

30 October 2023



104 Greenhill Road
Unley SA 5061

National Autism Strategy
Department of Social Services
GPO Box 9820
Canberra, ACT 2601

t: (08) 8373 8333
f: (08) 8373 8373

e: admin@purpleorange.org.au
w: www.purpleorange.org.au

By email: AutismPolicy@dss.gov.au

Dear Secretary,

Re: Consultation on developing the National Autism Strategy

Thank you for the opportunity to provide feedback to the Department of Social Services (DSS) regarding this initial consultation on the development of the National Autism Strategy.

JFA Purple Orange welcomes this initiative and acknowledges the vast breadth of important issues that the National Autism Strategy will encompass. It is critical the process to develop the Strategy places the voices and needs of Autistic communities at its centre, drawing on their experiences, insights, and ideas for change. In this submission, our focus is to highlight the value of diverse voices being heard in shaping the Strategy and to draw attention to some examples where we have been told by Autistic people that change is particularly urgent. It is not intended to provide a comprehensive analysis because we strongly believe a genuine co-design approach that directly involves a diversity of Autistic people in decision-making should be established to lead the Strategy's development and implementation.

Below, we discuss in more detail the need for genuine co-design and Autistic leadership to be core principles in the process to develop the Strategy. We also touch on our Agency's [Model of Citizenship Support](#) because we believe it can provide a useful lens through which to consider many of the themes set out in the Discussion Paper for this consultation. Then, we briefly focus on each of these themes with a strong emphasis on what Autistic people have told us across many aspects of our work, including co-design initiatives, consultations, our engagement with the range of peer networks that our Agency hosts, capacity building projects, and similar. Finally, we reiterate that the Strategy will only deliver outcomes if it is backed by a significant investment of resources to deliver on its commitments and if a robust monitoring and reporting framework is established. In preparing this submission, we have noted the Discussion Paper acknowledges the valuable insights already shared this year in the South Australian Government's Consultation Report for its first [Autism Strategy](#) and we reiterate the importance of listening to the Autistic voices included therein.

Principles underpinning the development of a National Autism Strategy

Adopt a genuine co-design process

In developing the new National Autism Strategy, the DSS has a significant opportunity to implement a co-design process that ensures Autistic Australians are not only heard, but also directly involved in leading, shaping, and making decisions about the Strategy. It is vital we see Autistic people in leadership roles during the development and implementation of this Strategy. Indeed, governments and government departments should proactively adopt genuine co-design processes as a means to enhance policy development across all areas of their work. However, we are concerned that many of the processes that governments are currently referring to as co-design fall well short of best practice and do not include active involvement in decision-making roles. The Autistic community has a wealth of knowledge, insight, and skills, and are the experts in all the themes identified in the Discussion Paper. We encourage the DSS to explore examples of best practice, for example, by accessing our Guide to Co-Design with People Living with Disability, which was itself co-designed, via our [website](#).

Recommendation 1: The Department of Social Services (DSS) should adopt a genuine co-design process including diverse representation from across Australia's Autistic communities. Autistic people should be central to this process and hold leadership and decision-making roles throughout the development and implementation of the National Autism Strategy.

Utilising the Model of Citizenship Support

The National Autism Strategy presents an opportunity for governments to take a whole-of-government, whole-of-life approach to policies affecting Autistic people. The Model of Citizenship Support, developed by our agency, provides a comprehensive contextual framework for organising policy and practice in support of people living with disability and is a useful lens through which to consider many of the issues that the Strategy will cover. It sets out how people can be supported to build their chances of a good life and maximise their *Citizenship* through four different interrelated types of assets, termed the Four Capitals. These are: Personal Capital (how the person sees themselves), Knowledge Capital (what the person knows and learns), Material Capital (money and the tangible things in our lives), and Social Capital (having people in our lives whom we know and know us). These Capitals apply to any person and can reveal what types of investment and assistance might be helpful for someone to build a good life for themselves. These Capitals can be enhanced or diminished by the choices and supports available to people.

The concept of *Citizenship* envisions each person being an active and valued member of their local community. *Citizenship* is fostered when people participate and have opportunities to personally define their choices. It is also founded on the idea that people grow through their involvement in meaningful activities and relationships characterised by acceptance, belonging, and love. *Citizenship* means having opportunities to assume roles that are valued by our communities, such as family member, friend, neighbour, employee/er, club member, customer, volunteer, and more. It means people contribute as equal members of their community and live fulfilling lives without discrimination or

segregation. *Citizenhood* is dynamic, shaped by individual circumstances and the opportunities available to them. The aim of the National Autism Strategy should be to advance people's chances to live active valued lives of *Citizenhood*. More information about the Model of Citizenhood Support can be found on our [website](#).

Recommendation 2: The Department of Social Services (DSS) should draw on the Model of Citizenhood Support as a framework to support the development of the National Autism Strategy underpinned by a whole-of-government, whole-of-life approach to policies and services for Autistic people.

Key Theme 1: Social Inclusion

There is a profound lack of knowledge about autism in the Australian community.¹ This means that everyday tasks are harder for Autistic people. A lack of understanding and awareness of autism also has flow on effects. It means buildings and environments rarely account for the needs of Autistic people. Additionally, a lack of understanding about autism impacts on experiences of community belonging – especially for those who are negotiating intersectional discrimination.

Improve outcomes for Autistic people through accessible environmental design

Good environmental design influences the quality of life of Autistic people.² In the course of our work, we have heard about a range of examples from both Autistic children and adults where good environmental design significantly changed the way they participated in community spaces. Several Autistic people have told us about the importance to them of 'quiet zones' with comfortable chairs, beanbags, and privacy, although there is sometimes a sense that these are designed with a younger cohort in mind and inadvertently exclude adults who also need sensory safe spaces. Similarly, initiatives that temporarily alter the sensory environment in a space, such as 'quiet hours' hosted by businesses like supermarkets, can have a positive impact for some Autistic people.

Sensory aspects of environments need to be considered in relation to a wide range of settings, including, but not limited to, public transport, shops, healthcare facilities, schools, cafes, restaurants, and entertainment venues such as music festivals. Autistic people have told us considerations of the sensory environment should be a core part of Universal Design approaches across all facets of life. Spaces should be designed with a range of sensory zones to suit different needs for the benefit of the whole community rather than focusing on a single space, such as a sensory room. Indeed, an Autistic person has expressed their frustration to us about feeling like they are expected to fit into spaces rather the spaces needing to be suitable for Autistic people.

Importantly, the design of environments has flow on affects for the way Autistic people interact with and participate in social, cultural, and economic life. Spaces that exclude people based on sensory needs reduce community participation and opportunities for Autistic people to take up value roles in community life. Therefore, there must be an emphasis on involving Autistic people in the design of spaces through meaningful co-design.

Recommendation 3: The National Autism Strategy should highlight the importance of good environmental design that is accessible and responsive to the diverse needs of Autistic Australians. It should reiterate the role of governments, businesses, and community organisations in ensuring environments are accessible, sensorily safe, and welcoming of all people.

Recommendation 4: The National Autism Strategy should recognise initiatives in support of the inclusion of Autistic people, including, but not limited to, the implementation of designated quiet spaces and times, throughout our communities. Such initiatives should reflect the diverse range of needs present in the Autistic community.

Recommendation 5: The National Autism Strategy should reinforce the importance of Autistic people being actively involved in co-designing spaces, services, programs, training, and events across governments, businesses, and communities to ensure they are genuinely responsive to needs. Co-design must involve Autistic people, not just their parents and/or support workers.

Strengthen opportunities for community belonging

It can be challenging for Autistic people to thrive in a society dominated by neurotypical norms and expectations. Due to the high prevalence of discrimination against Autistic people and of experiences of isolation within the Autistic community, it is even more important to maximise the benefits of peer networks as a valuable source of friendship, peer support, and representative advocacy. These peer networks may also take the form of shared special interest spaces. For example, we have heard time and time again about the importance of nurturing and being part of special interest groups, such as video gaming, Dungeons and Dragons, community arts, and similar. Many Autistic people have told us they see these avenues as fundamental to social participation and community belonging. Nevertheless, these options must not excuse exclusionary practices within broader community life. Indeed, they should be recognised as a response to prevailing circumstances, not a substitute for investing in achieving authentic community inclusion.

Autistic people are also more likely to identify as part of the LGBTIQ+ community or as gender diverse³ and experience increased intersectional discrimination as a result. Autistic people have told us that organisations, including government departments, health facilities, education providers, and so forth, need to develop a range of affirmative processes and strategies that specifically recognise and address the needs of the LGBTIQ+ community. Ideas include adapting intake and registration forms to ensure that organisations and businesses ask people an open-ended question about their 'gender' in ways that allow people the freedom to identify in their own words.

Recommendation 6: The National Autism Strategy should recognise the impact of peer networks and special interest groups in supporting Autistic Australians to navigate and thrive in a predominantly neurotypical society. It should commit governments to ongoing sustainable funding for peer networks and membership organisations across Australia, including, but not limited to, through the Information, Linkages, and Capacity Building (ILC) program, to ensure existing

groups can thrive and new groups can be established where there are unmet needs.

Recommendation 7: The National Autism Strategy should reinforce the obligation of governments, businesses, and organisations to ensure their communications are fully accessible for a diverse range of needs. For example, intake and registration forms should be welcoming of diversity and respectful in terms of allowing people to identify in ways that are meaningful to them.

Respect rights and address poorer safety and justice outcomes

Evidence suggests there is an over-representation of Autistic people in all areas of the youth and adult justice systems⁴ and in accessing homelessness services.⁵ Such evidence highlights the significant human rights issues facing the Autistic community. While Australia has ratified the United Nations Convention on the Rights of Persons with Disabilities, these commitments are yet to be realised across many facets of life. It is vital to recognise the additional barriers that arise for Autistic people negotiating systems like justice and housing.

Autistic people have told us they believe there is a desperate need for education and training about how Autistic characteristics may present and impact when Autistic people are in contact with the police and workers in the justice system. We have repeatedly heard Autistic people raise concerns about their safety when interacting with police or other authority figures. There have also been public examples where police misinterpreted the actions of Autistic people in ways that led to dire consequences and such examples have instilled a fear of police for some people.

Therefore, it is important to develop a targeted strategy to educate and upskill personnel across the police and justice workforces about neurodivergence and how to interact respectfully and effectively with Autistic people as an essential part of their day-to-day operations. For example, police may need training about the characteristics of autism so that they are more likely to recognise and respond accordingly. We have heard repeatedly that Autistic people want this training and workforce development to be Autistic-led. They believe that the lived experiences of Autistic people are crucial during training, as they can share their own experiences and knowledge to create change.

Recommendation 8: The National Autism Strategy should commit governments to fulfilling all their existing obligations under the United Nations Convention on the Rights of Persons with Disabilities, including by committing the necessary funding where required.

Recommendation 9: The National Autism Strategy should commit governments to funding consistent Autistic-led national education and upskilling of workers in critical government systems, including, but not limited to, policing, justice, and housing. This should include how to interact calmly, respectfully, and effectively with Autistic people as an essential part of their day-to-day operations.

Key Theme 2: Economic Inclusion

Evidence tells us that Autistic people face a great deal of prejudice, discrimination, segregation, and exclusion across their lifetimes starting from early childhood and continuing all the way through adulthood.⁶ This treatment particularly impacts opportunities for education and employment and has a significant impact on economic wellbeing.

Design education in ways that are inclusive

Inclusive education is a significant theme across our Agency's work. We urge DSS to engage with the Australian Coalition for Inclusive Education (ACIE), of which JFA Purple Orange is a member, to better understand the breadth and impact of exclusionary practices in schools and how to address these. Autistic children and young people have told us about the prejudice and lack of understanding among some teachers that leads to students 'getting in trouble' or feeling excluded and othered. An Autistic primary school student recently told us about how they wanted their school to embrace the idea that neurodivergence as a part of human diversity that should be celebrated rather than shamed or deemed as a problem. The school environment is critical in shaping how all people perceive neurodivergence, therefore schools' practices and attitudes have far-reaching consequences for society.

We have also heard of examples of teachers 'outing' Autistic students to their classmates or other parents, including referring to 'deficits', 'problems', and the 'accommodations' they make. Among other concerns, this fails to respect the Autistic student's privacy and autonomy in choosing when, how, and to whom they wish to disclose. This highlights the need to educate and upskill teachers in their approach to neurodiversity in schools. Other ideas to increase inclusion in schools include increasing awareness of an Autistic person's need for sensory regulation and/or routines, provision of more opportunities for sensory experiences and/or breaks, changes to the sensory environment such as quiet zones and alternatives to school bells, reviewing what foods and drinks are available in school canteens, relaxing school uniform requirements, shorter school days and/or more breaks, improved transition supports, and Autistic-led programs to educate non-Autistic students. These examples reiterate the importance of developing strategies within our education systems, and upskilling the people who work therein, to ensure schools are safe and affirmative places where Autistic children are supported to learn and grow on an equal basis with their peers. This sits at the core of inclusive education principles, which offer a sound pathway for the Strategy to drive change in how education systems meet the needs of all students.

Recommendation 10: The National Autism Strategy should commit governments to adopting, funding, and implementing inclusive education principles across all schools.

Recommendation 11: The National Autism Strategy should commit governments to funding Autistic-led training for teachers, including, but not limited to, how to make necessary adjustments to support Autistic children to learn and grow in mainstream schools.

Ensure work cultures and spaces support neurodiversity

Similarly, Autistic people face significant barriers to obtaining and retaining employment. It is vital the Strategy addresses these barriers and commits governments to leading by example in diversifying their workforces at all levels from junior positions through to executive leadership roles. Additionally, Autistic people have told us about the need to improve workplace cultures and change recruitment processes to be fully inclusive.

It is important to recognise that an affirmative workplace culture not only addresses prejudice and lack of understanding, but also proactively promotes an inclusive, safe, and respectful workplace environment for all. Autistic people have spoken to us about ideas to boost Autistic employment, including through recruitment programs and services that are more responsive to their needs, implementing sensorily appropriate workplace designs, for example, by avoiding fluorescent lights, Autistic-led training for supervisors and colleagues to ensure more supportive cultures, adopting regular rosters, allowing for short breaks and similar flexibility, tackling prejudice and discrimination, and providing choice between open plan desks and private workstations.

Some workplaces are already adopting these approaches successfully. An Autistic worker has shared their positive experience with us including how they are supported by managers and colleagues, rostered for routine shifts, allowed short breaks, provided with written procedures, and so forth. They highlighted how written procedures had supported all staff without singling them out. This is a crucial point because adopting inclusive practices benefits everyone in the workplace. In contrast, Autistic young people have expressed concerns about the fact that most entry level and casual jobs for teenagers are in retail and hospitality, which are often unsuitable sensory environments for Autistic people. They have spoken to us about the need for modifications to not just be agreed, but to be followed through in practice.

The process to develop the National Autism Strategy should consider the best ways that governments can facilitate inclusive workplaces, such as through implementing employment targets, regulating work environments such as through mandatory accessibility and/or sensory requirements, and investing in initiatives to increase work opportunities for Autistic people. Legislative obligations on governments and/or businesses should be considered as part of this work.

Recommendation 12: The National Autism Strategy should highlight the importance of autism inclusion training that is co-designed and delivered by Autistic people in all workplaces.

Recommendation 13: The National Autism Strategy should commit governments to actions that will ensure work environments are accessible and responsive to sensory needs, create targets to diversify the public sector workforce, and provide sufficient resources for programs designed to overcome the shortfall in employment outcomes for Autistic workers.

Recommendation 14: The National Autism Strategy should commit governments to investigating industrial relations mechanisms that will ensure Autistic workers have a right to request reasonable modifications to workplace environments and

arrangements, such as a desk located in a low sensory space, additional short breaks, and similar.

Key Theme 3: Diagnosis, Services and Supports

Barriers to an autism diagnosis include the cost, length of waiting lists, time pressures, and an assumption of some pre-requisite knowledge of autism in order to consider investigating such a diagnosis. Currently, diagnosis tools are also less likely to diagnose girls and women⁷ and adults⁸ who often present in different ways due to having different traits compared to boys, masking, compliance with social norms, and other pressures. We have heard from Autistic people about an urgent need to strengthen the allied healthcare workforce to better respond to the needs of Autistic people, educate practitioners about diagnostic overshadowing, facilitate earlier diagnoses, prioritise the underdiagnosis of girls and women, and address intersectional discrimination such as that against transgender people.

Autistic people have also spoken to us about their experiences of the diagnostic process and the issues that need to be addressed. We have heard many Autistic people describe the diagnostic process as confronting and traumatic, including due to the language used by practitioners. Autistic people have told us it is important to adopt a neuro-affirming/strengths based diagnostic process rather than a diagnosis focused on deficits. The medical model, which focuses on what Autistic people cannot do, is described as unhelpful and, in some instances, harmful.

Notwithstanding the above points, services and supports for Autistic people should not be dependent on a diagnosis. This is especially the case for children in the school system where they should be supported according to needs.

Recommendation 15: The National Autism Strategy should commit governments to investing in improving diagnostic processes, services, and training based on a genuine co-design methodology that includes girls, women, and gender diverse populations.

Recommendation 16: The National Autism Strategy should commit governments to providing sufficient funding to ensure that support is provided for students with additional learning needs irrespective of diagnosis status.

Key Theme 4: Health and Mental Health

Autistic people are more likely to experience co-occurring mental and physical health conditions across their lifetime⁹ compared to non-autistic people and, thus, are likely to be interacting with the health and mental health systems. Autistic people have told us the sensory experience of attending hospitals is often unpleasant, for reasons including the noise, smells, and white walls. Autistic people are often distrustful of, or traumatised by, health professionals. There is a lack of understanding of communication needs, particularly when stressed, and of differing pain tolerance thresholds for some Autistic people.

Autistic people have highlighted to us the need for better training for all healthcare professionals and emergency services personnel, particularly regarding co-morbidities. Access to mental health support at the point of diagnosis must be a priority and these services should be neuro-affirming. LGBTIQ+ identifying Autistic people have also described a shortage of specialist healthcare professionals and reduced access to services.

Recommendation 17: The National Autism Strategy should commit governments to investing in health and mental health services to ensure they are responsive to the needs of Autistic people and provide neuro-affirming care in an inclusive and accessible manner.

Recommendation 18: The National Autism Strategy should commit governments to funding Autistic-led and co-designed training and workforce development for all healthcare professionals.

Recommendation 19: The National Autism Strategy should commit governments to providing funding to link Autistic people with mental health support at the time of diagnosis.

Measurable targets and accountability for outcomes

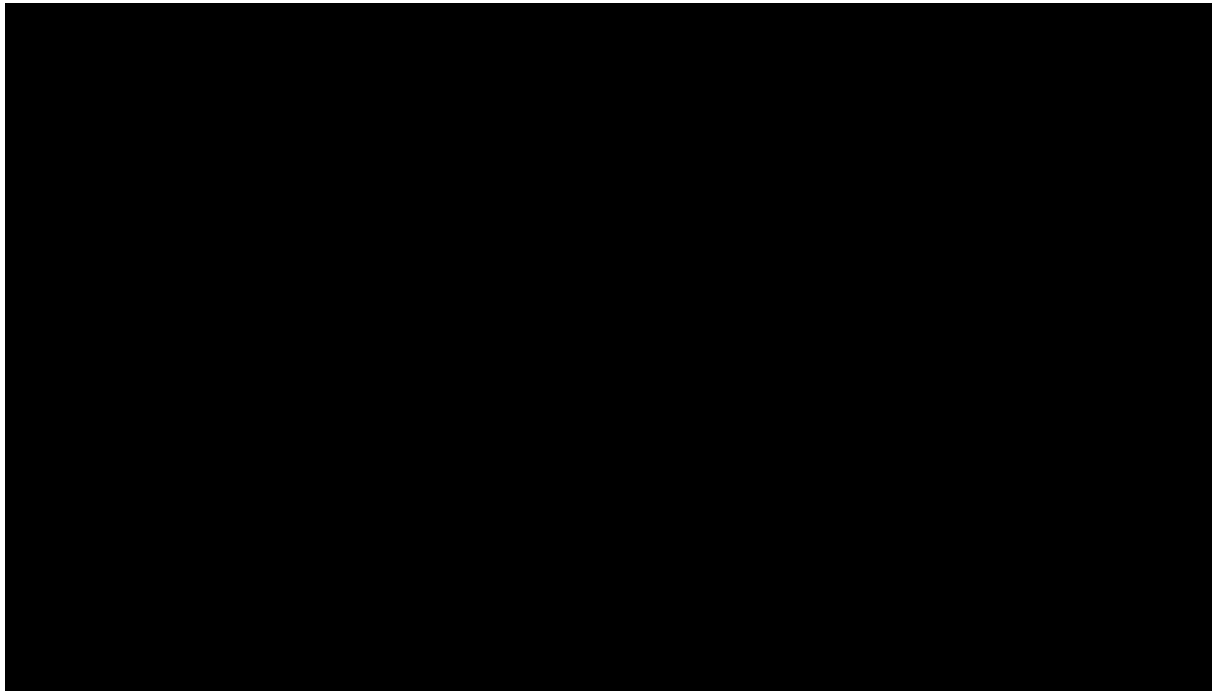
The Discussion Paper has identified the gaps that exist between Autistic and allistic people in key life domains and quantifies the scale of these disparities. Given all that has been written and said, all the reports and discussion papers produced, it is essential the Strategy becomes more than just aspirational words on paper, or content on a government website. We agree with the Senate Select Committee on Autism's Recommendation 5.71:

[T]he National Autism Strategy and accompanying implementation plan include an outcome framework, as well as specific and measurable actions, targets and milestones. Where appropriate, the framework and measurable items should align with those in other national strategies.¹⁰

Governments, responsible ministers, and departments must be accountable for their success or failure to implement actions and to meet targets and milestones under the Strategy. Accountability can be strengthened by ensuring that parliamentary scrutiny mechanisms, such as mandatory annual reporting of data, statements to parliament by ministers, and a requirement to articulate how any failures to meet target will be addressed. As alluded to in the Senate Committee's recommendation, the Strategy should align with the Outcomes Framework under *Australia's Disability Strategy 2021-2031*, which states “[a]bove all, the Strategy is focused on interrelated outcome areas with tangible, achievable policy priorities. Rigorous measuring, evaluation and reporting of outcomes are inbuilt.”

Recommendation 20: The National Autism Strategy should include an Outcomes Framework that aligns with *Australia's Disability Strategy 2021-2031* Outcomes Framework. This Framework should track progress on key targets and establish tangible accountability mechanisms that ensure regular and fully transparent

public reporting of data and mandate parliamentary scrutiny of responsible ministers and departments for any failure to meet targets.



Endnotes

¹ See, for example, The Senate Select Committee on Autism, 'Services, support and life outcomes for autistic Australians', Report, 2022, available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Report.

² See further, Tola G, Talu V, Congiu T, et al., 'Built Environment Design and People with Autism Spectrum Disorder (ASD): A Scoping Review', *Int J Environ Res Public Health*, (2021)18(6), p.3203.

³ See, for example, Warrier V, Greenberg DM, Weir E, et al., 'Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals.' *Nat Commun*. 2020 Aug 7; 11(1), p.3959; and Strang JF, Janssen A, Tishelman A, et al., 'Revisiting the Link: Evidence of the Rates of Autism in Studies of Gender Diverse Individuals.' *J Am Acad Child Adolesc Psychiatry*, 2018 Nov; 57(11), pp.885-887.

⁴ See, for example, Cashin A, Newman C. 'Autism in the criminal justice detention system: A review of the literature'. *J Forensic Nurs*, (2009)5(2), p.70.

⁵ See, for example, Osborn, E., & Young, R. (2022). 'Autistic and without a home: a systematic review and meta-ethnography of the presence and experiences of homelessness amongst autistic individuals.' *Journal of Social Distress and Homeless*, ahead-of-print.

⁶ See, for example, The Senate Select Committee on Autism, 'Services, support and life outcomes for autistic Australians', Report, 2022, available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Report.

⁷ See, for example, Ratto AB, Kenworthy L, Yerys BE, et al., 'What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills', *J Autism Dev Disord*. 2018 May, 48(5), pp.1698-1711.

⁸ See, for example, Ghanouni, P. and Seaker, L. 'What does receiving autism diagnosis in adulthood look like? Stakeholders' experiences and inputs'. *Int J Ment Health Syst* 17, 16 (2023).

⁹ See, for example, Mazzone, L., & Vitiello, B. (Eds.). (2016). *Psychiatric Symptoms and Comorbidities in Autism Spectrum Disorder* (1st ed. 2016.). Springer International Publishing.

¹⁰ The Senate Select Committee on Autism, *op cit*.