

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability

Promoting Inclusion Issues Paper

Submission by Autism Spectrum Australia (**Aspect**)

May 2021

Introduction

Autism Spectrum Australia (**Aspect**) is Australia's largest autism-specific service provider, with one of the biggest autism-specific schools programs in the world. We are a not-for-profit organisation and we work in partnership with people on the autism spectrum of all ages to deliver evidence-informed person-centred solutions across education, therapy, employment, community supports, diagnostic services and autism focused research, training and consultancies. All of our work is focussed on understanding, engaging and celebrating the strengths, interests and aspirations of people on the autism spectrum.

Aspect's approach to this response

Aspect supports and welcomes the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* and encourages others to read our previous submissions, which are available on our [website](#). Our submission does not address all questions in the *Promoting Inclusion Issues Paper (Issues Paper)*; rather we have provided comments that relate to a number of in the Issues Paper questions in a different format to minimise repetition of information. Aspect notes that some of the information provided in this response also has relevance for some of the questions posed in the Disability Royal Commission's *Rights and Attitudes Issues Paper*.

To develop this response to the Issues Paper, Aspect has drawn from internal and external research and literature reviews through Aspect Research Centre for Autism Practice (ARCAP) for known information related to barriers and inclusion. Aspect also took the following three questions to Aspect's inclusion reference groups and committees (Reconciliation Action Plan Working Group; Pride Committee; LGBTQIA+ Advisory Committee, Multicultural Committee, Disability Access and Inclusion Plan Committee, and the Aspect Think Tank for autistic perspectives) to ensure we could capture elements of intersectionality and the influence of that on the responses. The three questions posed to the reference groups were:

1. What makes an inclusive society for people on the autism spectrum?
2. What are the key barriers experienced by people on the autism spectrum?
3. What do we know is useful or works to achieve inclusion for people on the autism spectrum?

What makes an inclusive society for people on the autism spectrum?

Across all Aspect's inclusion reference groups, the uniting theme for achieving inclusion that was discussed was the attitudes and welcoming behaviours of others.

Inclusion occurs when a diversity of people of different ages, cultural backgrounds, genders and abilities:

- feel valued and respected;
- have access to opportunities and resources;
- can contribute their experiences, perspectives and talents to improve their communities;
- feel welcomed by everyone; and
- have a voice however they communicate (e.g. spoken word, AUSLAN or augmented and alternative communication).

Our reference group and committee members said there did not need to be significant adaptations to achieve inclusion. Often, common respect, courtesy and celebration of each of the unique characteristics and background of a person (and indeed all people in society) were all that were required.

Where adaptations are required, universal design for the development of facilities, premises and programs is favoured. Universal design means planning and designs of physical and digital environments, infrastructure or product packaging and labelling that is usable or accessible by a wide range of people, regardless of age, size, cognitive or physical ability. With universal design, adaptations are either readily accessible or minimal as it builds in accessibility from the outset. Accessibility can include considerations of safety (physical, emotional, cultural, etc.) as well as physical access. Without safe and available access, inclusion is simply not possible.

Members said such environments and contexts typically:

- reflect positive connotations about the use of supports;
- maintain a culture of person-centred inclusion and the inherent value in diversity;
- see people beyond labels and stereotypes;
- have a strengths-based approach;
- ask people with disability what it is that they need to be included;
- value the perspectives of people with disability and from diverse backgrounds through employment at all levels;
- ensure authentic voices are acted upon; and
- not only seek out but pay people with lived experiences for their consultancy and co-production to ensure meaningful rather than tokenistic representation.

In 2019, the [Aspect Research Centre for Autism Practice \(ARCAP\)](#) completed a literature review on the principles of best autism practice for transition and inclusion (Agius & Gibbs (2019), to inform the [Aspect Comprehensive Approach \(ACA\)](#). The ACA encapsulates more than 50 years of Aspect's expertise in providing services to children, young people and adults on the autism spectrum and is continuously reviewed against the most up-to-date research through ARCAP. This particular literature review looked at different life stages in a variety of environments, including early childhood services, primary and secondary education; tertiary education, employment and community settings, and identified three key themes across these environments and life stages:

1. The **design of the environment** facilitates or hinders inclusion. This includes sensory features, predictability & routines, calm spaces, visual communication etc. Ideally, we build inclusive environments from the beginning using universal / inclusive design, but we can and should also assess and adapt environments to remove barriers.

2. The nature of **supports for Autistic individual**. Good practice suggests that we promote people's advocacy for their rights and needs, and provide easy access to relevant networks and supports. There are a range of specific supports that people might need through their lifetime depending upon circumstances, health and wellbeing etc.

Active Support is one example of this. Autistic adults with intellectual disabilities are often not included in everyday activities and as a result can be bored, under-occupied and lose life skills. Active Support is an approach that deliberately includes people in everyday activities and is a key part of Aspect's adult support (with Active Support leader positions).

3. The **knowledge, beliefs and behaviours of other people** in these environments. There are many myths and misunderstandings about autism that can be resolved through co-delivered training. In addition, it is important to get to know each Autistic person and to individualise support that focusses on strengths and interests as well as support needs. It is important to note that cultures (of companies, schools, organisation, etc.) directly impact the people who deliver services and supports.

What are the key barriers experienced by people on the autism spectrum?

The existence of social, educational and economic exclusion makes it difficult for an individual to achieve their goals or be included in other life areas. Identifying the causes, mechanisms and effects of social exclusion is essential to formulate policies that will enable the greatest number of people to lead productive lives, and enjoy the economic and psychological benefits of fully participating and feel included within all settings and environments in society. This is a fundamental human right. However, for many individuals on the autism spectrum, experiencing authentic inclusion is difficult due to stigmatising societal attitudes and physical environments that do not consider the particular needs of autistic people. Inclusion as a concept, however, encompasses more than just an individual's presence within a particular setting, rather that the individual perceives themselves as *belonging* within the setting, whilst being *authentically* themselves and not needing to change who they are in order to 'fit in' (Jansen, Otten, van der Zee, & Jans, 2014).

Just as attitudes were considered by all Aspect's reference groups and committees to be the biggest enabler for achieving inclusion, so too were they considered to represent the biggest barrier. Inclusion as a human right could be summarised as everybody's right to *be, have, do* whatever everyone else *is, has, does*. Unfortunately, many barriers exist simply because inclusion is not seen as an inherent human right, but as optional or aspirational. Whilst it was acknowledged that Australia generally has good intentions to be inclusive, the lack of knowledge, awareness of diverse needs, and mandated drivers for inclusive human rights recognition entrenched in Australian law has resulted in an Australian society that is currently far from inclusive, and often not even accessible. This was highlighted by one member of Aspect's Think Tank who commented that "*Inclusion is SO slow. I'll be dead by the time we are included adequately*".

Pockets of good inclusion practice in Australian society have progressed in many government, non-government and public services through the implementation of Disability Inclusion Access Plans (DIAP), however, DIAPs have not been developed or implemented in all public services. Furthermore, DIAP and other disability access initiatives are likely to be in competition for funding over more discretionary service improvements, which was discussed

as causing people with disability to feel devalued. For example, the roll-out of free Wi-Fi on various Australian state public transport services has progressed in both trial and permanent instalments for over a decade, however the different state transport authorities acknowledge in the information available on their websites and individual DIAPs that full independent access for all people with disability across all public transport in their jurisdiction is not yet achieved. Whilst, arguably, access to the internet could support the availability of some online access and inclusion measures, it is not detailed anywhere in publicly available state transport information that the free Wi-Fi has been established for this reason.

Individuals on the autism spectrum often experience barriers to inclusion in many aspects of their life. This includes where they are discriminated against even before they put their foot in the door by diversion to disability specific pathways, without consideration of choice or interests as to the environment they wish to partake in. If individual inclusion needs are to be met, there needs to be a range of available options for provision in all public services. This includes, but is not limited to access to appropriate

- education, both during childhood and in tertiary settings;
- physical and mental health care;
- opportunities for employment; and
- opportunities for social participation.

Examples of the current barriers include high rates of school exclusion/detention amongst autistic children (Brede et al., 2017), elevated risk of premature mortality (Hirvikovski et al., 2016), higher rates of unmet health care needs, lack of access to appropriate mental health treatment (Adams & Young, 2020) and high rates of unemployment (Scott et al., 2015). In many sectors, whilst there have been ad hoc initiatives driven by invested staff who have sought out people with disability, advocates and representative organisations to inform and develop their inclusion practices, work has only just begun at a systemic level to include people with 'hidden disabilities'. (E.g. Psychosocial or cognitive impairments and people on the autism spectrum were explicitly considered for the first time in the current federal [Reform of the Disability Standards for Accessible Transport 2002](#)).

Often people are left to self-advocate for their own inclusion, particularly where there is no internal driver for better inclusion, or where mere access or integration rather than full inclusion is seen as the goal. Our reference groups spoke about this unfair expectation for people with disability having to lead the charge for their inclusion. At times, this results in people with disability experiencing fatigue over the societal lack of understanding of their own needs, which causes them to feel like giving up the fight to improve the circumstances. One Aspect Think Tank member commented "*I just need to feel like it's not a fight, like people want to hear my concerns and are enthusiastic to improve things and understand*". These barriers can be amplified when considering the background, culture and minority group status of a person with disability, that may be subject to exclusion criteria for entry into services that would assist in relevant adaptations or skill development. These additional barriers may be due to:

- citizenship or visa status;
- language barriers;
- locality in regional or remote areas; or even
- the impact of the disability itself (as it is seen for a large majority of people with disability who are not eligible for the NDIS).

Further stereotyping and lack of available supports for First Nations people or people who identify as LGBTQIA+ can at times result in double discrimination.

What do we know is useful or works to achieve inclusion for people on the autism spectrum?

Although research into facilitation of inclusion of individuals on the autism spectrum across the lifespan is reasonably recent, a number of practices/approaches have been found to be important. The practices/approaches described below are drawn from systematic reviews into inclusion across a range of areas conducted over the last five years (Hamuth et al., 2018; Mason et al., 2019; Adams & Young 2020; Toor, Hanley & Hebron, 2016):

- **Collaboration** between all who are involved in supporting an individual person is critical for successful inclusion. This is often problematic in practice, particularly when an individual is being supported by multiple professionals who often are working in isolation from one another.
- Support to foster inclusion needs to be **individualised and person-centred** aiming to understand the unique experiences of the Autistic individual, and plan for and implement strategies that address their challenges in a particular environment.
- Professionals and other support providers must be **appropriately trained and have an understanding and awareness of autism in particular**. The way in which teachers, other professionals and support people feel about their ability to provide support can impact inclusion of an individual on the autism spectrum. If support staff and professionals feel empowered in their role, have a strong understanding of autism and are equipped with strategies to provide support, individuals on the autism spectrum are more likely to be successfully included.
- It is also important that there is at least an equal focus on environmental factors that may be hindering or facilitating inclusion. Previously, inclusion was thought to be achieved by focusing on changing/improving the behaviour/skills of the individual, based on medicalised/ biological notions of autism. However, there is an emerging consensus that the **environment or setting should also be accommodated** to support the person on the spectrum. In addition, other individuals in the environment need to be educated about difference to improve their attitudes towards and beliefs about individuals on the autism spectrum.

Aspect's reference groups all spoke about meaningful, positive representation (visually and in all levels of leadership and decision making), with clear processes, and really listening to people on the autism spectrum of all diverse backgrounds and intersectionality as being fundamental to inclusion. It was discussed that co-production and co-design of environments and services were a step towards the disability rights mantra "Nothing about us, without us" and that the ultimate goal to achieve inclusion should be simply "Nothing without us". It was also pointed out that universal design principles were not just good for people with disability, with many people without disability finding improvements to their own access when universal design principles are applied; and that specific cultural lenses should be applied in addition to universal design principles to ensure cultural safety.

Aspect's inclusion journey

Aspect acknowledges that it is on a journey to continuously improve the way we work, look at what we are doing, where we are going well and what could be done differently. Inclusion at Aspect is underpinned by our [Embracing Diversity](#) policy. Tangible actions behind this policy include:

- Aspect’s Strategic Plan, led by its core strategies that include working in partnership with people on the autism spectrum and the delivery of inclusive services
- [ARCAP partnership research approach](#)
- Ongoing works in [diversity and inclusion practices at Aspect](#) to account for intersectional needs of the people we support and our staff, including:
 - [Engaging people on the autism spectrum](#) – including the [Aspect Advisory Council](#), Aspect Think Tank, [Aspect School Student Representative Councils \(SRC\)](#) and the employment of Inclusion Advisors
 - Aspect’s [Disability Access and Inclusion](#) plan that was developed in partnership with the Autistic Self-Advocacy Network (ASAN)
 - [Lesbian, Gay, Bisexual, Transgender/gender diverse, Queer & questioning, Intersex, Asexual/Aromantic and other gender or sexuality diversity \(LGBTQIA+\)](#) plan
 - [Aboriginal and Torres Strait Islander People](#) Reconciliation Action Plan, and the [Aboriginal and Torres Strait Islander Acknowledgement & Commitment policy](#)
 - [Multicultural Community Engagement](#) Plan
 - Use of Acknowledgement of Country and Inclusion Statements at all formal meetings
 - Providing [information about Aspect in easy read](#) English to support comprehension, and how to [access information in other languages](#)
 - Establishment of the Aspect Autistic Employees’ Network
 - Establishment of the Autistic Communications Working Group and other Autistic-representative groups to assist Aspect in the development of its corporate and fundraising communications
- Awareness raising, including:
 - [We Belong and We Belong Too](#) ongoing research program
 - [a different brilliant®](#) podcast – examples include the “[Nothing About Us Without Us](#)” episode and “[Autism Friendly](#)” episode
 - Internal and external [blogs](#), [videos](#) and [articles](#) written by autistic individuals or about autism – examples include “[What can an individual do to make the world more autism-friendly?](#)” and “[Ten Tips for an Autism-Friendly Holiday Season](#)”.
 - Our work with our [Strategic Partners](#)
 - Working with businesses and communities to create an [Autism Friendly Australia](#) – see further information in [Attachment 1](#)
- Delivering Aspect’s schools and services using the [ACA](#), with inclusion and quality of life being a major component of the ACA elements of support to guide evidence-based practice.
- Aspect also contributes to the production of training and resources targeted at culturally and linguistically diverse communities, as well as First Nations communities, through the delivery of [Positive Partnerships](#), which is funded by the Australian Government Department of Education, Skills and Employment.

Recommendations and Conclusion

“There is an emerging notion that inclusion relies on shifting social attitudes and the environment. To enable this, service providers need to understand the barriers and facilitators of inclusion at individual, environmental and systems levels in order to build an understanding of best practices that will then support the inclusion of individuals on the autism spectrum across all settings.” – Agius & Gibbs (2019).

Aspect's inclusion reference groups and committees were clear in their comments and suggestions that Australia is far from inclusive, from the systemic considerations in government policy through to the micro-design considerations like the impact of carpet patterns in a public building. Changes in the environment and cultural attitudes about inclusion requires the acknowledgement that there exists practical things that can and must be done. Passive goodwill about acknowledging diversity and inclusion needs without active tangible actions is not enough.

Aspect endorses the recommendations made within our inclusion reference groups and committees that the Australian Federal and State governments should:

- do more to encourage and promote inclusion for all people with disability represented across all intersectionality;
- make the state and Federal government itself as well as and non-government organisations more accountable to inclusion measures that are holistic, mandatory and adequately funded;
- lead from the top down to support the role of non-government and service providers to understand the value of inclusion, both in universal design and targeted disability initiatives (recognising that one size does not fit all and the importance of choice);
- invest in resources and timelines for completion that demonstrates the priority of ensuring all people are included in Australian society. This investment should:
 - extend to the development and implementation of frameworks for inclusion that can be replicated across different contexts and drive practice forward; and
 - prioritise spending streams, with basic access rights to all established prior to funding discretionary features in public services, as a mandate.

Genuine inclusion, as described in this paper, must be entrenched in Australian society in order for the human rights of people with disability to be fully realised.

Aspect would welcome the opportunity to discuss this Issues Paper response further.

Attachment 1: Promoting Inclusion in the Wider Community - Aspect’s Autism Friendly Framework

Aspect’s Autism Friendly Environments Framework is a unique framework utilised to consult, develop and create [Autism Friendly Environments](#), both internally at Aspect and with the wider community. The framework evolved over four years of autism friendly practice in Aspect Practice – a division of Aspect. The Framework was drawn from our expertise, listening to Autistic people and integrated a range of relevant research areas to develop something comprehensive and relevant to varying contexts. This framework is replicable in context and can and has been applied to settings such as airports, shops, museums, events such as opera or pantomime, zoos and office environments (including Aspect’s National Office).

Assessment

Application of the Aspect Autism Friendly Environments Framework starts with an assessment of the environment or setting to identify positives in each area of the Autism Friendly Environments Framework as well as any opportunities for improvement. Assessments are undertaken with at least one Autistic person to ensure authentic autistic perspectives of the environment subject to assessment, along with a professional with expertise in autism or universal design for general considerations. This is in part to recognise that every individual on the autism spectrum is unique and experiences will vary, so an Autistic person cannot be expected to represent all autistic people.

Aspect Autism Friendly Environments Framework

‘Typical Inclusion Strategies’	Explanation
1. Culture of Inclusion	Ensuring all people are explicitly made to feel welcome, understood and valued for who they are <i>e.g. a sensory map helped someone feel thought about and welcomed</i>
2. Preparation and Predictability	Sharing information beforehand about what to expect and the practicalities (who, what, where, when) for a person, the sensory environment, ‘hidden curriculum’ issues and positive behavioural expectations <i>The hidden curriculum is the type of behaviour rules that most people just seem to know for that situation</i>
3. Visual Structure, organisation and clarity	Organising the environment in a visual way (i.e. signs, symbols, wayfinding, rules), so that people are supported to know where to go & what to do without the need for extra verbal information. This reduces uncertainty and provides clarity.
4. Sensory adaptations	Reducing overwhelming sensory experiences, and making sensory experiences predictable. Making accommodations and adaptations where possible to support coping and control. Providing positive sensory experiences (e.g. chill out zones, quiet times).
5. Communication supports	Understanding and supporting differences in communication. Adapting to different communication strategies and providing resources and supports for meaningful communication.
6. Proactive problem solving	Anticipating any stressors or problems that might arise and finding ways to minimise the risk <i>‘If you can predict it, you can prevent it’</i>

7. Staff training	Training staff to understand, value and support people on the autism spectrum or with other disabilities, and support as needed with parent / carer advice.
8. Continuous Improvement	Regularly reviewing processes and encouraging, listening to and acting on feedback from people on the autism spectrum or with other disabilities about their experiences.

Consultation for intervention and possible adaptations

The environment or setting is provided with the results of the assessment in the ‘Typical Inclusion Strategies’ areas detailed in the table above. The organisation is consulted and supported to identify relevant context specific interventions and adaptations possible to improve autistic accessibility and inclusion, as well as existing identified strengths in these areas. Further feedback and evaluations of the process are set and scheduled for ongoing review.

Organisations have engaged with Aspect to complete focused support and development of individual ‘Typical Inclusion Strategies’ areas, or for comprehensive assessments and development across the whole Framework. Examples of these projects can be found on our [website](#), and in the case studies below.

Case study 1 – Autism Alert Card

In 2020 Aspect developed the [Autism Alert Card](#). Produced in collaboration with Autistic adults, the card is designed to assist Autistic individuals to communicate their need for support in situations that may be challenging. The card was developed after Aspect was contacted by a number of Autistic adults who identified situations – such as travelling through busy airports or talking to police – as being extremely stressful, often making communication difficult.

The card details why the person may be struggling to communicate and has a number of simple tips to explain:

- *How the person may present*
- *How to help the person communicate*
- *What to know about meltdowns*

Aspect are offering these cards free to people on the autism spectrum and have been incredibly well received by the autism community.

I am on the autism spectrum

- I am likely to be **extremely anxious** in unfamiliar situations
- I may become **uncommunicative or nonverbal** under stress
- My behaviour may appear to be **unpredictable or inappropriate**
- I may be **oversensitive** to light, touch or sound
- I may need the **help** of someone who is familiar with autism

Case study 2 – Inclusive Beaches program

In February 2018, Autism Spectrum Australia (Aspect) and Surf Life Saving Australia (SLSA) ran a pilot of an initiative to make beaches and Surf Life Saving Clubs, particularly Nippers, more inclusive for people with a disability, including those on the autism spectrum.

Informed by research conducted by the Aspect Research Centre for Autism Practice to identify the barrier and facilitators to inclusion at Nippers for autistic children and their families, The [Inclusive Beaches](#) project saw Aspect provide specialist autism-specific training, support and resources for people in the surf lifesaving community to understand the needs of children on the autism spectrum.

People on the autism spectrum can often be excluded from beach activities, due to difficulties with communication, specifically, challenges with understanding water safety with some families avoiding the beach completely because they believed they would not be able to keep their family member safe and may not be able to access appropriate support if required.

There are currently more than 40 Surf Life Saving clubs across Australia running inclusion programs for people with different abilities, with the aim of the program to assist Surf Life Saving clubs to support the inclusion of people of different abilities and backgrounds to join their local club and learn to be safe at the beach.

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