and families who had received an outcome letter from the NDIA Internal Review team confirming the original decision, with no other contact from the agency. All but two of the people who contacted SWAN regarding this issue had already missed the deadline to submit an appeal to the Administrative Appeals Tribunal (AAT). Each person advised that they were so **devastated** by the outcome letter that they couldn't face yet another fight. In these circumstances we supported them to gather more evidence, and submit an S48 Change of Circumstances Reassessment. In each of these cases, the S48 was accepted, but the outcome was still less funding than was recommended in the Functional Capacity Assessment report. This led to supporting those people to then submit another S100 Internal Review of Decision request. **This is hardly an efficient use of the NDIA's resources.**

Whilst we are hearing that participants are more frequently contacted by the NDIA's Internal Review team to discuss their S100 request, in late 2022 – early 2023 a new issue emerged. SWAN are now supporting participants and families to submit S100 Internal Review of Decision requests after grossly underfunded plans were issued, and they are receiving outcome letters stating that the requested supports were not asked for during the original planning meeting, and the participant needs to submit an S48 Change of Circumstances Request. We have then supported the participant to submit an S48 Change of Circumstances Request, the participant has received a slightly improved plan, and SWAN have then supported them with another S100 Internal Review of Decision request.



We are aware of at least 8 cases to-date where this has occurred. The participant / nominee requested specific supports during the planning meeting, but the LAC did not forward these requests to the NDIA Delegate – a clear breach of the NDIS Act 2013. Again, this is not an

efficient usage of NDIA's resources, nor of advocacy and ILC funding. SWAN remind the Panel that we are a small, regional DPFO. If we have witnessed 8 cases of this occurring, this issue is likely to be significant.

## NDIS Operational Guidelines

The NDIA has created an external website for the NDIS Operational Guidelines at <https://ourguidelines.ndis.gov.au/>. There is no centralised, integrated menu for the more than 508 webpages located on the site (as at November 2022), and being an external website separate to the primary website of <https://www.ndis.gov.au/>, the site remains unknown to most NDIS participants and families., and incredibly difficult for autistic people to navigate and understand. Concerningly, however, participants and nominees are being expected by NDIA and NDIS Partners in Community to comply with Operational Guidelines which are overly complicated, and without being advised of their existence. NDIA continuously add to and alter the webpages at <https://ourguidelines.ndis.gov.au/>, with no notification being given to participants and families of changes occurring.

In an attempt to be able to locate relevant Operational Guidelines, SWAN's CEO spent 16 hours collating an Excel spreadsheet of the then 508 webpages. This time was entirely spent collating a list of the webpages, not reading the actual content. In order to track the changes made to the content, we are spending 3-5 hours each month using the search function on the website to date-search for new and altered webpages for that month. This is increasingly difficult and time consuming, as of November 2022 the search function will only search by month and year, not date, and only displays changed landing pages rather than new or changed sub webpages. Frustratingly, we were dedicating time to staying abreast of the extremely complicated Operational Guidelines in order to build the capacity of participants and families we support, but this is no longer practicable. Due to the extreme complexity, NDIS Partners in Community and NDIA Delegates are often less knowledgeable about these changes, or interpret the Guidelines inappropriately.

Examples of specific issues with the NDIS Operational Guidelines which negatively impact autistic participants we have identified to-date include:

### **When Would We Decide Not To Change Your Plan?**

<https://ourguidelines.ndis.gov.au/your-plan-menu/changing-your-plan/when-would-we-decide-not-change-your-plan>

Several statements in this Operational Guideline are both offensive to NDIS participants and families, and harmful in how they are interpreted by NDIS Partners in Community and NDIA Delegates.

*“If your request is only about wanting more funding, or supports that other participants have”*

The primary reason that autistic NDIS participants and families seek a Plan Reassessment or Variation is due to insufficient funding to meet their needs. Additionally, people new to the Scheme, and to having a disability, typically have limited knowledge about suitable Reasonable and Necessary supports to request at their planning meeting, and how much these supports cost. Commonly, people learn about funded supports to meet their needs and improve their quality of life through peer networks. The statement above implies that NDIS participants and families are unnecessarily seeking more funding, or are somehow greedy and jealous, rather than genuinely seeking the Reasonable and Necessary supports they need.

*“[If informal, community or mainstream supports can meet your needs]... would reasonably expect family or friends to do for you, such as short-term care if the family members who usually support you are sick.”*

The above statement is concerning in that NDIS Partners in Community and NDIA Delegates have increasingly been placing more responsibility on informal carers to provide the majority of support to participants. Consequently, they are reducing funded supports, particularly in the Core budget for children and adolescents, most of whom have little or no Core funding. For NDIS participants being cared for by a single parent with no extended family support, this typically means that if the parent carer is hospitalised, there is no one able to step in and care for the participant. With little or no Core funding, this also means that Short Term Accommodation cannot be used. This statement also neglects to consider the situation for single parents caring for multiple children with disability.

When single parents of children without disability become unwell (e.g. hospitalisation), extended family, friends or neighbours are sometimes willing to step in and provide care. For children, youth and adults with disability, there is often no one in the community who feels sufficiently confident and capable to step in and provide care. This is a Reasonable and Necessary support which should be the responsibility of NDIS.

We are especially concerned by how both statements are interpreted by NDIS Partners in Community, NDIA Delegates, and how these kinds of statements reflect the culture within the NDIS.

### **Leaving the NDIS – How much time will you have to give us more information?**

<https://ourguidelines.ndis.gov.au/home/becoming-participant/leaving-ndis/are-you-still-eligible-ndis/how-much-time-will-you-have-give-us-more-information>

This webpage refers to NDIS participants for whom the NDIA has decided to reassess eligibility for the scheme. Concerningly, this Operational Guideline states that the NDIA will *“usually give you 28 days from the date of our first letter, so you can explain if you think you meet the requirements. This will give you an opportunity to give us any extra information or evidence to help us make the right decision.”* As we have previously noted, wait times with all therapy providers and most medical practitioners are excessive, so allowing a mere 28 days to supply additional evidence of eligibility is unreasonable. In contrast, the [NDIS Participant Service Charter](#) states *“Allow sufficient time for prospective participants to provide information, after the NDIA has requested further information - 90 days”* for participants applying for Access to the scheme.

### **Would We Fund It – Swimming Lessons in Early Childhood**

<https://ourguidelines.ndis.gov.au/would-we-fund-it/improved-health-and-wellbeing/swimming-lessons-early-childhood>

Families of autistic children frequently request funding for the difference in cost between private and group swimming lessons. The reason for this request is because many autistic children are unable to learn the life-saving skills of swimming in group settings, and require private swimming lessons throughout the year, often ongoing for many years in order to learn and retain this vital skill. Many autistic children are drawn to water, have limited or no understanding of risk or protective behaviours, and many are ‘runners’. Autistic children are at a [significantly higher risk of drowning than their peers](#). Drowning accounts for 46% of all injury deaths among autistic children, which translates to 160 times the chance of dying from drowning compared with other children ([Autism Swim 2016](#)). Again, this Operational

Guideline is typically being interpreted by NDIS Partners in Community and NDIA Delegates as a blanket 'No' on funding the cost difference between private swimming lessons and group swimming lessons.

After the devastating [death by drowning](#) of a 6yr old autistic and non-speaking child in WA on 27/03/22, the SWAN CEO wrote to former NDIA CEO, Martin Hoffman, former NDIS Minister, Linda Reynolds, and then Shadow Minister Bill Shorten regarding the NDIA's Operational Guideline for funding of Swimming Lessons, and how it is interpreted and applied by NDIS representatives. Only Mr Hoffman responded.

Excerpt from Martin Hoffman's letter to SWAN dated 20/04/22 :

*"For the NDIS to fund the cost difference for a child to attend private swimming lessons compared with group swimming lessons, we would firstly need to understand how the child's disability directly impacts their ability to participant in group swimming lessons. We also need to know how private lessons will help the participant meet their goals, facilitate their social participation, and represents value for money in relation to both benefits of the support and the cost of similar supports. We must also consider what families and other informal supports would usually provide. You can learn more about this criteria in the reasonable and necessary guideline.*

*We recognise the importance for all children to have the chance to take part in group activities. Group swimming lessons are a social activity and promote vital water safety learning and development of skills in children. We would not typically fund private swimming lessons as swimming lessons are considered a day-to-day living cost. Everyone has to pay for them whether or not they have a developmental delay or disability. Australian parents and carers are responsible for the costs associated with making sure their children are safe in and around water.*

*If due to a child's disability, they cannot attend group swimming lessons, we might fund the developmental delay or disability-related supports or assistive technology to help the child have the same opportunities as their peers. This means we may cover supports the child needs to take part in swimming lessons or water safety awareness activities.*

*Reasonable adjustments can also be explored for swimming lesson options within the local area of the child. For example, any existing capacity building budget within a child's NDIS plan can be used to work with their early intervention team to develop and share strategies with a qualified swim instructor. This can help the child be included in swimming lessons in a group setting."*

Concerningly, in his response, the former NDIA CEO prioritised the benefits of participating in a group over learning to swim, and this Operational Guideline reflects this viewpoint. The purpose of swimming lessons is to **learn to swim in order to prevent drowning**. There are many other more suitable opportunities for children with disability to benefit from participating in group activities. Further, there is no acknowledgement in the former NDIA CEO's letter of our expressed concern that the guideline is being interpreted by most NDIS representatives that the cost difference between private and group swimming lessons is not to be funded.

## Would We Fund It – Mental Health Supports

<https://ourguidelines.ndis.gov.au/would-we-fund-it/improved-health-and-wellbeing/mental-health-supports>

Despite all case studies in this Operational Guideline describing participants with psychosocial disability, requests for funding for psychologists to support participants with Intellectual Disability, Autism and developmental delay are being routinely denied, both by NDIS Partners in Community and by NDIA Delegates. Participants with these diagnoses are instead told to visit their GP for a Mental Health Care Plan, disregarding the fact that these diagnoses are neuro-biological in nature, not mental illnesses. Moreover, they are not listed as eligible diagnoses under the Medicare funded Better Access Initiative. For autistic people in particular, psychology has been considered the primary therapy support for more than 30 years, yet NDIS are routinely denying this reasonable and necessary support.

These ‘Would We Fund It’ examples clearly show that codesign and expert disability advice were lacking in the development of the Operational Guidelines. **All** of the ‘Would We Fund It’ examples are problematic in nature, and it’s questionable as to whether they comply with the NDIS legislation (see examples in [Team DSC article](#)). They show a lack of expertise and understanding of the disabilities described, and a failure to take into consideration how the guidelines would be interpreted by operational staff. Overwhelmingly the 508 webpages describe scenarios that NDIS would **not** fund. There are very few case studies describing requested supports that NDIS approved, and only one webpage ‘What **does** NDIS fund’ which details the NDIS Reasonable and Necessary criteria before yet again detailing what the NDIS won’t fund. Particularly disturbing is the fact that most NDIA Delegates and NDIS Partners in Community are viewing the Operational Guidelines as rules, when many appear to be non-compliant with the NDIS legislation (as per evidence given by Naomi Anderson of [Villamanta Disability Rights Legal Service](#) to the Joint Standing Committee Hearing in Geelong on 17<sup>th</sup> November 2022).

Whilst there is a new senior executive team at the NDIA, and we welcome this change, these Would We Fund It Guides and Operational Guidelines remain in place.

## 4) National Roadmap to Improve the Health and Mental Health of Autistic People

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### Overview

Autistic individuals in Australia experience significantly poorer health outcomes than the general population; our overall comparative mortality rate is about twice that of the general population. (University of New South Wales, 2019)

Autistic people have a life expectancy 20-36 years shorter than the general population, with even more significant reductions for those with a co-occurring intellectual disability. Injury, poisoning, and nervous system disorders, such as intractable epilepsy, are the leading causes of death among autistic individuals, in contrast to the general population where cancer and circulatory diseases are more common. (Autism CRC, 2019)

In addition, autistic individuals are at a higher risk of attempting or dying by suicide, with rates significantly higher than the general population.

The risk of suicide is also magnified by the presence of co-occurring mental health conditions, including schizophrenia, depression, and anxiety disorders, which occur at heightened rates. Poor health outcomes in autistic individuals can be attributed to a combination of factors, creating a complex interplay that affects our overall well-being.

These health disparities are a cause for concern and highlight the urgent need for tailored healthcare and support services to address the unique healthcare needs of autistic individuals and reduce the health inequalities we face.

## A Rights Based Approach

Article 25 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD), of which Australia is a signatory, requires not only equal access to healthcare for people with disability but also access to healthcare that is tailored to an individual's disability.

Australia has a legislative responsibility to meet our obligations under the following articles:

### **Article 1: Equality and Human Dignity**

People with disability are equal in their humanness, deserving of rights, and hold equal value and worth. Human dignity is the foundation of all human rights, as recognised by the CRPD, which sees 'disability' as socially constructed and values 'impairment' as part of human diversity and dignity. This reaffirms equal human rights for people with disability.

### **Article 5: Non-Discrimination**

People with disability have the right to all human rights and freedoms without discrimination, equal treatment before the law, and equal benefits. Individualised support may be needed to exercise their rights and avoid discrimination. The CRPD acknowledges the diversity among people with disability and intersectional discrimination.

### **Article 10: Right to Life**

People with disability have an inherent right to life on par with others, provided with necessary healthcare and social services for survival. Arbitrary denial of healthcare based on impairment is prohibited.

### **Article 12: Equal Recognition Before the Law**

People with disability are equal before the law, with the right to exercise their legal capacity equally. They may need support to express their will and preferences, which should be based on personal choice, proportionate, and safeguarded. The right to make decisions about healthcare and treatment, without decisions made on their behalf, is emphasized.

### **Article 25: Right to Health**

People with disability should enjoy the highest attainable standard of health without discrimination, having access to quality healthcare and specialist services. Healthcare should be based on free and informed consent, with no discrimination in the provision of care, services, or food/fluids based on impairment.

### **Article 4: Participation of People with Disability and Their Representative Organisations**

People with disability, including children with disability through their representative organisations, should be actively involved in the development and implementation of

legislation, policies, and decision-making processes affecting them, especially in healthcare. (United Nations, 2007)

A 2020 Statement of Concern (Disabled Persons Organisations Australia, 2020) from Disabled Persons' Organisations, key decision-makers, and Disability Representative Organisations suggests the approach of adopting an ethical framework of human rights principles in healthcare.

### **Framework of human rights principles for ethical decision-making**

1. Health care should not be denied or limited to people with disability on the basis of impairment.
2. People with disability should have access to health care, including emergency and critical health care, on the basis of equality with others and based on objective and non-discriminatory clinical criteria.
3. Health care should not be denied or limited because a person with disability requires reasonable accommodation or adjustment.
4. Health care should be provided on the basis of free and informed consent of the person with disability.
5. Health care should not be denied or limited based on quality-of-life judgements about the person with disability.
6. Ethical decision-making frameworks should be designed with close consultation and active involvement of people with disability and their representative organisations.

SWAN believes that this framework is appropriate and necessary for autistic individuals to receive equitable treatment in healthcare. We further note the current discussion around a Disability Rights / Human Rights Act in the wake of the Disability Royal Commission and believe that equitable healthcare rights should be included as a critical part of this approach.

## **Key Issues**

In Australia, the difficulties in obtaining accessible and inclusive healthcare for autistic individuals stem from a range of key factors.

The barriers are relevant to both health and mental health sectors and include attitudinal, environmental, and systemic barriers.

### **Attitudinal barriers**

#### **Failure to recognise characteristics of autism**

Healthcare providers often lack awareness of the social and communication skills exhibited by autistic individuals at the point of access or during treatment. A common issue occurs when autistic people's expression of pain is assumed to be behavioural in nature, leading to autistic people experiencing abscesses under their teeth, burst appendix or other severe medical crisis before medical care is provided. This knowledge gap acts as a barrier to help-seeking and accurate diagnoses, leading to inadequate, delayed or inappropriate treatment.

#### **Stigma, discrimination, and exclusion**

Stigma and discrimination act as barriers to equitable mental healthcare access for autistic people. This is compounded when autistic individuals belong to other population groups that also experience stigma and discrimination, such as Aboriginal and Torres Strait Islander

peoples, people from culturally and linguistically diverse backgrounds, and Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual (LGBTQIA+) people.

### **Co-occurring diagnoses**

Autistic individuals often experience a range of both physical and mental health conditions. Epilepsy, ADHD, Ehler's Danlos Syndrome, Hypermobility Spectrum Disorder, Dysautonomia, gastrointestinal problems, eating disorders and autoimmune conditions are common co-occurring health conditions. Rates of self-harm, suicidality, and psychiatric conditions like schizophrenia are higher among autistic people.

Note: Dual diagnosis is a term which is used interchangeably in some mental health settings as people who present with mental health support needs and alcohol and other drugs (AOD) support needs or people who have a diagnosis of autism plus a mental health condition.

### **Diagnostic overshadowing**

Diagnostic overshadowing is a phenomenon in healthcare and psychology where a person's physical or mental health condition is not accurately diagnosed or treated because their symptoms are mistakenly attributed to another disability they may also have, especially when that disability is more visible or prominent. This can lead to healthcare professionals overlooking or misinterpreting new health issues, which may result in delayed or inadequate treatment for the individual.

For example, if a person with a developmental disability presents with physical symptoms like pain or discomfort, healthcare providers might dismiss these symptoms as part of the individual's disability without conducting a thorough evaluation. A difficulty with verbal communication may be attributed to the person's autism diagnosis, rather than a hearing test being performed to identify an underlying hearing loss, for example. As a result, potentially serious health problems, as well as issues for mandatory reporters such as detecting sexual or other abuse, could go undetected and unaddressed.

## **Systemic barriers**

### **Systemic barriers to diagnostic services and treatment**

There are systemic gaps in providing care to autistic individuals, resulting in delayed diagnoses and inconsistent management approaches. Anxiety, fear of stigmatisation, and negative past healthcare experiences further hinder access to care.

These barriers are compounded when autistic individuals experience other systemic barriers due to their language, race, or gender.

There are also systemic barriers through intersecting systems, including disability systems like the National Disability Insurance Scheme. For example, provision of support through NDIS systems in hospital is often refused on the basis that it is 'duplication of support' or the responsibility of the hospital.

The NDIS's Operational Guidelines state that support will not be provided because it is 'likely to more appropriately given by the health system'. (National Disability Insurance Scheme, 2021) However, this is ineffective, given the current hospital crisis, the distinction between disability support needs and nursing and that the most effective support provided to an autistic person is by somebody who is familiar with the person and understands both support needs and communication style.

## **Delayed autism diagnoses in adulthood**

Autism diagnoses can occur later in life, relying on memory, access to medical records, and family support for developmental and medical history. Various factors, including geography, poverty, attitudes toward race or gender, diagnostic overshadowing, linguistic diversity, family history of diagnosed or undiagnosed disability, etc, can contribute to delayed diagnoses.

## **Accessibility to Telehealth**

The revised Telehealth guidelines, which came into effect in September 2023, (AHPRA, 2023) state that 'prescribing or providing healthcare for a patient without a real-time direct consultation, whether in-person, via video or telephone, *is not good practice and is not supported by the Board*' and that '*is not appropriate for all medical consultations and should not be considered as a routine substitute for in-person consultations.*'

These guidelines are of concern for autistic individuals living with limited support, funding, or access to transport, especially those in regional and remote areas. Autistic people are also far more likely to experience both social anxiety and agoraphobia.

A study in 2020 that investigated the prevalence of agoraphobia and social phobia in autistic adults without intellectual disability in Australia found that 23% of the participants had agoraphobia. According to the data, this means that the ratio of agoraphobia rates between autistic and non-autistic individuals in the study was 13:3. (Nimmo-Smith, et al., 2019)

## **Availability of general practitioners**

In some regions of Australia, there is no access to general practitioners due to regional shortages and the way that government identifies the need to resource an area.

The Royal Australian College of General Practitioners (RACGP) says that rural regions which are of lower socio-economic status are being disadvantaged by the way the Australian government identifies significant doctor shortages, while some wealthy areas are being classified as needing extra resources. (May, 2023) In addition, it is difficult to attract and retain medical staff for regional postings, especially in the midst of a pandemic and during a medical workforce shortage.

As per a report from Cornerstone Health, (Cornerstone Health, 2022) the shortage of General Practitioners (GPs) in Australia has reached a critical level. They predict that by 2032, there will be a deficit of 11,392 (28%) full-time GPs.

This shortage is exacerbated by the expected increase in demand for GP services, which is estimated to surge by 38.5% from 2021 to 2032, mainly due to population growth and aging. Major cities will experience the most significant spike in demand, projected at 47%. The report further states that demand for GP services is estimated to increase between 2021 and 2032 by 38.5% with a growing and ageing population. This growth in demand for GP services will be most pronounced in major cities, where it is predicted to grow by 47%. Full-time equivalent (FTE) GPs in major cities is projected to decrease over the next ten years by 15%.

The National Autism Strategy cannot be expected to remedy this issue. However, it should recognise the complexity of having to navigate a complex, costly and under resourced healthcare landscape – especially for those who need support in our daily lives and who often live with poverty. Understanding the difficulties presented for autistic individuals in accessing healthcare in 2023 must include recognition that the healthcare landscape has changed.

### **Lack of training by healthcare providers**

The lack of awareness and training among healthcare providers regarding the specific healthcare needs of individuals with autism has been identified in many studies as a key contributor to barriers to healthcare.

Research has shown that autistic adults face barriers including a lack of physician / provider knowledge and formal training, which can lead to difficulties in establishing rapport and implementing appropriate communication strategies with their autistic patients. (Bruder, Kerins, Mazarella, Sims, & Stein, 2012)

Healthcare providers report challenges in communicating with their autistic patients, which can lead to difficulty in establishing rapport and implementing appropriate communication strategies. (Zerbo, Massola, Qian., & Croen, 2015)

This knowledge gap can lead to the misinterpretation of behaviours or communication difficulties, resulting in misdiagnoses or inadequate care.

There is no specific requirement for neurodiversity awareness training within the training requirements for healthcare providers in Australia. While the importance of neurodiversity awareness in healthcare settings has gained recognition and understanding in recent years, it hasn't yet become a standardised part of training.

SWAN acknowledges the challenging task of developing and maintaining qualifications at both postsecondary and tertiary levels. Consideration should be given to the need for changes at the employer level, making it standard practice for providers to possess an up-to-date Disability Access and Inclusion Plan or Disability Inclusion and Action Plan (DAIP or DIAP) as well as employees undergoing annual training as part of their ongoing professional development. This would be similar to the way we routinely undergo annual training on subjects like cultural awareness or child protection.

### **Lack of research and data collection around mortality**

A body of work on data collection, including in mortality, has been compiled by UNSW (Trollor & Saloman, 2019), for example, giving consideration to how deaths of people with disability could be better flagged within the National Coronial Information System (NCIS) database. Autistic individuals have one of the lowest life expectancies in this country – without collecting accurate data around mortality, we will not understand and learn lessons about the causes of preventable deaths for autistic individuals.

## **Environmental barriers**

### **Environment**

Healthcare settings, such as hospitals and emergency departments, can be extremely challenging for autistic individuals. Factors like bright lights, loud noises, and other sensory stimuli often lead to heightened anxiety, distress, and sensory overload, making healthcare visits more complicated. (Amaze, 2018)

Navigating these environments is additionally complicated by the absence of a dedicated liaison person who understands autism and the specific needs of autistic individuals.

This gap is particularly noticeable in 2023, when the healthcare workforce is largely composed of casual employees. (Gilfillan, 2021)

## **Accessible communication infrastructure**

Many autistic individuals find it difficult to understand important information if it is couched in highly technical or non-literal language, or delivered in a way that is inaccessible to us. To address this, it's essential to consider visual cues and structural supports, such as infrastructure like whiteboards for visual prompts, accessible information, support for augmentative and alternative communication (AAC), and easy-to-understand materials.

## **Impact of the COVID 19 pandemic**

The pandemic has had a significant impact on Australia's healthcare and hospital systems (Australian Institute of Health and Welfare, 2023), preventing access to treatment, especially emergency treatment.

Autistic individuals are far more likely to access emergency departments, with the average number of emergency department encounters being approximately 30% higher for children with ASD, 70% higher for teens with ASD from ages 15 to 18, and twice as high for adults with ASD<sup>2</sup>. (Organization for Autism Research, 2019) This is linked in part with communication difficulties and difficulties with interoception (ability to recognise and interpret the internal workings of the body), as well as pain symptoms in autistic people being misinterpreted by care-givers and professionals as behavioural in nature. These and other difficulties result in medical treatment being delayed until the autistic person is experiencing a medical emergency.

## **Other barriers**

### **Socioeconomic disadvantage**

Cost is also a significant factor – there is currently no national approach to diagnosis, resulting in burdensome and expensive pathways to treatment in states like Western Australia. The cost of an adult diagnosis is prohibitive (\$1800-\$2,500, on average).

A recent study by Emerald Insight found that many autistic adults in Australia are financially disadvantaged. The mode of income levels is below AU\$25,000, which is substantially lower than the mean annual Australian full-time income of AU\$89,123 34. (Cai, Gallagher, Haas, Love, & Gibbs, 2022)

### **Co-occurring intellectual disability (ID)**

Autistic individuals with ID face additional challenges in accessing services, compounding their disadvantage in health outcomes and service access. They include diagnostic overshadowing by clinicians, communication barriers and reliance on disability service providers to ensure timely access to healthcare.

### **Communication**

Another significant issue for autistic individuals accessing healthcare is communication challenges.

Many autistic individuals face difficulties in effectively expressing their health concerns, whether they are speaking or non-speaking communicators.

A key aspect of this problem can be attributed to the failure to uphold communication rights. This failure may occur due to various factors, such as limited access to augmented and alternative communication (AAC), inadequate service provision, or insufficient funding through NDIS or other disability support systems. While AAC is typically unique to each individual, access to visual communication systems and strategies in health care settings is sorely lacking. Where an autistic patient presents to health care settings without their

personal AAC system, there is high risk of the person's medical needs being misinterpreted due to lack of communication access.

### **Dental Care**

Many autistic children, adolescents and adults experience difficulties with dental care, which can seriously impact their physical health. Due to sensory difficulties, maintaining dental hygiene on a daily basis is a common area of difficulty. This is exacerbated by difficulty accessing dental treatment due to:

- Prohibitive costs – a higher proportion of autistic people and families are living in poverty than the rest of the Australian population.
- Sensory difficulties – many autistic people struggle to cope with dental treatment, and may avoid.
- Reluctance by dentists and orthodontists to provide dental and orthodontic treatments to autistic people due to assumed 'difficulties' about treating autistic patients.
- Access to general anaesthetic to enable dental care and treatment for autistic and intellectually disabled people requiring this option. General anaesthetic for dental care is only available in hospital, and typical at high out-of-pocket cost to autistic people and families (approximately \$2,000-\$4,000 per occasion). Further, general anaesthetics for dental care are not prioritised by hospitals, which can lead to autistic people experiencing debilitating dental pain for weeks, months or years without treatment.

### **Healthcare transition**

Autistic adolescents and adults often face challenges when transitioning from paediatric to adult healthcare services, leading to interruptions in care and decreased continuity.

### **Additional barriers**

Accessing healthcare can be difficult due to barriers like transportation challenges and access to funding, disability care and support, especially for those in congregate environments and/or without formal support.

## **Mental Health**

The need for psychology supports for autistic individuals has been recognised as the primary support for decades. However, in 2021 the National Disability Insurance Agency updated its Operational Guidelines to add a policy on mental health supports for people with psychosocial disability. While autism is not a psychosocial disability, this policy is consistently being interpreted by NDIA delegates and Local Area Coordinators alike as a blanket 'No' on funding psychology supports for autistic people. Likewise, Autism is not a diagnosis eligible for a GP Mental Health Care Plan. In most cases, the need for psychology supports are entirely due to the difficulties an individual experiences as part of their autism diagnosis:

- Difficulties recognising, understanding and regulating emotions
- Difficulties with theory of mind (understanding that other people have a different perspective, experience, thoughts and feelings)
- Difficulties with sensory regulation, including difficulties with interoception (recognising, interpreting and responding to the internal workings of the body)
- Difficulties with expressive and receptive communication
- Difficulties with executive function, organisation, problem-solving and decision-making
- Autistic burnout, meltdown and shutdown

The above difficulties compound to trigger the fight~flight~freeze response of the sympathetic nervous system, in the same way that anxiety does. It's clear that these difficulties are directly due to the individual's autism diagnosis, and thus the responsibility of NDIS to fund. However, NDIS representatives routinely deny funding for psychology supports to autistic participants, or where funding is approved, participants are instructed to use the GP Mental Health Care Plan first, then claim the small number of NDIS funded psychology hours after that. Note that the purpose of the psychology supports is for capacity building skills, which according to the [APTOS Principles](#) is the responsibility of NDIS. Autism is not a curable medical condition and is not a psychosocial disability – autism is a neurobiological condition, and thus does not fall under the remit of the Medicare Mental Health Care Plan.

“The NDIS will be responsible for supports required due to the impact of a person's impairment/s on their functional capacity and their ability to undertake activities of daily living. This includes “maintenance” supports delivered or supervised by clinically trained or qualified health professionals (where the person has reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) and integrally linked to the care and support a person requires to live in the community and participate in education and employment.” (APTOS Principles p. 3)

“The NDIS will be responsible for ongoing psychosocial recovery supports that focus on a person's functional ability, including those that enable people with mental illness or a psychiatric condition to undertake activities of daily living and participate in the community and in social and economic life. This may also include provision of family and carer supports to support them in their carer role, and family therapy, as they may facilitate the person's ability to participate in the community and in social and economic life.” (APTOS Principles p. 6)

In addition to the areas of difficulty experienced by autistic people living in a predominantly neurotypical society, there is a high prevalence of mental health problems and co-occurring mental illness in autistic individuals. Contributing factors impacting the mental health of autistic people include:

- Delayed or no access to diagnosis, and correlated delay in access to relevant supports
- Discrimination and stigma against autistic people
- Bullying, violence, abuse and neglect of autistic people, resulting in post-traumatic symptoms
- Barriers and lack of access to:
  - Quality, effective supports
  - Employment
  - Education
  - Health care
  - Mental health care
  - Financial / income support

When diagnosed autistic people seek access to mental health services, they are commonly denied access. Public funded mental health services such as Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services routinely deny service provision to autistic people, redirecting them to NDIS or to autism peer support organisations such as SWAN. As a further barrier, CAMHS and AMHS no longer accept referrals from private psychologists or Headspace, requiring that psychologists refer patients back to their GP in order for the GP to refer them to the public mental health service – delaying access to crisis mental health care and at additional expense to the patient. When autistic people

experience a mental health crisis, their presentation and affect is often quite different to neurotypical individuals experiencing mental health crisis, and this is often misinterpreted by mental health clinicians, health professionals and police. Exacerbating the difficulties autistic people face when attempting to access mental health supports, the environment of these services are not accessible. There is an over-reliance on verbal communication, intake forms are complicated and bureaucratic, and the environment itself is inaccessible, with harsh fluorescent lighting (which buzzes and flickers), loud, busy and echoing spaces and a lack of visual communication strategies. An overwhelmed autistic person experiencing a mental health crisis is very likely to experience situational mutism, or experience severe difficulty understanding and responding to questions and instructions.

Many undiagnosed autistic adults experience mental health crises due to lack of appropriate support, understanding and self-awareness. They try to undertake daily life in a neurotypical way, with a brain that's wired differently. This leads to severe autistic burnout and huge impacts on mental health and wellbeing. If health, allied health and education professionals were able to identify autism early, this outcome is entirely preventable. Whether diagnosed or undiagnosed, all autistic people have experienced trauma, and a large portion have post traumatic symptoms. It's unfortunately common for autistic adults, especially autistic women and non-binary people to be misdiagnosed with Borderline Personality Disorder by mental health professionals, before eventually being identified as autistic. Better training is needed for health and mental health professionals in the early stages of their training and career to enable them to identify, appropriately support and refer autistic people.

Where autistic people are experiencing a mental health crisis, in-line with the APTOS Principles, responsibility for providing mental health crisis care lies with the State-based mental health services. In the south west region of Western Australia, these are:

- [Child and Adolescent Mental Health Service \(CAMHS\)](#)
- [South West Mental Health Service \(SWMHS\)](#)

The reality, however, is very different. SWAN are frequently contacted by autistic people and families desperately seeking access to crisis mental health support for suicidal ideation, Non Suicidal Self Injury (NSSI) and other severe mental health conditions such as psychosis. When contacting or being referred to CAMHS or SWMHS, autistic people are routinely denied access to both services and redirected by staff to NDIS and to SWAN. Please note that SWAN is not a counselling service, we are funded for Information, Linkages and Capacity building (ILC) supports only.

When the same people contact NDIS seeking increased funding to meet the autistic person's increased support needs due to the mental health crisis they are experiencing, NDIS deny funding, and redirect them to public funded mental health supports or to their GP for a mental health care plan. Autistic individuals and families are pinged back and forth between NDIS and mainstream mental health services repeatedly, being denied access and support by both. It's quite common for autistic children, adolescents and adults to be referred to CAMHS or SWMHS as many as 5-8 times before obtaining a service intake meeting, only for the service to triage after the consult and refer the person back to NDIS and SWAN yet again.

Recently SWAN was contacted by the parent of a 27 year old undiagnosed autistic person experiencing mental health crisis and severe suicidal ideation. Staff met with both, and learned that they had been referred to SWMHS multiple times, but had been denied access on the assumption that they were autistic. They also presented to the Emergency Department at the hospital in mental health crisis. Due to difficulties communicating while in crisis, and hospital staff not directly asking key questions about their mental health, they

were sent home. Both SWMHS and the hospital Emergency Department referred them to SWAN. We reiterate, SWAN is unable to provide mental health supports or diagnostic services. Our role is peer support. A 27 year old man living in south west WA was denied access to mental health crisis care on the assumption that they were autistic.

## Intersectionality

There is a firm relationship between being a member of the LGBTIQ+ community and being autistic. There are a number of implications around this when it comes to mental health and autism – for example, we know that people who belong to the LGBTIQ+ community are exceptionally marginalised and experience hate crime, bullying, vilification and abuse.

Consequentially, there is a higher risk of suicide - A study by the University of Melbourne found that 43% of transgender Australians had attempted suicide<sup>1</sup>, and a systematic review and meta-analysis found that suicidality is highly prevalent in both autistic and possibly autistic people without co-occurring intellectual disability<sup>2</sup>. The review also found higher prevalence of suicidality in autistic people who are transgender and gender non-conforming compared to those who are cisgender<sup>2</sup>.

For autistic people, who already have a higher rate of suicidality than the general population, the risk is compounded. The risk of exclusion, bullying, hate crime, and harassment is doubled and amplified. In addition, hate crimes against transgender members of the community are on the rise. In Australia, we have no way to adequately measure the number of hate crimes carried out against members of the community – we are one of the few Western countries not to have legislation protecting us from hate crime and hate speech. However, self-reporting, surveys and overseas studies indicate that the current trend is escalating.

In brief;

- In America, FBI data reveals a **13.8 percent increase** in hate crimes based on sexual orientation and a striking **32.9 percent surge** in those targeting gender identity compared to the previous year<sup>1</sup>.
- The number of transgender hate crimes recorded by police forces in England, Scotland, and Wales has risen by **81%**<sup>3</sup>.
- In Australia, advocates for the transgender community have reported a new wave of hate crimes<sup>1</sup>.
- A study found that 72% of LGBTIQ people in Australia had experienced verbal abuse, 41% threats of physical violence, and 23% physical assault<sup>2</sup>.
- Research showed 60% of transgender people in Australia have experienced verbal abuse and one in five had experienced physical abuse because they are trans<sup>3</sup>.
- The Law Council of Australia concluded that hate crimes are “a common occurrence throughout Australia”<sup>4</sup>.

The intersection between hate crime and being members of multiple marginalised communities is rarely explored but is well documented. For example, the victims of Snowtown were both members of the LGBTIQ+ and disability communities.

In terms of point of diagnosis and referral, there are few existing relationships between mainstream autism peer support groups and LGBTIQ+ groups, despite the high prevalence of both. There is a missed opportunity to cross refer services in many states, both to clinicians, to specialist mental health support and to advocacy and peer support organisations. In addition, mainstream violence prevention agencies and organisations as well as refuges do not have good relationships or understanding of the needs of autistic

individuals. The gaps between health, mental health, disability and community support are ringfenced so thoroughly that it can be hard to ensure a cross disciplinary approach.

Other forms of intersectionality include being a First Nations or CALD autistic person, where there may be additional considerations around understanding cultural barriers from both a cultural and disability standpoint, or being a regional or remote person.

One of the most difficult areas to address in mental health is 'co-occurring disability' and approaches by both the disability and mental health sectors. It is easy for the mental health sector to dismiss the needs of autistic people as resulting from having a mental health condition – conversely, there is a tendency for the disability sector to dismiss mental health issues, or use diagnostic overshadowing to dismiss the signs of trauma or other serious mental health conditions.

## Co-occurring disability

One of the oft-raised and concerning issues for autistic individuals is that many of us have a co-occurring diagnosis and because of the lack of a multi-disciplinary approach, our needs are not met in either psychiatric or disability care.

This becomes especially complicated when the person has additional complex needs and/or is non-speaking, with or without an intellectual disability.

Conditions where other health, medical and psychiatric conditions include the following;

- **Epilepsy:** The prevalence of epilepsy in individuals with ASD varies, with studies suggesting it's present in 5-46% of individuals. (Sources: Amiet C, Gourfinkel-An I, Bouzamondo A, Tordjman S, Baulac M, Lechat P, Mottron L, Cohen D. Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biol Psychiatry*. 2008 Oct 1;64(7):577-82. doi: 10.1016/j.biopsych.2008.04.030.)
- **Schizophrenia:** While exact prevalence rates are not readily available, it's known that individuals with ASD may also have an increased risk of schizophrenia. (King BH, Lord C. Is schizophrenia on the autism spectrum? *Brain Res*. 2011 Mar 22;1380:34-41. doi: 10.1016/j.brainres.2010.11.031.)
- **Intellectual Disabilities:** Around 31% of people with a diagnosis of autism also have an intellectual disability<sup>1</sup>.
- **Mental Health Conditions:** Research from Monash University estimates that around 66% of people with an autism diagnosis are currently co-living with a mental health disorder, and up to 81% will live with a mental health disorder at some point in their lifetime<sup>1</sup>.
- **ADHD:** Autism and ADHD share some common characteristics. Many autistic children have behavior that's very similar to ADHD, and 30-80% meet the criteria for an ADHD diagnosis<sup>2</sup>.
- **Anxiety:** Anxiety is common in autistic children, and 40-60% of autistic children have anxiety<sup>2</sup>.

- **Depression:** is a common co-occurring condition with Autism Spectrum Disorder (ASD). According to Autism Spectrum Australia (Aspect), at least **50%** of Autistic adults experience mental health issues like anxiety or depression<sup>1</sup>.
- **Psychosis:** The prevalence of psychosis in individuals with ASD is a topic of ongoing research. One analysis of 14 studies found an average of **9.5%** of individuals diagnosed with Autism Spectrum Disorder to also have a psychotic disorder<sup>1</sup>. Another study found that the pooled prevalence of psychotic experiences in autism spectrum disorder was **24%**<sup>2</sup>. It is clear that psychosis is significantly lower in the general population (the rate is at around **0.5%**). This suggests that individuals with ASD may have a higher risk of experiencing psychosis compared to the general population.

There are also a number of developmental conditions that are considered to be co-occurring with autism, including Down syndrome and Fragile X syndrome. Recent estimates suggest that the prevalence of autism in individuals with Down syndrome is much higher than previously thought, ranging from **16% to 42%**<sup>1</sup>. Another source suggests that up to **40%** of children with Down syndrome are also Autistic<sup>2</sup>.

Studies suggest that the prevalence of ASD in individuals with Fragile X Syndrome is much higher than previously thought, ranging from **16% to 42%**<sup>12</sup>. Another source suggests that up to **50%** of males and nearly **20%** of females with FXS also have ASD<sup>2</sup>.

These conditions present additional challenges for non-inclusive health settings and autistic patients often have poor outcomes as a result. There are serious implications, also, for people with co-occurring mental health and disability if psychosocial disability is ‘outsourced’ from the National Disability Insurance Scheme – what, then, for those whose disabilities and mental health conditions are so closely intertwined that they are impossible to separate?

The historical issues faced by these populations in systems like the National Disability Insurance Scheme should teach us valuable lessons, where people’s cumulative needs are not met because they have been forced to ‘choose a primary disability’.

## Other Cross-overs

### Autism and Eating Disorders

The link between autism and eating disorders is well established. Autism Spectrum Disorder (ASD) and eating disorders represent two distinct diagnostic categories, each with its unique set of characteristics. However, recent research has highlighted a significant overlap between these two conditions, particularly in terms of prevalence and shared traits<sup>123</sup>.

In Australia, research suggests that 20-30% of adults with eating disorders are Autistic<sup>2</sup>. Another study found that one in four people with an eating disorder also have autism traits<sup>1</sup>. These figures underscore the significant overlap between ASD and eating disorders.

The overlap between ASD and eating disorders can be attributed to several factors. Sensory differences related to food, including not recognising hunger or fullness (known as interoception), can contribute to the development of eating disorders in Autistic individuals<sup>2</sup>. Food, counting calories, and exercise can become an intense interest or obsession, or be used to manage general anxiety levels<sup>2</sup>.

Moreover, the rigid thinking patterns often associated with autism can contribute to the development of strict rules around eating, which is a common characteristic of many eating disorders<sup>4</sup>. Additionally, social communication difficulties inherent in ASD might exacerbate feelings of isolation or misunderstanding, potentially leading to disordered eating as a coping mechanism<sup>4</sup>.

Diagnosing eating disorders in Autistic individuals can be challenging due to the overlap in symptoms. For instance, restrictive eating behaviours could be attributed to sensory sensitivities common in ASD rather than anorexia nervosa<sup>4</sup>. Therefore, healthcare providers need to consider the individual's overall context, including their diagnosis, when assessing for eating disorders.

Moreover, standard diagnostic tools for eating disorders may not capture the unique ways these conditions manifest in Autistic individuals. Therefore, there's a need for more autism-informed diagnostic tools and assessment strategies<sup>5</sup>.

Treatment approaches should be tailored to address the unique needs of Autistic individuals with eating disorders. This includes considering food and sensory sensitivities, social communication challenges, and rigid thinking patterns. Incorporating elements of social skills training and sensory integration therapy into traditional eating disorder treatments may enhance their effectiveness for this population<sup>5</sup>.

## **Autism and LGBTIQ+**

The link between being a member of the LGBTIQ+ community and being autistic is well established. These intersectional identities mean that those members of both communities are more at risk for a number of issues, including suicide.

Some studies reveal;

### **Autism and Being Transgender**

- People who do not identify with the sex they were assigned at birth are three to six times as likely to be autistic as cisgender people<sup>1234</sup>.
- A study suggests that autistic people report higher rates of non-cisgender identities, and gender diverse folks self-report higher rates of autistic traits<sup>2</sup>.

### **Autism and Being a Member of the LGBTIQ+ Community**

- Autistic adults and adolescents are approximately eight times more likely to identify as asexual and 'other' sexuality than their non-autistic peers<sup>6</sup>.
- Current research indicates that autistic people have higher rates of LGBT identities and feelings than the general population<sup>7</sup>.

## **Issues in Mental Health Settings**

### **Restrictive practices**

Autistic people are extremely likely to be subjected to restrictive practices in a variety of settings, including schools, disability services, supported accommodation and group homes, hospitals, mental health facilities, and prisons<sup>1</sup>. However, the exact number of autistic people subjected to these practices is not readily available.

In terms of the broader disability population, the NDIS Quality and Safeguards Commission reported 302,690 unauthorised uses of restrictive practices for 2019/2020<sup>2</sup>. In the past three

years, the number of reports of unauthorised restrictive practice has increased five-fold – from almost 290,000 in 2019-2020, to 1.4 million in 2021-2022<sup>3</sup>.

It's important to note that these figures include all disabilities, not just autism. Also, these numbers represent reported instances of restrictive practices, not the number of individuals affected.

SWAN welcomes the following recommendations by the Disability Royal Commission;

*State and territory governments should immediately:*

- *Adopt the list of prohibited forms of restrictive practices agreed by the former Disability Reform Council in 2019 and provide that the use of seclusion on children and young people is not permitted in disability service settings.*
- *Provide that the following are not permitted in health and mental health settings:*
  - *using seclusion and restraint as a means to reduce behaviours not associated with immediate risk of harm*
  - *using seclusion and restraint as a form of discipline, punishment or threat*
  - *restrictive practices that involve or include deliberate infliction of pain to secure compliance*
  - *using prone or supine holds, using any restraint intended to restrict or affect respiratory or digestive function, or forcing a person's head down to their chest*
  - *secluding a person who is also mechanically restrained*
  - *secluding a person who is actively self-harming or suicidal*
  - *using metal handcuffs or hard manacles as a form of mechanical restraint (unless under police or other custodial supervision while in the health facility)*
  - *vest restraints for older people*
  - *neck holds*
  - *drugs, or higher doses of drugs, that create continuous sedation to manage behaviour*
  - *seclusion of children and young people*

Differences in approach, definition and setting dictates how restrictive practices are defined, how data is collected and how the issue is addressed. For example, the Australian Institute of Health and Welfare reports that during 2020–21 there were **19,690 physical restraint events** and **1,108 mechanical restraint events** in mental health care<sup>1</sup>. This is aside from chemical restraint, which is administered routinely to people in a number of disability and psychiatric settings.

For example, Risperidone is often prescribed to autistic people in Australia to manage behaviours of concern, even in the absence of a formal psychiatric diagnosis<sup>1</sup>. This practice is considered a form of chemical restraint<sup>2</sup>.

The NDIS Quality and Safeguards Commission has prepared an evidence summary on the use of Risperidone for behaviours of concern in children, adolescents, and adults with autism<sup>1</sup>. The summary provides the most up-to-date research evidence on the benefits and harms of Risperidone when it is used to manage 'behaviours of concern' in individuals with ASD<sup>1</sup>. The behaviours of concern include irritability, aggression, and behaviours that result in self-injury<sup>1</sup>.

The evidence summary found that Risperidone reduced 'behaviours of concern' by around **30%** in the short term<sup>1</sup>. However, they were not able to make any conclusions about the benefits and harms of Risperidone use in adults with ASD as the clear majority of participants in these trials were under the age of 18<sup>1</sup>. Side effects were reported in people

receiving Risperidone, including sedation, raised heart rate, tremor, increased weight, excessive salivation, and constipation<sup>1</sup>.

A study published in *BJPsych Advances* discusses psychotropic medication prescribing in people with autism spectrum disorders with and without psychiatric comorbidity<sup>3</sup>.

Another study published by MDPI states that there is currently no registered clinical trial of Risperidone that has provided evidence for its use in treating the core ASD signs and symptoms in children<sup>4</sup>.

The Victorian Office of the Senior Practitioner estimates that **10–15%** of persons with disability will show ‘behaviours of concern’ and between **44–80%** of them will be administered a form of chemical restraint in response to the behaviour<sup>2</sup>. Reports suggest that **20-45%** of people with an intellectual disability are taking psychotropic medications and, of those, **14-30%** are taking medications to manage behaviours of concern<sup>2</sup>. However, this statistic is for people with disability rather than solely autistic people.

## The Mental Health Environment

Autistic people have great difficulty navigating the mental health landscape as a general rule. For unsupported people, there are real risks around the intersection of mental health, autism and other areas – for example, policing. According to a report from the Australian Institute of Criminology, almost half of the people involved in critical incidents with New South Wales police over the past five years were experiencing a mental health crisis<sup>1</sup>. Another report states that close to half the people shot dead by police over the past 22 years had some form of mental illness<sup>2</sup>. If an autistic person does not understand an instruction by police, if they are unable to speak because of a meltdown or a psychotic episode, etc, there are poor outcomes for the autistic person.

A trial in Western Australia, the Mental Health Co-response (MHCR) program had reported excellent outcomes in this area. The trial was a joint initiative between the Western Australia Police Force, the Mental Health Commission, and the Department of Health<sup>1</sup>. The program allowed WA Police, mental health clinicians, and Aboriginal mental health workers to jointly attend crisis situations where mental illness was identified as a likely factor<sup>2</sup>.

The aim of the MHCR program was to divert people experiencing mental health distress away from the criminal justice system and hospital emergency departments<sup>1</sup>. This approach recognises that individuals experiencing a mental health crisis often require healthcare intervention rather than law enforcement.

There are also significant barriers for autistic people who must deal with inhospitable and inaccessible physical environments, including in emergency waiting rooms. There are a number of dementia strategies that have been implemented to ensure that older people have a calm and soothing environment as well as a hospital liaison person to meet them when they access the hospital – however, this approach does not seem to have been replicated for autistic individuals in mental health care settings.

## 5) Our Recommendations

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### Social Inclusion

- 1) Commonwealth Government to prioritise strengthening the Disability Discrimination Act 1992 (DDA), enabling prosecution of and sanctions against individuals and organisations who breach the DDA.
- 2) Desegregation of autistic people and people with other disabilities in all settings to be prioritised by Commonwealth and State Governments, with a significantly faster time frame than proposed in the Disability Royal Commission final report.
- 3) Commonwealth to prioritise development of hate crime legislation to protect autistic people and people with other disabilities from violence, abuse and neglect by others on the basis of their disability.
- 4) Commonwealth and State Governments to fund schools, hospitals and other mainstream services to retrofit physical environments to reduce sensory stimuli and overload experienced by autistic people. Eg. removal of fluorescent lighting, breakout rooms etc.
- 5) Requirement that all University qualifications for education, health, police / justice and other mainstream services include co-designed training about autism and other disabilities.
- 6) Mandatory co-designed training about autism and other disabilities to all current education, health, police / justice and other mainstream service professionals.
- 7) Autistic people and people with other disabilities to be supported to live independently wherever possible, rather than in segregated group home settings. Autistic people have the right to full choice and control over where they live and who they live with, as laid out in the UNCRPD.

### Economic Inclusion – Education

- 1) The Commonwealth Government to facilitate desegregation of education throughout Australia, with the goal of reaching full desegregation in a significantly shorter timeframe than that proposed by the Disability Royal Commission final report.
- 2) Develop a Working Group consisting of autistic adults, Disabled Persons and Families Organisations (DPFOs), Allied Health Professionals, Education Professionals and representatives from the Autism CRC to co-produce a mandatory, fully funded autism training program for all school staff (inclusive of Administration personnel) in each state.
- 3) The State Governments to allocate funding and resources:
  - a) for all students experiencing difficulties in their learning, without requirement of a formal diagnosis of disability.
  - b) specifically to support the individual needs of the student for whom the funding has been allocated (rather than to support other students not eligible for funding who may be disruptive in class).
  - c) provision of an Education Assistant (EA) in each classroom to support the learning of all students; with a separate EA (or more as needed) to support eligible students with

disability. We note that this would create the bonus effects of reducing stigma for students with disability, and reduce staff burnout and exit from education.

- 3) Requirement that all University institutions include a minimum of one mandatory course unit on disability and autism to be completed by all undergraduate Education students.
- 4) The State Governments to increase funding allocation to the School of Special Education Needs – Disability (SSEND) or equivalent in each state; and implement a minimum of one visit per school term to each public school in Western Australia in order to support school staff to appropriately support students with disability attending the school, and monitor the progress of schools in supporting individual students. Adequate time must be allocated based on the number of students with disability attending each school, and the complexity of their individual needs.
- 5) The State Governments to create and fund staff within each Department of Education dedicated to performing the role of access and inclusion monitoring and audit of all schools. These auditors would be tasked with the role of ensuring that minimum support standards for students with disability are implemented consistently across all Australian schools, with observation, training, ongoing monitoring, feedback from students, families and the wider community, and imposing sanctions and retraining on schools who fail to meet the minimum standard. Further, schools providing support for students with disability to a high standard should be recognised and awarded.
- 6) The State and Commonwealth Governments to invest in infrastructure throughout Australian schools to enable smaller class sizes (maximum appropriate class sizes to be determined by the Working Group mentioned in recommendation #1), in addition to ensuring each school premises include a minimum of:
  - a. one accessible sensory space for students experiencing overwhelm and related distress.
  - b. one room allocated for students with disability to engage in therapy sessions to support their skill development.

Note: Where individual schools have high numbers of autistic students or students with multiple disabilities; or school premises consist of both primary and secondary school students, a minimum of two of each type of room is required.

- 7) The Education Department of each state to implement minimum standards of support for autistic students (and all students with disability), with ongoing monitoring of outcomes for students with disability and audits of school performance in support provision (including consideration of feedback from parents/guardians and the students themselves).
- 8) On recommendations from the Working Group mentioned in recommendation #1, all public school classroom environments be upgraded in consideration of the sensory and learning needs of neurodiverse students (e.g. incorporation of visual strategies in class lessons, retrofitting rooms with dimmable LED downlights, noise reduction strategies and air conditioning).
- 9) The Education Department of each state to instruct all schools in their state to immediately cease punishment strategies for 'poor attendance' of students with disability (e.g., Withholding Keys4Life certification, disallowing participation in end of term reward activities.). This policy actively discriminates against students with disability, many of whom struggle with maintaining school attendance due to insufficient supports to meet

their needs, seriously impacting their physical and mental health; absences to attend medical and therapy appointments; and other medical issues impacting their health. Further, it is inappropriate to punish students for poor attendance during an ongoing, highly infectious pandemic.

- 10) The Education Departments commit to improving complaints processes by ensuring that all:
  - a. staff are aware of and have access to an anonymous complaints process without fear of repercussions;
  - b. public schools prominently display complaint processes on premises, on their website and in information provided to families;
  - c. public school administration staff are trained in appropriate, responsive and empathetic complaint handling processes;
  - d. schools implement continuous improvement processes, seeking feedback from staff, students, families and community about their support systems, and work to address issues of concern raised;
  - e. staff, students and families are offered and able to access free, independent support and advocacy to make complaints, and mediation support where needed; and
  - f. Staff, students and families are offered and able to access free, independent complaints processes without fear of reprisal.

## **Economic Inclusion – Employment**

- 1) Desegregation of autistic people and people with disabilities in all employment settings.
- 2) Elimination of the Supported Wage System as an urgent priority of the Commonwealth Government, and that all Australians, regardless of disability status, be paid the minimum wage.
- 3) Improve access to employment supports for young autistic people and people with other disabilities from the legal age of employment in each state, either through NDIS funded supports or Centrelink funded employment supports.
- 4) Improve access to and eligibility for Disability Support Pension, and simplify the application process to improve accessibility for autistic people and people with other disabilities. The current application process is far too complex for most people without disability to navigate.
- 5) Development of a Disability Support Pension type 2 to financially supplement autistic people and people with other disabilities who may have capacity to work more than 15 hours per week, but do not have capacity to work full time.
- 6) Redesign of recruitment processes to improve employment opportunities for autistic people.
- 7) Development of an 'employer kit' to provide guidance for employers on supporting autistic employees in the workplace.

## **Diagnosis, Services and Support**

- 1) Enable Medicare rebate for autism diagnostic assessment via General Practitioner (GP) referral, as per other disability diagnostic assessments, rather than via Paediatrician / Psychiatrist referral.
- 2) Increase Medicare rebate to fully subsidise diagnostic assessment to enable access to diagnosis for all Australians, regardless of socio-economic status.
- 3) Expand Medicare rebate for autism and disability diagnostic assessment to cover all age groups, not just 0-25 years.
- 4) Standardise autism diagnostic assessment requirements nationally, and develop a register of diagnosticians who meet the assessment requirements. This would enable individuals and families to access quality diagnostic assessment.
- 5) The Commonwealth Government to provide ongoing funding for Disabled Persons and Families Organisations supporting autistic people and families in local communities throughout Australia. These organisations provide peer support, information, referral and advocacy to autistic people, assisting them to access and navigate the various disability and mainstream services.

## NDIS

- 1) Improved training of NDIS delegates and partners in community to understand the needs of autistic participants of all ages, how their disability impacts them, and appropriate supports to meet their needs (eg. Capacity Building Psychology supports). Ensuring that NDIA develop staff's expertise in specific disability types rather than having minimal general knowledge of all disabilities would significantly improve outcomes for participants. Further, we strongly recommend that all staff and partner organisations ensure all staff undertake training in:
  - Trauma Responsive Practice
  - De-escalation Skills
  - Conflict Resolution
  - Incidental Counsellingas part of ongoing professional development.
- 2) All communication from the NDIS must be provided in formats accessible to the participant. Culturally and Linguistically Diverse (CaLD) participants must be provided an NDIS plan in their language, or funding included in the plan for a translator to do this. Vision-impaired and blind participants must be provided a copy of their plan in large text or braille if required, and the NDIA must ensure that the rollout of PACE will enable screen readers to accurately read the plan. Participants requiring Easy Read versions of their NDIS plan must be provided the plan in this format, or funding included to produce an Easy Read version. Plain English must be the minimum standard for all communication from the NDIS. We note also that Easy Read documentations must be released at the same time as standard versions, not weeks or months later (or not at all).
- 3) NDIS must shift from a focus of keeping funding in participant plans as low as possible to a focus on ensuring that the participant's NDIS plan accurately reflects their needs and reasonable and necessary supports. NDIS needs to get the participant's plan right – the first time, wherever possible. Planning meetings need to be conducted by NDIA Delegates, and need to be a negotiation between the participant / nominee and the Delegate. This can be achieved by providing a draft of the plan to the participant /

nominee, and have them sign their approval of the plan in order to finalise it. This system was successfully used in the WA trial sites for the State version of NDIS. We note also, that getting the plan right in the first place will immediately address the issue of inter-plan and intra-plan inflation.



- 4) NDIS representatives to regularly check the accuracy of participant information on file – directly with the participant and their supporters regularly. SWAN’s advocacy work is increasingly identifying very significant errors in NDIS participant records which seriously impact participants. We are uncovering errors such as NDIS Access Requests being entered into the NDIA’s operating system incorrectly, diagnoses listed incorrectly (e.g. diagnoses missing from the participant’s file), and more. In April 2023 SWAN’s CEO sought feedback in several NDIS related peer support groups on whether NDIS representatives are checking that participant information on file is correct. These polls identified that more than 80% of participants have never had their information checked for accuracy by NDIS representatives.
- 5) NDIS Planning meetings must be held with the actual decision-maker, not with LACs / ECA Coordinators. Currently, too many LACs and ECA Coordinators are acting as gate-keepers, refusing to draft plans which accurately reflect the supports requested by participants and families. When the participant or their nominee submit an S100 Internal Review Request, we are increasingly seeing the requested changes rejected because there is no record of the original support being requested. Outcome letters from the Internal Review team state that the support was not requested at the planning meeting, and to request an S48 Change of Circumstances Reassessment. Further to this, LACs and ECA Coordinators are submitting S100 Internal Review Request forms without the input of the participant, and failing to provide the participant with a copy of the submitted form. If the participant is forced to appeal to the Administrative Appeals Tribunal, they then need to request release of their information from NDIS, which takes as long as 5 months to receive. Notably, this information generally includes only the case file notes, but doesn’t include the S100 form.
- 6) NDIS participants must be provided an explanation of all decisions made by the NDIA about them and their supports, without the requirement of the participant or their supporters to submit a Freedom of Information request. This explanation must be provided in the accessible communication format required by the participant.
- 7) All participants, regardless of age, must have a minimum Core budget in their NDIS plan which can be used flexibly to meet their needs. The majority of children and teens, particularly in the south west region of WA, have no Core budget, or as little as \$100-\$300 for Core supports. Typically we see Capacity Building – Daily Living only NDIS Plans for 7-14yr old children of \$4,000-\$9,000 per year. To illustrate the inadequacy of this, \$5000 equates to less than 1 hour of Speech Pathology or Occupational Therapy

per fortnight, with no funding allocation for assessments, writing of reports required by NDIS, or therapist travel costs.

## Health

- 1) All University and TAFE health qualifications to include compulsory co-designed training about autism and other disabilities. Training to include dentists and pharmacists, as well as Doctors and nurses.
- 2) Compulsory co-designed training about autism and other disabilities to be provided to all existing health professionals. Training to include dentists and pharmacists, as well as Doctors and nurses.
- 3) Commonwealth and State Governments to fund retrofitting of all public health facilities to improve the physical environment and reduce sensory stimuli for autistic patients. Eg. Replacement of fluorescent lighting, installation of sensory-friendly rooms in Emergency Departments and on Wards, etc.
- 4) Full Medicare rebate for autistic people and people with other disabilities requiring general anaesthetic (GA) for dental or other medical procedures which would typically be performed without GA.
- 5) Prioritisation of urgent dental and other procedures for autistic people and people with other disabilities in extreme pain by hospitals.

## Mental Health

- 1) Denial of access to mental health services on the basis of an autism diagnosis to be considered a breach of the Disability Discrimination Act.
- 2) Commonwealth and State Governments to invest in training of mental health clinicians to provide best practice, inclusive mental health supports to autistic people and people with other disabilities.
- 3) Commonwealth and State Governments to invest in retrofitting public mental health facilities to reduce sensory stimuli. Eg. Replacement of fluorescent lighting, sensory friendly rooms etc. Note that this change would also improve outcomes for non-autistic people experiencing mental health crises requiring hospital admission.
- 4) Commonwealth Government to invest in research and trialling of best practice methodology for supporting autistic people experiencing eating disorders.
- 5) Commonwealth Government to fund training of clinicians throughout Australian in provision of best practice clinical interventions and support to autistic people experiencing eating disorders.
- 6) NDIS to fund Capacity Building Psychology supports for autistic participants as requested. These are reasonable and necessary disability-related supports. Psychology supports for autistic people to build skills and capacity provide a preventative measure in reducing the likelihood of developing mental health problems.

## 6) Conclusion

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On behalf of SWAN members and the wider autistic community, we are grateful to the Australian Government for investigating the systemic barriers and difficulties experienced by autistic people and their supporters. As the peak body supporting autistic people in the south west region of WA, we would be happy to discuss the issues further with the Panel Members conducting the consultation on the development of the National Autism Strategy.

## 7) Contact Details

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