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## **SENATE SELECT COMMITTEE ON AUTISM**

### **SERVICES, SUPPORT AND LIFE OUTCOMES FOR AUTISTIC PEOPLE IN AUSTRALIA**

**Submission from:**

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## **Senate Select Committee on Autism**

### *About Scope*

Scope (Aust) Ltd (“Scope”) is a leading provider of services to people with disability in Victoria, and one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children’s Society of Victoria. Scope is today one of the largest not-for-profit disability service providers in Australia, supporting 7,000 people with complex intellectual, neurological, physical and multiple disabilities.

Scope’s mission is to enable each person we support to live as an empowered and equal citizen. Scope’s commitment is to work with and advocate for people with the most complex support needs, to promote and support their access to mainstream services, and to build an inclusive community for all.

Scope provides services including accommodation (supported independent living and short-term accommodation), therapy, individual support, communication access and supported decision making across metropolitan and regional Victoria. Scope works with corporate and community organisations to improve inclusiveness for people with disability and has been active in research for 30 years. As part of its commitment to research led and evidence-informed policy and practice, Scope has a long-term partnership with the University of Melbourne.

### *About the University of Melbourne*

The University of Melbourne is Australia’s leading research-intensive university. The university’s stated purpose is ‘to be a leading force in advancing Australia as an ambitious, forward – thinking country while increasing its reputation and influence globally’. The university community includes researchers across a wide range of disciplines, including academics with the lived experience of disability, working to advance the health, wellbeing and quality of life of people with disability, and promoting an inclusive society. The university has a strong commitment to the co-design and co-production of research in partnership with people with disability, their families and service providers such as Scope Australia.

### *About the Scope-University of Melbourne Partnership*

Scope and the University of Melbourne have a formal partnership that is founded on a shared commitment to improving the lives of individuals living with disability through the promotion of programs that empower people with disability. The partnership has created the position of Professorial Fellow of Disability and Inclusion, a joint appointment between the University and Scope, as well as joint programs in research, teaching and learning, and community engagement.

The partnership draws upon the interdisciplinary expertise of staff from both the University of Melbourne and Scope, and the emerging expertise of University of Melbourne students (including dedicated PhD scholarship holders), to be a leader in disability research, teaching and advocacy, informed by rigorous scholarship and the lived experience of people with disability.

The partnership applies authentic and rigorous scholarship to address inequality and optimise the social inclusion of people with disability. With an emphasis on applied outcomes for those with multiple and complex disability, output includes:

- Peer reviewed publications
- Informing policy and practice
- Plain language reports
- Government submissions
- Conference content
- Educational content for both higher education and industry focused courses

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\* Several of the contributors to this submission identify as Autistic.

#### *About terminology*

Throughout this submission, we have used the terms 'Autistic' and 'on the Autism spectrum' interchangeably. Our purpose for doing so is to acknowledge and respect the various preferences of individuals in the Autism community and is consistent with a diversity model approach (Andrews, 2016; Forber-Pratt, Mueller, & Andrews, 2019). Over the past few years, the Autism advocacy movement has strengthened, and is being driven largely by Autistic-led organisations, including the Yellow Ladybugs (YLB), the I CAN Network and the Autistic Realm Australia Inc. Several of these advocacy organisations promote the use of identify-first language – Autistic. For example, Yellow Ladybugs offer the following rationale

for this position: “being Autistic is not only an intrinsic part of our tribe’s identity, but something to be embraced and celebrated” (Yellow Ladybugs, n.d.).

It has been suggested by previous government inquiries that in order to best support individuals on the Autism spectrum, consultation with the Autistic community is imperative (Parliament of Victoria, 2017; State of Victoria, 2017). We therefore respect the preference of the majority of individuals in the advocacy space to use this identity-first term. However, we also acknowledge that there are differing views in the Autism community and some individuals do not identify with the identity-first term Autistic. This is echoed by the I CAN Network's Founder and CEO, Chris Varney, who noted that "As Australia's largest Autistic-led service provider, I CAN Network proudly uses identify-first language, however we also meet a family or school community where they're at in terms of their own language choices, and influence with integrity from there" (Personal communication, 6 July, 2020). To honour a truly inclusive approach, we have used a more person-centred term, ‘on the Autism spectrum’ as a factually correct term for individuals who have an Autism diagnosis, to respect the views of those individuals as well.

As part of this submission, we therefore recommend that legislative instruments and government policy be framed in ways that respect the diversity of opinion in the community and encompasses both person-first and identity-first language. Furthermore, we have framed the recommendations in this submission to be enacted not only in consultation with people on the Autism spectrum, but to be co-designed and co-produced with people on the Autism spectrum.

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## Introduction

According to the Australian Bureau of Statistics there were 205,200 people aged under 40 on the Autism spectrum in Australia in 2018, up 25.1% from the 164,000 people in 2015 (Australian Bureau of Statistics, 2019). A recent study by May, Brignall and Williams (2020) places the current prevalence of Autism spectrum Disorder (ASD) in Australia at 2.4-4.4% of the population which equates to between 600,000 and 1.1 million people (May et al., 2020). There is a paucity of research documenting the prevalence, lived experience and support needs of adults. Estimates of worldwide prevalence vary, but according to the World Health Organization in 2019, one in 160 children worldwide has an Autism spectrum disorder (World Health Organization, 2019).

Autism spectrum disorder is currently the most prevalent primary diagnosis of children aged 0–14 years entering the NDIS (National Disability Insurance Agency, 2020b). In 2020 31% of all NDIS participants, and 53% of participants aged 0 – 14 identified Autism as their primary diagnosis (National Disability Insurance Agency, 2020a). As such, it is timely that the Australian Senate Standing Committee on Autism should convene this inquiry into the services, support and life outcomes for Autistic people in Australia and the associated need for a National Autism Strategy. The Scope-University of Melbourne Partnership welcomes the opportunity to provide a submission to the inquiry.

This submission is a collaboration between one of Australia’s leading disability service providers and leading academics from the University of Melbourne on key issues relating to the services, support and life outcomes experienced by Autistic people in Australia and the associated need for a National Autism Strategy. The submission is grounded in research evidence and contains both policy and practice recommendations. Importantly, several of the contributors to this submission identify as Autistic, and in addition to their academic and professional experience bring to the submission the expertise of their lived experience.

The Scope-University of Melbourne Partnership submission to this inquiry will focus on key issues relating to the services, support and life outcomes experienced by Autistic people in Australia, specifically focusing on the areas of advocacy, education, employment, health and mental health and the NDIS.

## Advocacy

In Australia, there are currently several different groups/individuals involved in Autism advocacy. These include organisations that are Autistic-led; organisations that are not Autistic-led but do consult with the Autism community; and individuals or self-advocates. There are also a number of organisations that are not Autistic-led and do not consult with the Autism community, and it is important to note that many of these organisations promote views which are not accepted by a large part of the Autism community. In its inquiry into services for Autistic people, the Victorian Government Family and Community Development Committee (Parliament of Victoria, 2017) found that Autistic people objected to having policies and programs in relation to Autism developed without their involvement. The development of policies and services need to go beyond traditional and simplistic 'consultations' with stakeholders. Rather, they need to be grounded in and shaped by the contemporary principles of *co-design* and *co-production*.

Comprehensive advocacy needs to represent a plurality of perspectives. We wish to emphasise throughout this submission that the voices of people on the Autism spectrum should be prioritised when considering key issues relating to their services, support and life outcomes. As such, we support the rights of Autistic people to engage in self-advocacy and call for adequate support and resourcing of systemic advocacy for the Autism sector, particularly from Autistic-led organisations.

Funding for Autistic self-advocacy groups and/or access to supports for self-advocacy are therefore critical to upholding Autistic people's rights and establishing an inclusive community. The policy mechanisms to achieve these ends need to be included in any future national Autism strategy

### **With respect to advocacy the Scope-University of Melbourne Partnership recommends that:**

- Australian governments increase funding for Autistic self-advocacy groups, in particular, those which undertake systemic advocacy, to ensure that the Autism community is facilitated to lead the design and implementation of the services that support them, and the legislation and public policies that affect them.
- Australian governments ensure that all funding for Autistic self-advocacy groups throughout Australia is protected in the face of any future budget cuts or austerity measures following the COVID-19 related economic downturn.
- Schools and workplaces should be supported by the government to provide training in advocacy, designed by, or at least in consultation with, Autistic individuals, for staff and students to enhance their ability to advocate for themselves within these environments. Such training should be integrated in school curriculum to normalise and support its delivery.
- Advocacy services should be supported to commission and participate in research and development activities consistent with their lived experience and interests.

## Education

### *Background*

The *United Nations Convention on the Rights of Persons with Disability* (UNCRPD, United Nations, 2006), to which Australia is signatory, along with the *Commonwealth Disability Discrimination Act 1992* (Cth), clearly articulates the rights of Autistic people to access high-quality education on an equal basis with others (United Nations, 2006). Article 24 of the UNCRPD encompasses more than just inclusion in the academic components of schooling, and, highlights the important role of Australian governments in enabling ‘persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community’ (United Nations, 2006).

Although Australia’s ratification of the UNCRPD was an important step in signifying a commitment to high-quality education for every Autistic Australian, the lived experiences of Autistic students and families demonstrate that Australia is a long way from realising this inclusive vision. Many families of Autistic children experience resistance to their child’s enrolment at local, mainstream schools, (frequently reported by families of children with a co-occurring intellectual disability), or then, when they are enrolled, report being made to feel unwanted, and that their children are placed on restricted hours of attendance or separate play and learning schedules from their peers. Autistic adults enrolled in VET sector institutions and Higher Education institutions / Universities report similar experiences of isolation and at times exclusion where their learning needs are not understood and reasonable adjustments to the curriculum delivery and assessment are not made.

Defined as creating learning environments that cater to the needs of every student (Berman & Graham, 2018), inclusive education offers an alternative. Beginning with this understanding, inclusion requires systematic changes to content, teaching methods, approaches to behaviour management, and power structures within the school, to ensure that every student can access the full range of opportunities offered to them by our schools (Hehir et al., 2016). Rather than trying to change Autistic students, educate them in segregated settings, or provide individualised supports to integrate them into settings that remain otherwise inaccessible, inclusive education is primarily concerned with making these systematic changes to facilitate the agency of all students and to celebrate the differences within our community. These same principles and practices, currently applied in primary and secondary schooling, need also to be incorporated into and applied in VET sector institutions and Higher Education institutions / Universities.

Creating inclusive educational systems requires considering how to establish a shared learning environment in which diverse individuals have opportunities to thrive. In order to ensure that the needs of all individuals are met, we need a system that uses evidence-based practices to pre-emptively optimise our schools by identifying what universal supports will support most students (inclusive of Autistic students), and then look to individual accommodations and adjustments if the universal supports are ineffective for individual students. This approach is known Universal Design for Learning (UDL) (or Universal Design for Instruction (UDI), Burgstahler & Cory, 2008), which provides a set of principles for

designing learning environments built on flexible approaches that can be customized and adjusted based on individual learner needs (CAST, 2012).

There is a strong body of evidence to support a UDL approach in order to optimise the learning experiences of Autistic students (see Chia & Kee, 2014; Walker, McMahon, Rosenblatt, & Arner, 2017). The UDL approach prioritises supporting educational institutions to remove ableist barriers to plan for a diversity of functional needs regardless of formal diagnosis, and provides a framework for addressing the challenges currently experienced by Australian Autistic students.

While we recognise the issues facing Autistic students and their families are numerous and complex, this submission focuses on four broad areas that we believe require immediate attention. These are:

- creating sensory-inclusive environments,
- supporting inclusive social communities,
- providing effective supports for transitions between stages of education (importantly, including transitions beyond compulsory education to vocational and higher education), and
- building professional knowledge and capacity in all schools and post-school educational settings (e.g. TAFE colleges and universities).

Addressing these four areas will serve as an important step in fostering inclusive cultures within our educational institutions. This submission uses the language of UDL when exploring each of these four areas and draws on the best practice principles in making recommendations to address particular areas of challenge identified within our education systems.

#### *Creating sensory-inclusive environments*

We have been observing something of a shift in thinking in the fields of cognitive psychology and occupational therapy about conceptualising the ideal classroom environment, with a notable trend towards optimising spaces for learning. An example of this is the Melbourne Graduate School of Education's partnership with the Melbourne School of Design on their Innovative Spaces and Pedagogy project. The Scope-University of Melbourne Partnership has also driven the development of sensory sensitive student study spaces in key locations across the University of Melbourne Parkville campus.

Consideration of the impact of the physical environment on students' experiences of education demonstrates a positive shift for the Autistic community, as elements such as visual and auditory stimuli are being more consciously considered as either barriers or enablers to conducive learning. The presentation of sensory processing difficulties amongst Autistic students vary widely and little is understood about the underlying mechanisms that cause these variations ((Uljarević, Baranek, et al., 2017). Some suggest that sensory-friendly environments in education settings are needed to promote inclusivity, accessibility and engagement (Cage & Howes, 2020) and this can arguably be extended to employment settings. Proactive support and inclusive, accessible environments have also been identified as factors that can mitigate the risk of drop-out for Autistic university students.

One area of concern for students with sensory differences is the recent re-emergence of open plan classrooms. Open plan classrooms are designed to align with pedagogical approaches that are commonly termed 'student-centred'. Student-centred pedagogies have remained popular over the last fifty years. There was a temporary shift away from open plan classrooms in the 1990s, however they have since seen a resurgence, once again using these pedagogies as a rationale (Shield, Greenland, & Dockrell, 2010). We have observed that new or renovated classrooms are being designed to encourage and privilege verbal communication between students, and provide sufficient space for group-based activities. These wide-open spaces are typically designed to hold in excess of 60 students. While benefits do exist, there has been near-universal agreement that open plan environments have been less than ideal for neurodiverse students with sensory differences. Beyond educational institutions, these issues are yet to be investigated in the workplaces of the wider community. Research needs to be commissioned examining what might constitute reasonable adjustment in the workplace for when students transition from education to employment (Hayward, McVilly, & Stokes, 2019; Hedley, Cai, et al., 2018).

It is widely acknowledged that a number of Autistic individuals experience auditory processing difficulties, and students, teachers and audiologists report that the cumulative volume within these spaces make it difficult for anyone to focus, and almost impossible for many Autistic students to tune out background sounds (Ocak, Eshraghi, Danesh, Mittal, & Eshraghi, 2018). The American Speech-Language and Hearing Association states that the required signal-to-noise ratio for effective learning for all students is +15dB meaning that the teacher's voice needs to be 15 decibels louder than background noise in the classroom in order to be perceived (American Speech-Language Hearing Association, 2005). It is estimated to be closer to be + 25dB for students with an auditory processing difficulty. The average signal to noise ratio in most classrooms is +0dB, meaning that the teachers voice is at the same level as the background noise. This situation can be even poorer in open plan classrooms, significantly reducing the possibility of effective learning opportunities for many Autistic students. Furthermore, the aesthetics of learning spaces using bright colours and cluttered displays can create visual stimuli that can be distracting for many students. In these environments many Autistic students are unable to discriminate between important information and non-essential visual 'noise'. Open plan spaces are also challenging for Autistic students in terms of knowing where they should be at a given time, often resulting in anxieties related to not understanding the expectations of movement within the learning space.

In addition to the need for educational settings (including primary schools, secondary colleges, VET sector institutions and Higher Education institutions / Universities) to understand and consider the effects of over-stimulation or sensory-overwhelming environments, it is just as essential for there to be an understanding of the need that many Autistic students have for sensory input. There are three terms often used to describe the sensory needs of individuals on the Autism spectrum – hypersensitive, hyposensitive and sensory-seeking. It is common for individuals to be a combination of these three, regarding different neurological systems. For example, being hypersensitive to light, hyposensitive to touch, and sensory-seeking for vestibular input (needing frequent movement). While educators in the primary and secondary school systems are gradually becoming more aware

of over-stimulation or hypersensitivity, it is our experience that very few are aware of hyposensitivity and the need to seek sensory input. Awareness among teaching staff in VET sector institutions and Higher Education institutions / Universities is yet to be formally investigated, but anecdotal evidence suggests this is negligible. Obtaining certain forms of sensory input can be essential for enabling Autistic students to regulate themselves, to attend, to interact with others and to learn effectively. A combination of sensory tools designed to give input with targeted movement activities can meet these needs, if targeted to individual students. In the absence of such knowledge among educators and consequently the absence of appropriate adjustments in teaching, student engagement and learning is compromised and the likelihood of students continuing their education greatly reduced.

**With respect to creating an inclusive education system and inclusive school environments the Scope-University of Melbourne Partnership recommends that:**

- Planning for all new schools and other educational environments should be required to clearly demonstrate how they meet the needs of students with sensory differences in line with Australia's commitments to bringing its education systems into compliance with the human rights requirements stipulated by the UNCRPD (United Nations, 2006) and the Disability Discrimination Act 1992 (Cth).
- Australian governments engage Educational Audiologists and Occupational Therapists during the design process of any new educational buildings, to ensure a design which minimises over-stimulation and enhances the learning capacity of all, including Autistic, students.
- Increased funding should be made available for individual Autistic students in order to improve the supports available and build the capacity of mainstream schools (i.e. working towards integration on our way to systemic inclusion).
- All schools with Autistic students be provided with funding to engage an Occupational Therapist to evaluate students' needs for sensory input and provide recommendations for sensory toolkits, environmental modifications and movement activities that can be incorporated into daily routines.

*Supporting inclusive social communities*

As differences in social interaction and communication are defining characteristics of Autism (World Health Organization, 2019), the reception of these differences by the school and other educational communities can have a significant impact on the degree to which an Autistic student feels like they belong. The visibility of these differences has been partly responsible for sustaining the misconception that Autistic children have little desire for regular social connection (Blacher & Christensen, 2011). There is now a significant body of research refuting this assumption (Petrina, Carter, Stephenson, & Sweller, 2017; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016). Instead, Autism can manifest in differences in understanding social norms, varying interpretations of which social skills are considered appropriate for use in particular contexts, and preferences for alternative modes of communication when interacting with others. Students with neurological differences such as Autism are more susceptible to bullying, particularly as a result of a perceived power

imbalance between the bully and victim (Attwood, 2016; Beckman, Hellström, & von Kobyletzki, 2020).

While bullying can often involve unsophisticated acts of violence, it also often includes more subtle and systematic forms of social exclusion (Parliament of Victoria, 2017). For Autistic students in particular, differences in understanding the shades of meaning and social context that separate playful banter from malicious teasing can present feelings of insecurity and anxiety (Attwood, 2016; Beckman et al., 2020; Bellini, Peters, Benner, & Hopf, 2007). The meaning of laughter is a good example of this. People can laugh at something in an inclusive way, inviting everyone to participate in acknowledging the humour in a situation, it can be an involuntary response to a feeling of awkwardness, or it can be a derogatory, conscious effort to ridicule someone and to bring on negative feelings in the victim. It is well established that bullying can result in Autistic students avoiding social interactions, cutting themselves off from the world and, in extreme cases, can lead to suicide attempts (Attwood, 2016; Beckman et al., 2020; Maiano, Normand, Salvat, Moullec, & Aimé, 2016). In order to reduce the risk of bullying of Autistic students within Australian schools we need to provide positive school cultures and provide supported opportunities for social engagement.

Key to fostering inclusive environments for Autistic students is ensuring the creation and maintenance of positive school / institutional cultures. School Wide Positive Behaviour Interventions and Support (SWPBIS) can build positive school cultures for Autistic students when genuinely implemented in partnership with the Autistic community. SWPBS builds on the well-established principles and practices of Positive Behaviour Support (PBS), which has been repeatedly demonstrated over the past 40+ years to be the intervention of choice to address behaviours that impede a person with disabilities' engagement and integration in society and to improve their quality of life (McVilly, Bristow, Foreman, & Goddard, 2012). This partnership should be designed to ensure the views of the Autistic community are reflected and that the differences of Autism are celebrated and not sought to be changed. This is re-iterated by Tom Tutton, Clinical Psychologist and Positive Behaviour Support Specialist at Aspect (Autism spectrum Australia) who states that "there are risks if the approach isn't applied with accommodations" and "significant adaptation to meet the needs of Autistic students" (Personal communication, 8 July, 2020).

SWPBIS is an increasingly popular framework that Australian schools are adopting when attempting to develop positive school cultures. Although official figures are unavailable for some jurisdictions within Australia, Poed and Whitefield (2020) have estimated that 31% of Australian schools have received implementation training. We recognise that due to some of the behaviourist assumptions of SWPBIS, the use of this framework as a support for Autistic children is controversial. A key concern is the use of this framework to set expectations which 'normalise' the behaviours of Autistic children. When implemented without the voices of Autistic students and allies who promote the voices of the Autistic community, SWPBIS can act as an extension of Applied Behaviour Analysis (ABA), a practice which many members and allies view as being responsible for inducing significant trauma and ignoring the human rights of Autistic students. Where possible, we strongly endorse a focus of an inclusive model of SWPBIS that takes a pro-active approach by first looking to transform the school environment, rather than changing behaviours that may not be

understood by others. A clear example of this is the acceptance of ‘stimming’, or self-stimulating behaviours such as repetitive flapping of the hands. We also recognise that there are limits to this approach and some behaviours cannot be accommodated and need to be changed. Furthermore, there is an urgent need to investigate and establish how the principles and practices of SWPBS might be incorporated into VET sector institutions and Higher Education institutions / Universities.

By consulting with the Autistic community and their allies to co-develop a set of expected school behaviours for all students, to explicitly teach these behaviours, and develop a school-wide culture which embrace neurodiversity by reinforcing the positive performance of these behaviours we believe that all students should be able to attend their local school. We recommend that schools with Autistic students receive additional training and consultation to implement SWPBS, to ensure that the practices and strategies being used across the school are inclusive and recognise that some behaviour patterns adopted by Autistic students may differ from those of non-Autistic students. This is particularly the case at the Tier 1 (first) level of support which looks at setting expectations for student behaviour across the school. Most importantly for this review, explicit instruction and consistent application of behaviour management policies are essential for Autistic students in understanding what others expect of them within their school environments (D. McDonald, Astbury, & St Leger, 2011; Mitchell & Sutherland, 2020). This is particularly true for students in high school, where multiple teachers can often result in differing rules and expectations.

While other students might be able to ascertain the implicit expectations of teachers and peers through observing the actions of others and how these actions are received within the school community, we know that the differences of Autism often result in Autistic students not being able to learn social behaviours through this process (Müller, Schuler, & Yates, 2008). It is here that the diverse behaviours of Autistic students must be considered to ensure that behaviour expectations are not set to ‘normalise’ behaviours which serve important functions for Autistic students. This consultation and implementation process and schools collecting data to support what they are doing is a key part of SWPBS. Paraphrasing SWPBS expert Tom Tutton, if schools are not implementing SWPBS in partnership with their Autistic communities, they are not doing positive behaviour well (Personal communication, 8 July, 2020). Again, how these principles and practices might be deployed to support Autistic students in VET sector institutions and Higher Education institutions / Universities remains to be investigated.

Beyond providing a whole school approach to supporting positive behaviour, a sense of social connection is required for Autistic students to feel like they belong in their schools, VET colleges and universities. Providing regular opportunities for supported social engagement through interest-based clubs presents an opportunity for addressing these challenges (Harrison, 2019; Ringland, Wolf, Faucett, Dombrowski, & Hayes, 2016; Wolfberg, 2016). An example of this in action is the recent emergence of video games clubs, which have been described as ‘virtual playgrounds’ (Harrison & Gesthuizen, 2019; Ke & Moon, 2018). By using areas of strength and familiarity as contexts for promoting social interaction, Autistic students can use their established knowledge as a basis for engaging with their neurotypical peers. This positions Autistic students as relative experts often providing much needed confidence (Ringland et al., 2016). In Victoria a growing number of school-based

gaming clubs use this approach, where students come together to play video games supported by staff. Despite the proliferation and purported successes of these programs, there has been very little research into the conditions in which these clubs can best support Autistic students in developing social competencies and building sustainable inclusive communities

#### AAC Diverse communication modes and social interaction styles

As noted above, it is well established that many Autistic individuals use a diversity of communication styles and traits within communication and during social interaction, and may experience difficulty understanding the rules of social norms. In addition to this, many people on the spectrum may communicate using echolalia (Neely, Gerow, Rispoli, Lang, & Pullen, 2016), which can be difficult for unfamiliar communication partners to interpret, or have little-to-no functional speech altogether and rely on alternative forms of communication (Aydin & Diken, 2020). For many people, augmentative and alternative communication supports (AAC) provide an alternative, both to communicate messages to others, and to understand information.

AAC has traditionally been used as an umbrella term to describe the collection of aids and devices used to support the communication of individuals with speech, language or communication difficulties (e.g. Beukelman & Mirenda, 2013). More recently, however, inclusive terminology recognising the value of communication diversity, acknowledges that AAC benefits all communicators. Thus, AAC as a term has grown to encompass all methods of communication other than speech. The broad spectrum of AAC is typically categorised into unaided forms, such as body language, facial expressions or manual sign languages (e.g. Key Word Sign, AUSLAN), and aided forms, which includes both high-tech systems (such as electronic speech-generating devices or iPad apps) and low-tech aids (such as non-electronic communication boards or books) (Ocak et al., 2018, p. 367). Many individuals with speech difficulties who have acquired literacy will use an orthographic (alphabet) system to spell out their messages, such as an alphabet board or finger spelling. For individuals whose literacy skills are emerging or developing, language can be represented in a variety of alternative forms, including natural gestures, manual signs, photographs, line drawings and pictographs, whole words, and written phrases.

While there is a wide range of multi-modal communication options to support communication for Autistic children, we note that these are rarely made available to children in mainstream school environments, typically due to teachers' lack of knowledge about AAC options, as well as a lack of available training to support teachers to upskill. A culture of AAC-free environments may also discourage teachers from introducing such supports. Mainstream schools instead frequently preference programs which provide social skills intervention. We consider this to be problematic for three primary reasons.

Firstly, the right to live in conditions which ensure dignity, enshrined under Article 3 of the UNCRPD (United Nations, 2006), requires that Autistic people be accorded the same value and respect as anyone else. Thus, policies and practices which seek to change the mannerisms, behaviour or communication style of only one group of people is considered discriminatory, and a violation of dignity under international law. All forms of communication, consistent with the diversity message, should be valued and respected.

Secondly, the most widely used definitions of 'normative' social skills and social communication are highly culturally biased, defined by the values and behaviour of western, neurotypical populations, rather than an approach to examining social and communication efficacy. For example, most recently, a study undertaken by a team inclusive of researchers on the Autism spectrum found that interaction between Autistic people is just as effective and meaningful as interaction between non-Autistic people, both when the Autistic individuals are communicating with other Autistic people, as well as with neurotypical peers (Crompton, Hallett, Ropar, Flynn, & Fletcher-Watson, 2020).

Finally, and most importantly, the dangers of not acknowledging and celebrating Autistic diversity are well documented. For instance, a 2018 study found that along with unmet support needs, therapy and intervention that focuses on 'training' Autistic people to behave differently (also known as 'camouflaging', 'passing' or 'masking') was amongst the highest risk factors of suicide in Autistic people (Cassidy, Bradley, Shaw, & Baron-Cohen, 2018). As an Autistic blogger explains,

Masking is exhausting. What's worse, because of the way my social experience improved as I got better at masking, I learned that I was only allowed to have friendships if I successfully fooled people into thinking I was someone I'm not. Years of teaching myself to mask may have improved my life on the surface, but with those improvements came an Anxiety Disorder, suicide attempt, and the belief that my value as a person is entirely dependent on my ability to act like someone else (name withheld, 2019).

Adopting an inclusive approach to education and supporting inclusive social communities throughout Australian jurisdictions has the potential to instead facilitate inclusion and celebration of communication diversity, heading off some of the most negative impacts on individuals in the earliest, most formative years of their lives.

**With respect to supporting inclusive social communities the Scope-University of Melbourne Partnership recommends that:**

- Schools, VET sector providers and Higher Education providers / universities should consult regularly and comprehensively with their Autistic students when determining their values and rules. This is a key component to creating inclusive education systems.
- After consultation with Autistic students, education providers should pre-emptively and explicitly teach the agreed-upon values of the institution, to all students. This will help institutions to define an inclusive culture and to reduce the instances of, for example, bullying.
- Education providers take an approach to behaviour management policies which recognise the individual needs of students, acknowledge the function of behaviours Autistic students may exhibit, and provide a consistent experience for the students.
- State and Commonwealth governments should support schools in adopting inclusive School Wide Positive Behaviour Intervention and Support frameworks for promoting positive school cultures, in consultation with the Autistic community, while ensuring schools with students on the Autism spectrum receive additional training to meet

the needs of these students. In addition, funding and support should be provided to VET sector institutions and Higher Education institutions / universities to adapt and adopt similar policies and practices.

- State and Commonwealth governments should ensure that institutional-based activities that support the talents and interests of Autistic students are properly resourced and embedded in policy to achieve consistency across all States and Territories. This should be promoted through the development of interest-based clubs (e.g. STEM clubs, Makerspace), which can provide a strength-based space for developing social connections and developing collaborative social skills.
- For schools and other educational providers to provide opportunities for non-Autistic students to learn about various communication methods (non-verbal, communication devices) and ways to interact and play with students on the Autism spectrum.

#### *Providing effective supports for transitions between stages of education*

A change in environment can be difficult for any person, child, adolescent, or adult. Regardless of the stage of the transition in an individuals' educational life, transition is significant and includes increased academic demands, complex social environments, reduced support and changes in rules and routines. The short and long-term impact of successful school transitions have been investigated at an international level (Dockett, Petriwskyj, & Perry, 2014). Short-term benefits include improved social adjustment and improved academic performance (Ahtola et al., 2011), while longer-term benefits include systematic financial savings from elevated taxable income resulting from increased employability (Schweinhart et al., 2005). The effectiveness of transition programs has the potential to greatly impact a child's later school success (Dockett & Perry, 2004). Transition has been described as two distinct categories of changes; changes across services and programs, and changes within services and program (Rous & Hallam, 2012). Parents and children have expressed more anxiety and worries about transition than their non-disabled peers and have differing experiences and views on what they perceive as a successful transition (Daley, Munk, & Carlson, 2011; Dockett & Perry, 2004; McIntyre, Eckert, Fiese, Reed, & Wildenger, 2010; Rous & Hallam, 2012).

Within our education system, the first transition is typically from the home environment to preschool. This commonly occurs between the ages of two and four, during a stage of typical rapid cognitive development. The first signs of developmental differences during this period may manifest initially as the failure to reach developmental milestones, or with uneven or atypical skill acquisition. Understanding variable patterns of development in addition to the specific areas of strength, challenge and interest of a child is crucial for effective early intervention and therapy regardless of diagnostic labels (Gallahue, Ozmun, & Goodway, 2012). Likewise, recognising the variability of development at this early stage is essential for successfully teaching all students within an inclusive preschool system. Each individual has their own timetable for the acquisition of abilities and skills (Gallahue et al., 2012). This is specifically true for individuals with neurological differences, whether they are formally diagnosed with Autism or share similar functional needs. Without this knowledge, preschool teachers cannot adequately provide an inclusive environment to tailor for the functional differences of Autistic students.

Extending beyond initial preschool settings, it is important that educators have the required professional knowledge moving into our formalised school systems. A key part of managing these transitions is the effective use of Individual Education Plans (IEPs). In the kindergarten, primary school and secondary school years many Autistic students will have an IEP, outlining personalised goals and strategies. While the departments of education across the nation have recognised the need to review the IEP processes in our schools, particularly in relation to the consistency of implementation, the fact that these documents exist is preferable to the lack of documentation in higher education. Likewise, prior to higher education Autistic students are generally flagged as needing extra supports during transitional stages. These students are likely to have an informational file that moves with them from one year level or teacher to the next. Again, this 'hand over' process does not occur post high school. Universities, in particular, pose the additional challenge of students being expected to be much more self-sufficient. Tasks such as enrolments, fee management, communication with lecturers/tutors are all required to be done by students themselves, as opposed to secondary school where students are given support to do the same or similar tasks. The requirement to be so self-sufficient, while also managing a new and extremely large environment, increasing academic requirements and an entirely new social landscape almost places greater strain on Autistic students than what they've ever previously experienced, and yet most or all supports are taken away.

Finally, becoming an adult is typically equated with becoming a full and equal participant in the social, economic and political life of one's community. However, the transition to adulthood remains a significant challenge for many Autistic individuals, due to the lack of opportunities and supports devoted to this phase of life (Lawson et al., 2020; Strnadova, Cumming, & Danker, 2016). As a result, the completion of high school, when individuals' age out of education and other supported services provided by governments, has been described by many in the Autistic community as similar to 'falling off a cliff' (McMinn, Schulz, & Ludlow, 2019). The breadth and depth of this problem is reflected in the theme of the UN 2020 World Autism Awareness Day, Transition to Adulthood, which drew attention to the need for greater supports and innovations targeted at assisting Autistic youths to navigate the transition to adulthood, including engagement in VET sector education and Higher Education / universities, and onwards to employment.

**With respect to effective transitions within and beyond Education the Scope-University of Melbourne Partnership recommends that:**

- Governments implement policy drivers to ensure a consistent approach across all States and Territories on the transition process from Primary to Secondary School for Autistic children. Recommended transition activities include:
  - Students engaging in more frequent visits to their new school prior to starting and be provided with visual supports where appropriate, such as a school map, photos of the school and teachers, implementation of developmentally appropriate transition tools (i.e. checklists, schedules, transition songs, visual cues).

- Once students commence, having a peer buddy, positive relationships with staff, structures for recess/lunchtimes, and a system of communication which suits the students' needs, would also assist.
- Providing students with developmentally appropriate self-regulation tools (coping strategies, emotion thermometer) developed in conjunction with their allied health professionals.
- Parents of Autistic students be supported by being informed of all supports and funding available to them (both by the school and in the community).
- Parent and teacher collaboration first with Autistic students and allied health is a key aspect to successful transitions and ongoing support.
- Greater focus on providing transition supports for Autistic school-leavers, including:
  - Facilitated peer groups, to support the loss of school-based social networks.
  - Explicit training sessions focused on employment expectations and social interactions in the workplace.
  - 1:1 support, potentially through the NDIS, to explore employment options and opportunities.
  - Explicit training to support transition from secondary school to VET sector and Higher Education / university opportunities
  - Transitional programs and files to move between Secondary School and vocational and higher education. Examples of this include Autistic-friendly welcome/information packs for enrolling students (created by Autistic individuals), peer mentoring programs for enrolling Autistic students (to be mentored by other students or alumni on the Autism spectrum).
- Training for all academic staff in vocational and higher education regarding making courses more inclusive of the needs of Autistic students. This includes ensuring that all teaching and supervisory staff understand the differences of Autism, common areas of challenge and how to effectively redesign learning experiences to be as inclusive as possible.

#### *Building professional knowledge and capacity within schools*

In order for Autistic students to be able to access inclusive education systems, it is imperative that staff working within these institutions have the professional knowledge and skills required to ensure successful academic and social outcomes for these learners. Staff not only need to understand the specific needs that can manifest from Autism, but they must have the knowledge and skills to plan, implement and monitor evidence-based interventions to support Autistic students.

Currently Australian teachers are overwhelmingly enthusiastic about teaching Autistic students but often feel they do not possess the knowledge to be effective in supporting this population (Garrad, Rayner, & Pedersen, 2019; Mills & Chapparo, 2018). The perspectives of staff in VET sector and Higher Education / university institutions remains unknown and requires investigation. To build both professional knowledge and confidence, and to implement the previous recommendations there needs to be a system wide prioritisation of upskilling in-service teachers and ensuring that inclusive education is a core component of all initial teacher education programs and included in the professional development of VET sector and Higher Education / university staff.

In order to upskill staff already working in schools, there needs to be adequate resources allocated for mandatory, ongoing training for all staff working with students. We want to emphasise that this need for quality training not only includes all teachers but must also include teaching assistants and school leadership teams – Principals, Assistant Principals and non-teaching staff who interact with or are responsible for students on the Autism spectrum. Teaching assistants are often working with a high frequency with Autistic students and hence require the specialised knowledge and skills to support these learners, although the research is also very clear that teaching assistants should not replace the role of the teacher for these students (Poed, Graham, Berman, & McKay-Brown, 2016). It must be emphasised that this training cannot be occasional disconnected sessions, as there is a significant body of evidence suggesting that only ongoing training alongside structured professional reflection can bring about sustainable changes to teaching practices and school culture (Dinham, 2008; Goos, Bennison, & Proffitt-White, 2018).

If inclusive education is to become a reality, leadership is required (Poed & Whitefield, 2020). We contend that every educational institution requires a dedicated professional embedded within the setting who possesses the specialised knowledge and skills to lead these training programs. It is essential that this individual understands the local needs and challenges of the students, staff and broader educational community but also is familiar with the evidence around best practices in Autism support and intervention. We believe that each educational institution requires a Learning Intervention Coordinator (LIC) who has a post-graduate qualification in supporting learners with disabilities and neurological differences. Ideally this training should be extended to Principals and Assistant Principals as well to enable them to support the work of the LIC. The LIC would be responsible for leading the inclusive education agenda within a school, including the oversight of individual learning plans, the promotion of evidence-based pedagogies and in ensuring that the school is promoting an inclusive school culture.

As Australia transitions to a system of inclusive education we need to ensure that the next generation of teachers, instructors and lecturers also have the required knowledge and skills from the outset of their careers. This requires a significant reform to Initial Teacher Education (ITE) programs and graduate programmes (e.g. diplomas and degrees in VET sector and tertiary teaching). Currently there is minimal focus on inclusive education in many courses, resulting in a high of variability in teacher knowledge dependent on the institution at which they received their training.

We would like to highlight the present gold standard that has been set by Queensland University of Technology's ITE program, with every teacher regardless of specialisation completing a minimum of two subjects focused on supporting the implementation of inclusive education. For teachers to be able to support Autistic students, we believe that each course should feature a minimum one core subject dedicated to training teachers for working in inclusive schools. Within inclusive education subjects, teachers should be explicitly taught the legal rights of students with disabilities and neurological differences under Australian and international law, the types of functional challenges experienced by many students with disabilities and differences, and practical evidence-based strategies for supporting these learners within their classrooms.

**With respect to building professional knowledge and capacity within schools the Scope-University of Melbourne Partnership recommends that:**

- Australian governments ensure that all school staff and teaching staff in the VET and Higher Education sectors receive high quality and ongoing training in evidence-based strategies to support the academic and social inclusion of Autistic students.
- Every Australian educational institution should be supported to appoint a full-time Learning Intervention Coordinator responsible for ensuring that all staff have the capacity to support Autistic students, and to ensure that Autistic students are receiving the supports they require to thrive. The person in this leadership position must have a post-graduate specialised qualification.
- The Australian Institute for Teaching and School Leadership (AITSL) should work with state teacher registration bodies to ensure that there is minimum one unit focusing specifically on inclusive education for all university initial teacher education courses. Key focuses within this unit should be 1) the diverse communication and social interaction styles used by many Autistic individuals, 2) augmentative and alternative modes of communication, 3) sensory diversity and sensory support requirements, and 4) executive functioning needs.
- A minimum of one unit of training in inclusive education should be included in early childhood training in the VET sector courses preparing people for childcare and classroom assistance.
- State governments ensure that all schools receive training and/or information sessions delivered by Autistic individuals – Autistic professionals and students (post-school and school-age) in order to learn directly from the lived experience.
- That Universities Australia (the peak body for Higher Education) establish policies and promote practices among Higher Education provides that support the inclusion of Autistic students.

## Employment

Employment is widely recognised as a critical determinant of health, wellbeing, and quality of life. Here it needs to be noted that unemployment and underemployment are major issues for Autistic people. Our research estimates that there are at least 45,994 Autistic Australians who are unemployed and many more who are underemployed. Furthermore, we estimate the cost to the Australian economy of Autistic people remaining unemployed to be approximately \$381, 000, 000 per annum in lost taxation revenue alone (Hayward, 2019).

The disadvantage that Autistic people experience in employment and subsequently their impaired economic participation in society can be attributed to a multitude of factors that could be addressed in policy and systemic interventions (Hayward et al., 2019). Difficulties with and solutions for their engagement in the education system (including at school, in VET sector institutions, and in Higher Education institutions / universities) have already been addressed in this submission. Beyond supporting engagement with the education system, there are both supply side and demand side issues in the employment sector that need to be addressed.

With respect to the supply-side issues, Autistic people would benefit from specialist employment programmes designed to prepare them for and support them into employment in the open labour market (Hayward, McVilly, & Stokes, 2018). This is in contrast to policies and programmes that have previously channelled people into supported or sheltered employment, involving work that underestimated and underutilised their skills, and which was poorly paid relative to their potential contribution to the community and the economy.

With respect to the demand-side of the equation, employers would benefit from information (education) and practical support to employ Autistic people, to maximise their contribution to the workplace. Furthermore, employers would benefit from specialist services to design and implement reasonable adjustments that would maximise the contribution of Autistic people to the workplace and mitigate any potential difficulties arising from, for example, aversive environmental stimuli in the workplace or communication and social interactions difficulties that might occur.

Our research has generated a 'pathway model' to support employment that includes consideration of issues that relate to school and post-school education systems, issues related to transition from education to work for individuals, organisational policies, processes and procedures relating to both recruitment processes and sustaining employment, and the development of career paths that look beyond simply 'getting a job' to personal and professional development across the life span (McVilly, Murfitt, Crosbie, Rouget, & Jacobs, 2019).

One evidence-informed approach that seeks to address both supply-side and demand-side issues in the employment equation is Customised Employment. We are currently engaged in research investigating the adaptation of Customised Employment for the Australian labour market.

Customised Employment is an umbrella term that describes a range of approaches and strategies designed to enhance the employment prospects of people with disability, and other marginalised groups in the community, who experience barriers to gaining and sustaining meaningful and successful employment. It can involve supporting the person to gain work with an employer or, alternatively working for themselves in a small business enterprise. The US Office of Disability Employment Policy (ODEP), within the US Department of Labor, defines Customised Employment in 2002 as the process of:

*'individualizing the employment relationship between employees and employers in ways that meet the needs of both. It is based on an individualized determination of the strengths, needs, and interests of the person with a disability, and is also designed to meet the specific needs of the employer. It may include employment developed through job carving, self-employment or entrepreneurial initiatives, or other job development or restructuring strategies that result in job responsibilities being customized and individually negotiated to fit the needs of individuals with a disability. Customized employment assumes the provision of reasonable accommodations and supports necessary for the individual to perform the functions*

*of a job that is individually negotiated and developed.'* (U.S. Department of Labor, 2002).

Customised employment approaches are designed for job seekers with significant disability and disadvantage in the open labour market. They provide evidence-informed strategies to support such individuals to attain integrated, community employment, with pay at or above the minimum wage. This is made possible by negotiating with employers to target unmet needs of the workplace, tasks better performed by others at a lower pay grade (but still at or above minimum wage), and tasks that would benefit the employer in some discrete manner (Callahan, Griffin, & Hammis, 2011).

Customised employment can involve the adaptation of existing jobs to enable their completion by an employee with particular skills, or the creation of an entirely new job, based on the needs of the employer and specific skills and attributes of prospective employees. Importantly however, the job must be valued by and critical to the employer and their core business. The job must warrant the payment of a living wage.

The typical Customised Employment process begins with the individual job seeker. They are engaged in a formal process sometimes referred to as Discovery (Griffin, Hammis, & Geary, 2007). This process is designed to assist the person, in consultation with those who know them well, to identify their vocational motivations and interests. They also participate in focused Informational Interviews, to refine their motivations and interests into specific jobs to investigate.

The person then engages in work experience in their identified areas of interest. Based on their reaction to and outcomes arising from their work experience, there is then a process of working with employers and developing bespoke employment options that are both of value to the employer and of interest to the person. Sometimes this process involves job carving (Griffin et al., 2007; Moore, McDonald, & Bartlett, 2018; Smith, McVilly, McGillivray, & Chan, 2018). The process of job carving involves the identification of specific tasks that are of value to the employer and which, when combined, constitute a new position in the organisation.

In Customised Employment, systematic instruction is used to induct the person into the workplace and their new job. So too organisational strategies are developed to support the workplace to make the adjustments necessary to secure the persons full integration into the workplace, at both an operational and social level. The need for ongoing supports is regularly reviewed, to ensure the person's skills remain current and that they are able to participate in any workplace transitions that are necessary or take advantage of opportunities to undertake new tasks or pursue promotion.

**With respect to employment, the Scope-University of Melbourne Partnership recommends that:**

- Commonwealth employment policy support specialist programs and strategies to enable Autistic people to obtain open (mainstream) employment and to pursue

small business enterprises, and to support generic employment services to better understand and meet the need of Autistic people.

- Commonwealth employment policy together with the funding mechanisms available through the National Disability Insurance Scheme give priority to programs utilising evidence-informed Customised Employment strategies.
- The National Disability Insurance Scheme, through its Information, Linkages and Capacity Building program (Community Awareness stream) support initiatives to increase the demand-side of the employment equation through initiatives to educate and support employers about the advantages of employing Autistic people and how they can easily make (and at minimal cost) reasonable adjustments to maximise the productivity of and sustain employment for Autistic people in the work place.
- Commonwealth and state governments collaborate in funding programs to support Autistic people in their transition from education (including secondary school, VET sector institutions, and Higher Education / university providers) to employment, including programs utilising Customised Employment.

## Health

### *Health outcomes for Autistic Adults*

Health services research suggests that Autistic adults have different health-related needs, as well as higher rates of healthcare needs, than non-Autistic adults (Croen et al., 2015; Zerbo et al., 2019). However, there is very little research to inform policy or practice that describes or explores therapeutic interventions or determinants of health outcomes amongst Autistic adults, with the vast majority of health and allied health intervention research in Autism focusing on the efficacy and application of interventions and supports in early childhood (Benevides et al., 2020). More research is required to guide health and disability-sector policy and service provision for Autistic adults, including increasing identification and recognition of the health-related needs of Autistic adults by their service providers and support workers. In particular, research priorities should be focused on health interventions and services which are desired by the adult Autism community, and address community-priority health outcomes, such as improvements in quality of life and wellbeing (Bertilsdotter Rosqvist et al., 2019). Community-based research methods, such as participatory and emancipatory collaborative research within disabled communities (e.g. Bertilsdotter Rosqvist et al., 2019; Stone & Priestley, 1996), would assist in facilitating these research outcomes by including the Autism community in all stages of the research process, and lead to higher quality research (Bertilsdotter Rosqvist et al., 2019; Waltz, 2009). Such research has the capacity to discover and interrogate issues, and generate policy and practice solutions that traditional epidemiological and clinical cannot. The recent announcement of the establishment of National Disability Research Partnership by the Commonwealth government is an encouraging development, and it is hoped that it will add to the evidence base on health outcomes for Autistic adults, but further funding is needed.

**With respect to health outcomes for Autistic adults the Scope-University of Melbourne Partnership recommends that:**

- Australian governments, through agencies such as the NHMRC, establish explicit funding priorities and provide funding for research into health interventions and services which are desired by the adult Autism community, and address community-priority health outcomes, such as improvements in quality of life and wellbeing. This research should particularly focus on collaborative methods that ensure research priorities are guided by the Autism community.

*Accessibility of Mainstream Health and Allied Health Services*

The lack of research into therapeutic interventions or determinants of health outcomes amongst Autistic adults is matched by a lack of training regarding the needs of Autistic individuals in mainstream health and allied health service providers in Australia. This manifests in a lack of understanding and resources to accommodate the communication, sensory and functional needs of Autistic children and adults, and can result in Autistic individuals not being able to describe their symptoms, communicate pain, and/or have their symptoms validated and taken seriously. In turn this can affect the care and treatment they receive in the health system. This can result in additional health care costs when symptoms and supports needs become acute, and can contribute to disproportional mortality.

Further exacerbating the health situation of Autistic people, Hospitals and other health and medical services can be inaccessible environments for people on the Autism spectrum (O'Halloran et al., 2019). In our collective experience, which includes consultation with many families and individuals on the Autism spectrum, the unpredictability of these environments combined with overstimulation and lack of retreat spaces can result in extreme and sudden overload for Autistic individuals, potentially preventing them from accessing essential appointments and procedures. This barrier is more commonly experienced by Autistic adults, as there are a number of specialist services for Autistic children.

Finally, a lack of collaboration between services, service providers and across service sectors means that service provision is highly specialised and segregated. Consequently, intersectional service needs, such as any needs of Autistic individuals that are not related specifically to Autism, are poorly supported. For instance, it is well established that women with all types of disability who are victims of sexual assault or domestic and family violence are not able to access adequate support within the disability service sector, but that domestic violence services are inaccessible to them (Thiara, Hague, & Mullender, 2011).

One evidence-based option for addressing these issues is to apply the principles of universal design in health services as a means of removing barriers to accessing mainstream health and allied health services. This is particularly relevant to the Autistic community given the prevalence of under-diagnosis in the adult population, as without a diagnosis, people may not be able to request the supports that they require.

One example of an emerging practice that aims to build the capacity of mainstream services to facilitate access and inclusion by operationalising the principles of universal design and its underlying philosophy of fostering barrier-free environments and inclusive cultures, is Scope's Communication Access Symbol program. Scope's Communication and Inclusion Resource Centre (CIRC) is a world leader in communication access, having pioneered the development of the Communication Access Symbol (see Figure 1), which has now been awarded to over 250 businesses and services across Australia (Bigby et al., 2019; Solarsh & Johnson, 2017a, 2017b; Speech Pathology Australia, 2018).

According to Solarsh et al. (2013), *"Communication access occurs when people are respectful and responsive to individuals with communication difficulties and when strategies and resources are available to support successful communication."* Scope's Communication Access Symbol program aims to increase the capacity of mainstream services, businesses and organisations to have the requisite skills, knowledge and attitude to provide accessible and inclusive services to people who may experience communication difficulties, inclusive of Autistic individuals. The Communication Access Symbol is an emerging and promising initiative. We fully support investments in research to further build the research base backing communication accessible communities for the Autistic population and broader community.

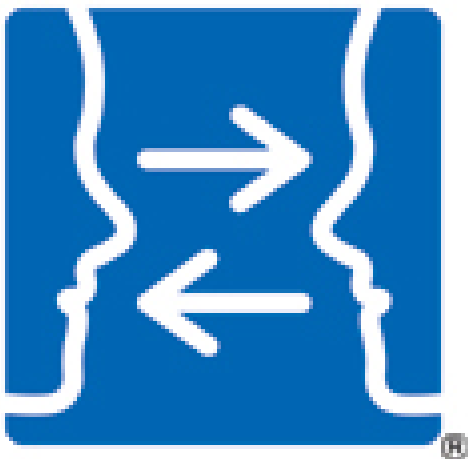


Figure 1: The Communication Access Symbol (source: Scope Australia)

**With respect to accessibility of mainstream health and allied health services the Scope-University of Melbourne Partnership recommends that:**

- Australian governments, regulatory authorities e.g. the Australian Health Practitioner Regulation Agency (AHPRA) and Higher Education providers / Universities provide increased training for health and allied health service providers in the communication, sensory and functional needs of Autistic children and adults.
- AHPRA and other professional bodies such as Speech Pathology Australia and Occupational Therapy Australia require registered allied health practitioners to undertake accredited high quality, Autism-specific professional development as part of their continuing professional education.

- AHPRA-approved tertiary education courses in allied health fields include mandatory training in the communication, sensory and functional needs of Autistic children and adults in the curriculum, and the delivery of such training include Autistic people as lecturers and tutors.
- State and Commonwealth authorities work to ensure health services apply the principles of universal design as a means of removing barriers to accessing mainstream health and allied health services for individuals on the Autism spectrum, with a particular focus on improving access and inclusion for Autistic adults.
- Improved collaboration between services, service providers and across service sectors to ensure that non-Autism related health needs are adequately supported by mainstream services.
- Governments increase funding for research to extend the evidence base promoting communication accessible communities for the Autistic population and broader community.

## Mental health

### *Background*

Mental ill-health is experienced by a high portion of children, adolescents and adults on the Autism spectrum. In addition, mental ill-health has a pervasive negative impact on affected individuals, often above and beyond the impact of Autism itself. However, despite high prevalence and impact, there is a paucity of research and consequently evidence to inform preventative and therapeutic interventions. We lack comprehensive understanding of the risk and resilience factors related to poor mental health outcomes in Autism, and consequently, we lack key data points for informing effective, individualized intervention and support approaches. Given the potential for benefiting long-term outcomes of people with Autism, and additional positive societal and economic impact, mental health of people on the Autism spectrum, particularly for adolescents and adults, needs to be a high priority for research, policy development and practice innovation. However, what we do know is that the mental health conditions prevalent in the general population are also of major concern to Autistic people.

### Prevalence of mental ill-health

Both anxiety and depression are more frequently experienced by people on the Autism spectrum, compared to the general population, and at least 50% of people on the Autism spectrum experience anxiety and depression symptoms at or above the clinically significant threshold (Hedley, Uljarević, Wilmot, Richdale, & Dissanayake, 2017; Uljarević et al., 2019; for an overview see Uljarević et al., 2020). These high rates highlight an area of urgent research into the mental health support needs of Autistic people, as well as the need to understand and characterise the facilitators and barriers to mental health that people on the Autism spectrum experience. Such research evidence can then be used to inform policy and practice innovation.

### Anxiety

Studies reveal that high rates of anxiety are experienced by children, adolescents and adults on the Autism spectrum. Although exact prevalence varies widely across studies, recent large-scale studies and systematic reviews have suggested that at least 40% of children and adolescents on the Autism spectrum meet the criteria for clinically significant anxiety (Van Steensel, Bögels, & Perrin, 2011; see also White & Roberson-Nay, 2009). The rates of anxiety experienced by adults on the Autism spectrum is less well explored, however, recent studies suggest that up to 60% of adults on the Autism spectrum may be affected (Buck et al., 2014; Lever & Geurts, 2016; Uljarević et al., 2019). Furthermore, results from a recent study of Australian adolescents and adults on the Autism spectrum (aged 15 to 80 years) suggest that regardless of the age, at least 40% of people experience clinically significant levels of anxiety. These findings support the call for urgent action to provide both specialist mental health services for those with the most complex support needs, and to up-skill generic mental health services to be able to respond appropriately to others on the Autism spectrum who present with anxiety.

### Depression

Similar to anxiety, reported rates of depression experienced by people on the Autism spectrum have been consistently high. In their meta-analysis of 66 studies, Hudson, Hall, and Harkness (2019) found that rates of depressive disorder were highest when individuals were required to report their own symptoms or when a standardized interview was used, with lifetime rates ranging from 28.5% to 48.6% and current rates from 15.3% to 25.9%. Moreover, a study conducted in the United States found individuals on the Autism spectrum were four times more likely (11.7% to 16.6%) to experience lifetime depression than their typically developing peers (Kessler, Chiu, Demler, Merikangas, & Walters, 2005; Merikangas et al., 2010). Our own work with Australian adolescents and adults on the Autism spectrum supports these findings by consistently identifying that a significant portion (at least 35%) experience high levels of depression (Hedley, Cai, et al., 2018; Hedley, Uljarević, Foley, Richdale, & Trollor, 2018; Hedley, Uljarević, Wilmot, et al., 2017; Uljarević et al., 2019). As with the case for Anxiety, these findings support the call for urgent action to provide both specialist mental health services for those with the most complex support needs, and to up-skill generic mental health services to be able to respond appropriately to others on the Autism spectrum who present with depression.

### *Barriers to good mental health outcomes for people on the Autism spectrum*

In addition to research which establishes the clinical needs of Autistic people, the research also indicates that a significant proportion of people on the Autism spectrum experience barriers to achieving and sustaining good mental health. These barriers include both systemic issues related to policy and resourcing of services and the availability of appropriate technologies for assessment and the provision of therapeutic interventions. practice.

### Assessing Anxiety and Depression

Although assessment of anxiety and depression in non-Autistic populations is a streamlined and standardised process, there are several significant issues related to the assessment of mental health in individuals on the Autism spectrum (see also M. Uljarević et al., 2020 for a

comprehensive overview; Uljarević, Nuske, & Vivanti, 2016). Firstly, the majority of studies exploring anxiety and depression have used questionnaires and interviews designed for general, non-Autistic populations, and several studies have suggested that these instruments do not perform in an optimal manner when used with the Autistic population. More specifically, it has been demonstrated that existing instruments have unstable factor structures in Autistic samples (Magiati et al., 2017; Uljarević, Labuschagne, Bobin, Atkinson, & Hocking, 2018). Crucially, current measures can wrongly ascribe some of the core Autism symptoms to anxiety or depression (for instance, lack of social engagement can be interpreted as either social anxiety or withdrawal) and might miss anxiety and depression symptoms that individuals on the Autism spectrum might express in non-standard ways due to core Autism symptoms, sensory sensitivity or interoception (for example, reduction in special interest can be wrongly interpreted as improvement while it is a symptom of developing depression). Finally, people on the Autism spectrum can experience types of anxiety that are not captured by the current measures (for instance, rare phobias; Halim, Richdale, & Uljarević, 2018). Development in this area requires research and development to address both the adaptation of existing tools and the development new tools.

#### Individual and Social impacts of mental ill-health

Depression and anxiety negatively impact on concurrent and long-term outcomes across differing aspects of functioning. The complex interaction between individual differences and environmental factors is largely under-explored. However, of particular concern are figures suggesting a disproportionate risk of suicidality amongst people on the Autism spectrum (Cassidy et al., 2018; Hedley & Uljarević, 2018; Hirvikoski et al., 2016) and the associated risk between anxiety, depression and suicide. Research has demonstrated that depression and anxiety is associated with suicide risk in both people on the Autism spectrum and individuals that are not on the Autism spectrum (Cassidy et al., 2018; Hedley, Uljarević, Foley, et al., 2018).

The reported higher rates of suicide amongst people on the Autism spectrum compared with individuals not on the Autism spectrum is of further concern (Cassidy et al., 2018; Hedley & Uljarević, 2018; Hirvikoski et al., 2016). A recent systematic review of research suggests that Autistic traits are associated with significantly increased vulnerability to suicidal ideation, suicide attempts, and deaths by suicide (Hedley & Uljarević, 2018). This review summarised studies that included samples of individuals on the Autism spectrum, the general population and; was supplemented through the exploration of personal accounts of individuals on the Autism spectrum. Given the devastating consequences of the suicidality to individuals, their families and the broader community, it is imperative that we have a better understanding of the factors that facilitate and inhibit this risk. Increased knowledge of these factors can inform the design, delivery and evaluation of the appropriate support and services required. Such knowledge and skills need to be built into the pre-service and in-service training requirements of health and allied practitioners, and the community service workforce broadly.

#### Individual and environmental factors

In addition to mental health as a risk, a link between the vulnerability to suicidality and a range of individual and environmental factors appears apparent. For example; perceived social isolation (Cassidy et al., 2018; Hedley, Uljarević, Foley, et al., 2018; Hedley, Uljarević,

Wilmot, Richdale, & Dissanayake, 2018; Pelton & Cassidy, 2017), pressure to ‘camouflage’ Autism traits to match societal norms (i.e. ‘masking’) (Hull et al., 2017; Leedham, Thompson, Smith, & Freeth, 2020) and difficulty accessing health services (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2019) are risk factors to suicidality that need to be addressed.

More specifically, elevated levels of anxiety and depression are associated with increased severity of restricted and repetitive behaviours (Uljarević, Richdale, Evans, Cai, & Leekam, 2017), a range of externalising problems (Mattila et al., 2010), loneliness (White & Roberson-Nay, 2009), higher support needs and poorer employment outcomes (Hedley, Uljarević, Cameron, et al., 2017) and; increased parental levels of affective symptoms (Kerns, Newschaffer, & Berkowitz, 2015). The proposed relationships amongst these variables is complex and further study is required to provide the evidence based needed to inform both policy and practice (Culpin et al., 2018; Gotham et al., 2018; Maddox, Trubanova, & White, 2017).

Given the noted contributing role of mental ill-health as a risk, supporting and addressing mental health needs with people on the Autism spectrum is a crucial first step. Below we consider some of the key risk and resilience factors for anxiety and depression that impact individuals on the Autism spectrum that can be addressed by both universal and individually tailored supports and services.

When considering core Autism symptoms as risk factors for anxiety and depression, it is crucial to go beyond broad generalisations and adopt an individual differences approach that considers fine-grained profiles of strengths and weaknesses across distinct symptom domains.

For instance, although it’s stereotypically thought that people on the Autism spectrum lack the motivation to engage in social interactions and form friendships, our work has suggested that there are considerable differences in the desire to form friendships among people on the Autism spectrum (Phillips et al., 2019). However, heightened social motivation can in some situations put people on the Autism spectrum at a higher risk for poor mental health outcomes in situations where they don’t receive appropriate support. For example, it has been shown that preserved social motivation in combination with impaired social and communication skills may lead to repeated social failures, increased emotional pain and isolation, which, in turn, contributes to the emergence of anxiety (Bellini, 2004; Pickard, Rijdsdijk, Happé, & Mandy, 2017; Mirko Uljarević et al., 2020).

**With respect to barriers to mental health for people on the Autism spectrum the Scope-University of Melbourne Partnership recommends that:**

- Government funding, through agencies such as the ARC, is increased for research into the risk and resilience factors related to poor mental health and psycho-social outcomes in Autism, including the associated risk between anxiety, depression and suicide, to enable evidence informed policy to be established and implemented in practice.

- The National Disability Insurance Agency, through its Information, Linkages and Capacity Building program (Community Awareness stream) build knowledge in the community surrounding the prevalence and manifestations of mental ill-health amongst people on the Autism spectrum and the skills needed to respond appropriately.
- Australian governments, through agencies such as the NHMRC, increase funding for research to improve the assessments of anxiety and depression in people on the Autism spectrum.
- The National Disability Insurance Agency, through its Information, Linkages and Capacity Building program (Community Awareness stream) build awareness and understanding in the community of the challenges and opportunities that people on the Autism spectrum face specifically in relation to the barriers and facilitators to mental health.
- Government in collaboration with regulatory agencies (e.g. AHPRA), professional associations (e.g. for health and allied health practitioners, and educators) and education providers (in both the VET sector and Higher Education) increase the knowledge, skills and readiness of practitioners to more effectively recognise, assess, treat and support Autistic people experiencing mental ill-health and to address the circumstances contributing to such conditions.

#### *Provision of flexible and adaptable supports*

While we don't have an in-depth understanding of the mechanisms behind anxiety in people on the Autism spectrum; our research has identified a range of individual and external environment factors that are associated with the manifestation of mental ill-health.

#### *Risks*

Loneliness, lack of friendships and social support are all major issues affecting people with disability including people with Autism (McVilly et al., 2006a & 2006b). Such social factors have been shown to predict depressive scores (Hedley, Uljarević, Wilmot, et al., 2018; Mazurek, 2014). In addition, social challenges faced by people with Autism account for a large portion of risk for anxiety and depression (Rai et al., 2018).

Importantly, atypical sensory features, in particular sensory hyper-sensitivity, have been consistently implicated as risk factors for both anxiety and depression (Kerns et al., 2015; Lidstone et al., 2014; Uljarević, Lane, Kelly, & Leekam, 2016). Indeed, our work has demonstrated that both children and adults who are particularly sensitive to sensory stimuli from the environment have considerably higher anxiety levels when compared to people with Autism who are less sensory sensitive (Hillman et al., 2020; Mirko Uljarević et al., 2016). This work utilised person-centred statistical approaches such as model-based cluster analysis and factor mixture modelling.

#### *Minimising the need for escalation of support*

The need for structure and predictability that characterises a large portion of people on the Autism spectrum are effective strategies for managing the environment including interactions and warding off anxieties (Leekam, Prior, & Uljarevic, 2011; Uljarević et al., 2019; Uljarević, Richdale, et al., 2017). However, situations where routines and schedules

are interrupted can exacerbate stress and anxiety and lead to negative mental health outcomes.

Additional, non-Autism specific factors such as the ability to regulate emotions are also important risk and resilience factors for mental health. Overall, our recent review provides strong evidence that individuals on the Autism spectrum use less adaptive emotion regulation strategies than individuals who are not on the Autism spectrum (Cai, Richdale, Foley, Trollor, & Uljarević, 2018). In addition, our recent research examining interactions between adaptive and maladaptive emotion regulation strategy use in people on the Autism spectrum suggest that the higher use of an adaptive strategy might be a protective factor for psychological wellbeing in individuals who also show high use of maladaptive strategies (Cai, Richdale, Dissanayake, Trollor, & Uljarević, 2019; Cai et al., 2018).

Given that anxiety and depression have a significant negative impact on the functioning of individuals on the Autism spectrum and their families, often over and above the contribution of core-Autism traits and developmental level, addressing the facilitators of mental health experienced by people on the Autism spectrum should be a priority in the field. Crucially, all the risk and resilience factors identified in this submission are readily addressable if the appropriate policies and supporting practices were established. Individually tailored supports and services can ensure better outcomes for people on the Autism spectrum.

For instance, by enabling adjustments to educational and vocational environments that enable people Autism on the Autism spectrum follow their preferred structure and routines that minimise unpredictability and exposure to loud sensory environments; it is possible to significantly reduce sources of anxiety and stress.

Crucially, through the implementation of appropriate support strategies that minimise stress and anxiety, modifications can have a range of additional benefits such as improving mental health as has been found to have positive flow on effects related to educational and vocational outcomes (Hedley, Uljarević, Cameron, et al., 2017).

**With respect to the provision of flexible and adaptable supports the Scope-University of Melbourne Partnership recommends that:**

- The National Disability Insurance Agency, through its Information, Linkages and Capacity Building program (Community Awareness stream, and Capacity Building for Mainstream Services stream) increase understanding of how available support programmes already implemented across clinical, education and vocational settings can be adjusted and tailored for people on the Autism spectrum based on their specific profiles of strengths and areas of support need.
- Governments, through agencies such as the ARC and NHMRC, increase funding and research efforts aimed at designing and trialling dedicated, individualised support programmes aimed at addressing key risk factors behind anxiety and depression in people on the Autism spectrum following gold standard treatment design and evaluation practices, in particular randomised controlled trials;
- The National Disability Insurance Agency, through its Information, Linkages and Capacity Building program (Community Awareness stream), in partnership with people on the Autism spectrum and their allies, increase awareness and

understanding of the principles and practices of universal design including effective management strategies that support reciprocal adaptivity in social and built environments. Particularly in relation to the promotion of inclusive and accessible: attitudes, awareness, skills and knowledge; built environments including sensory friendly spaces; and communication and engagement practices

#### *Accessibility of mainstream mental health services*

Due to the high prevalence of mental ill-health experienced by people on the Autism spectrum, it is imperative that mainstream service practitioners are aware of and are appropriately equipped with the competencies and resources required to deliver individualised supports and services. As equally important, is the quality of engagement between people on the Autism spectrum, their allies and mainstream services personnel.

#### **With respect to accessibility of mainstream mental health services the Scope-University of Melbourne Partnership recommends that:**

- The National Disability Insurance Agency, through its Information, Linkages and Capacity Building program, increase funding to build the capacity of mainstream services to deliver individualised supports and services, including the provision of reasonable adjustments in vocation and education settings (ILC Capacity Building for Mainstream Services stream) and, to appropriate referral pathways for specialised supports and services (ILC Information Linkages and Referrals stream).

#### The NDIS

The Scope-University of Melbourne Partnership considers the efforts of the NDIS to both address individual needs and foster systemic change in support of Autistic people a critical arm of government policy. Autism is currently the most prevalent primary diagnosis of children aged 0–14 years entering the NDIS (National Disability Insurance Agency, 2020a). In 2020 31% of all NDIS participants, and 53% of participants aged 0 – 14 identified Autism as their primary diagnosis (National Disability Insurance Agency, 2020b).

#### *Therapeutic Service Provision*

Individualised health and allied health supports, that are both supported by empirical evidence and demonstrate Autistic cultural competency are critical to achieving the best possible outcomes for all Autistic individuals under the NDIS, and effective intervention requires such programs to be delivered by experienced practitioners (e.g. Prior, Roberts, Rodger, Williams, & Sutherland, 2011). However, the systemic uptake of research findings and integration of research evidence into clinical practice in Autism remains an ongoing challenge in Australia (e.g. J. M. Paynter et al., 2017; J. M. Paynter & Keen, 2015).

Several factors influence this, including:

- Competing demands on practitioners (e.g. Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015).
- Time and organisational barriers (e.g. Olswang & Goldstein, 2017).
- Limited knowledge of the research evidence and best practice guidelines in Autism (J. Paynter, Sulek, Luskin-Saxby, Trembath, & Keen, 2018).
- Insufficient accredited professional development and training opportunities (both pre-service and in-service) for practitioners in interventions that have evidence of effectiveness for Autistic people (Elsabbagh et al., 2014; J. Paynter et al., 2018).

The structure and implementation of the NDIS has been identified as exacerbating many of these challenges. Firstly, service needs and funding allocations are typically determined by consumers, in collaboration with NDIS Planners and Local Area Coordinators, many of whom have little experience in the disability services sector in general, and in Autism in particular, with little consultation with experienced practitioners and certainly very little allied health or other professional assessment to support planning decisions (Malbon, Carey, & Dickinson, 2018; M. McDonald, Davis, & Mahar, 2016). We have observed that this further results in clinical areas of need being overlooked in the NDIS planning phase. We have also observed a tendency to prioritise diagnostic classification over functional assessments when allocating supports for Autistic children. For example, a child with a Level 1 Autism diagnosis not being accepted into the scheme and therefore missing out on much needed supports. While a Level 2 or 3 diagnosis is on List A<sup>1</sup> for automatic acceptance into the scheme, a Level 1 diagnosis is on List B<sup>2</sup> which requires further investigation.

In addition, the standard amounts of funding packages allocated for supports in individual NDIS plans has resulted in practitioners being driven to make decisions about treatment dosage and intensity based on the available funding, rather than clinical best practice or individual client needs. Such circumstances point to the possibility of the National Disability Insurance Scheme progressing a US-style managed health care model.

Additionally, retaining allied health practitioners with the appropriate knowledge and skills to meet the needs of Autistic NDIS participants is proving to be a challenge across the disability sector (Malbon et al., 2018). In 2018, National Disability Services reported that allied health practitioners were the most difficult staff to attract and retain in the disability service sector, particularly in regional and remote areas (National Disability Services, 2018). Similarly, less than half (43%) of disability service providers indicated that they expect to be able to meet future demand for services (National Disability Services, 2017).

A final observation from our practice is that while the NDIA recognise and register music, art and animal-assisted therapists as providers, we are aware that Autistic individuals are rarely provided with funding for these therapies, even when they specifically request them and have reports from therapists to prove that these therapies are working for them.

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<sup>1</sup> List A: "Conditions which are likely to meet the disability requirements in section 24 of the NDIS Act" (NDIA, 2019)

<sup>2</sup> List B: "Permanent conditions for which functional capacity are variable and further assessment of functional capacity is generally required" (NDIA, 2019)

Autistic individuals often respond much better to non-talk-based therapies i.e. music therapy, art therapy and animal-assisted therapy, rather than traditional counselling or psychology (Eren, 2015; Schweizer, Knorth, & Spreen, 2014; Wijker, Leontjevas, Spek, & Enders-Slegers, 2020).

**With respect to therapeutic service provision the Scope-University of Melbourne Partnership recommends that:**

- Government in collaboration with regulatory agencies (e.g. AHPRA), professional associations (e.g. for health and allied health practitioners, and educators) and education providers (in both the VET sector and Higher Education) work to ensure Autism-specific training is provided University All University-level pre-service and in-service professional development and training in Autism should include content around Autistic cultural competency, co-developed and delivered by Autistic lecturers and trainers.
- Funding is provided by the NDIS within the disability services sector for allied health practitioners operating under the NDIS to undertake high quality, Autism-specific professional development, similarly co-developed and presented by Autistic teachers and trainers.
- Funding be made available by the NDIS for health and allied health professionals to support Autistic individuals and families entering the scheme for the first time to prepare for their first NDIS plan.
- NDIS plans to be informed by the provision of reports (funded by the NDIS) with recommendations for individualised funding.
- Individuals with an Autism diagnosis should only be allocated an NDIS planner/LAC with training/knowledge/lived experience of Autism.

### Concluding summary and recommendations

The Scope-University of Melbourne Partnership appreciates the opportunity to make this submission to the Select Committee on Autism addressing a range of issues that draw on our collective professional and academic expertise, and for several involved in the preparation of this submission our professional and academic expertise has been combined with our lived experience of Autism. We provide evidence-informed perspectives across each of our five topic areas while being mindful of their intersectionality. We believe that greater clarity is required from Australian governments in defining the way that mainstream services and supports work to complement specialist services and supports and improve outcomes for Autistic people. Our recommendations are therefore formulated with a view to generating both systemic and ground-level change. In closing, the Partnership wishes to reiterate the vital importance of engaging with Autistic people in the co-design and implementation of research and the subsequent formulation of public policy that affects them, ensuring always that their preferences for communication and social interaction are respected.

## Appendix A: Glossary

**Ableist language:** language that is derogatory, abusive or negative about disability. Ableism is the systemic exclusion of people with disability, often through language.

**Comorbidity:** the co-occurrence of one or more disorders in the same child or adolescent either at the same time or in some causal sequence

**Dual disability:** a person with a dual disability has a developmental disability (intellectual disability or autism spectrum disorders) and a mental illness

**Echolalia:** Many people on the autism spectrum use echolalia, which means they imitate things that they have seen or heard. This might be the words, sentences or actions of other people, or a favourite video, sound or song. Echolalia can be immediate (i.e. repeating something that was just seen or heard), or delayed (i.e. repeating something that was seen or heard a while ago). People typically use echolalia to communicate something to others, but it can also be a form of verbal self-stimulation.

**Neurodiversity:** the concept that variations in the brain are normal, as are conditions such as autism spectrum disorder which stem from differences in the brain. A person on the Autism spectrum may identify as being neurodiverse.

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