

# SQUARE PEG ROUND WHOLE SUBMISSION TO NATIONAL AUTISM STRATEGY CONSULTATION



*“Education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms.”*

**Article 13, United Nations International Covenant on Economic Social and Cultural Rights**

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## Who we are

Square Peg Round Whole is a national grassroots advocacy group with state-based branches in NSW, SA, QLD, Victoria and WA. Our community of member advocates are almost exclusively parents and carers of neurodivergent and disabled children, who come from all walks of life and bring a diverse range of experience and expertise. Many of us are also neurodivergent and disabled ourselves.

Our members are parents, but they are also teachers, doctors, researchers, lawyers and healthcare workers, who are raising children who are autistic, have ADHD, dyslexia, anxiety, giftedness, trauma and dyspraxia among other conditions and disabilities. Although our member demographics are varied, their experiences of navigating schools are strikingly similar.

Our community was established [REDACTED] [REDACTED], just two years ago, and now represents over 2000 member advocates nationally.

We are a committed collective seeking meaningful systemic change. We receive no funding, have no material or vested interests, and we have no income generating activities. Our member advocates are all volunteers, who give willingly of their time, energy and experience because of our shared belief that every child in Australia deserves the opportunity to realise their potential through their educational career and to flourish as members of the community.

## What we believe

Our community is united through our collective belief in a human rights-based approach towards education reform.

Specifically, our member advocates subscribe to our core principles of:

- 1) Inclusive education: It is every student's human right to be educated alongside their peers (both disabled and non-disabled), in the same classrooms and participating in the same curriculum. Our belief in inclusive education is underpinned by the UNCRPD definition of inclusive education.
- 2) The education system must replace the current model of behaviourism with neuroaffirming, culturally responsive, trauma sensitive models of care. Behaviourism based responses (including PBIS & PBL) should be phased out of schools due to the harm it causes autistic and neurodivergent students, and be replaced with practices such as Dr Ross Greene's [Collaborative Proactive Solutions](#).<sup>1</sup>
- 3) "Nothing about us, without us" – Autistic and neurodivergent voices must be heard in regards to issues and approaches that affect autistic and neurodivergent people.

We work with many other neuroaffirming groups and individuals also championing the changes we advocate for. We endorse, and urge the strategy team to closely read, the Australian Coalition for Inclusive Education: [Driving Change: A Roadmap for Inclusive Education in Australia](#)<sup>2</sup>

We are providing this submission because our members have significant lived experience relevant to the issues raised in the discussion paper, and because we know the impact of other

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<sup>1</sup> [OUR SOLUTION – LIVES IN THE BALANCE](#)

<sup>2</sup> [ACIE Roadmap – Australian Coalition for Inclusive Education](#)

rights such as the right to education, health, housing, community participation etc. impact the ability to exercise and enjoy the right to education. This is particularly the case for Autistic students and students with disabilities. Without timely and accurate diagnosis and access to supports, it is very difficult for Autistic students to participate effectively and enjoy their school experience.

If a child spends even a short time being unfairly disciplined for behaviours associated with undiagnosed Autism and/or other neurodivergences, the damage that this does to their relationship with school and future educational career is very difficult to repair. This can impact on a child's education and long-term outcomes<sup>3</sup>. It is critical that trauma-sensitive, culturally responsive and neuroaffirming practices are embraced across all services and sectors in our society.

Our community of members wholeheartedly believes in the importance of neuroaffirming supports to achieve better outcomes for Autistic children. This belief is also shared by the wider community. We draw the Strategy team's attention to this petition for the adoption of Collaborative Proactive Solutions in the Australian school system<sup>4</sup>; at the time of writing, almost 23 000 Australians have signed this [petition](#).

Square Peg Round Whole (SPRW) welcomes the opportunity to contribute to the consultation on the development of a National Autism Strategy and strongly agrees that a National Autism Strategy is an important step to improving quality of life, outcomes and wellbeing for Autistic Australians and their families.

## Comments on the Discussion Paper

Square Peg Round Whole focusses its advocacy on education reform, so we will be directing the majority of our submission towards that section of the discussion paper. However, it is the universal experience of our members that the inequities experienced by Autistic people are not limited to education, and that educational disadvantage is compounded by areas of challenge in other aspects of life. Reforming the education system to better attend to the human rights of Autistic children is an essential aspect for addressing exclusion and isolation for autistic people across the life course. For that reason, we will be touching on other elements of the strategy related to other key themes such as social participation and employment throughout the submission.

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<sup>3</sup> Graham LJ, Gillett-Swan J, Killingly C, Van Bergen P. Does It Matter If Students (Dis)like School? Associations Between School Liking, Teacher and School Connectedness, and Exclusionary Discipline. *Front Psychol.* 2022 Mar 3;13:825036. doi: 10.3389/fpsyg.2022.825036. PMID: 35310270; PMCID: PMC8927887.

<sup>4</sup> [Petition - Stop the Aussie school system punishing vulnerable kids! - Change.org](#)

## Key Theme One: Social Inclusion

Square Peg Round Whole agrees fully with the points raised by the discussion paper in relation to key theme one – social inclusion. Autistic children have a fundamental right to participate in their communities, with opportunities for meaningful participation in a wide range of educational, cultural, social, physical, artistic and other recreational activities<sup>12</sup>. Meaningful participation / inclusion is imperative for wellbeing across the life course. Social inclusion goes way beyond being a participant in a particular setting, it includes the positive and meaningful experience of being in that setting. With the majority of Autistic children (86%) reporting ‘having difficulty’ at school, primarily difficulties with fitting in socially, learning and communication (ABS, [2012](#)), and significantly higher rates of unemployment and underemployment than non-autistics and people with other types of disability, it is clear there is a long way to go for achieving meaningful social inclusion for Autistic people.

### Issues experienced by Autistic people and their families and carers that prevent their inclusion in the community:

It is widely acknowledged that Autistic people continue to be excluded rather than included in mainstream education, occupational, recreational and health settings<sup>13</sup>. Many members of SPRW repeatedly tell us of challenges experienced by themselves and their autistic loved ones to access mainstream services and supports. There is consensus among our members on a fundamental lack of accessibility and inclusion in accessing many community programs and services.

Our members report issues of accessibility and inclusion at different ages and stages, and in different settings. For example, members have reported that social support available for Autistic children in mainstream educational settings during the primary years tends not to be as widely available in the high school years, despite the need for ongoing social support. Members also report a lack of recreational and social opportunities for adolescents – with these activities primarily oriented at young children or young adults.

Many families have experienced outright discrimination – with participation being denied for government subsidised programs and supports, or through private providers. This includes participation in mainstream education and recreation programs, as well as school holiday programs run in educational and private settings.

Many of our members have been denied the opportunity to enrol their children in things like swimming lessons, social and recreational programs or sporting programs. They have been told

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<sup>12</sup> UNICEF. The Convention on the Rights of the Child [Internet]. United Nations General Assembly; 1989

<sup>13</sup> Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2021). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people’s experiences. *Journal of Autism and Developmental Disorders*, 1-12.

that these programs are not designed for “special needs” participation, or have been re-directed towards other specialist (segregated) programs, which denies autistic children the right to community participation alongside their non-disabled peers. Without adequate funding, parents are left paying additional costs to access these programs – such as having to pay for one-to-one swimming lessons due to mainstream swimming lessons not meeting the needs of Autistic children. Autistic children remain marginalised and miss out on opportunities for social interaction that come through inclusion. It is well recognised that social connections and a sense of belonging are important to mental health and well-being, yet Autistic people continue to be denied opportunities that can enhance their sense of connection and belonging in education and society more broadly.

### Example from parents/carers

We have also been told on many occasions that the engagement and participation of their autistic children in mainstream programs would be easier with adult support – for example, with the provision of government subsidies or funding to add additional staff members to support the whole group and alleviate the time demand on a single adult teacher or coach. In addition, the provision of funding particularly for this purpose could allow for the purchase of adaptive materials or resources that would benefit not only Autistic participants but also their allistic peers.

*“My son attended Cub Scouts for one (difficult) year. Because of the reliance on volunteer staff, and the limited capacity of these volunteers, the onus was on me to provide (out of pocket) a support person who would support the team leader with the whole class, and offer personalised support to my son as and when he needed it. This was the only way he was accepted as a participant in our local Cub Scout Troop”*

### Examples from teachers

*“I work part-time three days a week and have close to 200 students. That’s under two minutes per day one on one with each student during class time. For non-contact time, it equates to mere seconds per child to do all the other stuff”*

*Teacher to SPRW*

*“It is demoralising not being able to help my 150ish students plus communicate with their parents communicate with their parents adequately and meaningfully. No wonder we are burnt out”*

*Teacher to SPRW*

## Examples from the literature

Evidence indicates that the transition from primary to secondary school is particularly challenging for Autistic students, with the negative outcomes predominantly associated with school- and system-level factors rather than child-level factors<sup>14</sup>. Yet school based interventions are primarily designed to ‘upskill’ the Autistic student to improve their social skills, rather than addressing the systemic issues contributing to negative /discriminatory attitudes and environmental factors which maintain the exclusion of autistic people <sup>15</sup>.

Evidence shows that social skills interventions follow the medical model – as these are targeted and made available for the autistic child and other neurodiverse children at school – rather than upskilling the wider school community on how they may be able to improve their social skills to interact more positively with autistic children/people.

## How can we better support the social inclusion of Autistic people?

We recommend that the strategy:

- provides a clear conceptualisation of inclusion, to facilitate improved understanding of inclusion, implementation, and evaluation across settings and sectors.
- outlines autism specific guidelines for inclusion within and across multiple settings and for children and adolescents and young adults
- addresses the need for adequate funding, support and adaptations across society to support inclusion for Autistic people, so that support is more consistently available within and across settings, sectors and life stages. include approaches which consider an intersectional lens so as to account for the many layers of discrimination which further undermine social inclusion for Autistic people such as race, gender, ethnicity and poverty <sup>16</sup>.
- Standardised processes for therapists and support people to enter school grounds to conduct therapy and support that aligns with student outcomes, rather than it being at the discretion of school principals.

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<sup>14</sup> Makin, C., Hill, V., & Pellicano, E. (2017). The primary-to-secondary school transition for children on the autism spectrum: A multi-informant mixed-methods study. *Autism & Developmental Language Impairments*, 2, 1–18.

<sup>15</sup> Koller, D., & Stoddart, K. (2020). Approaches that address social inclusion for children with disabilities: A critical review. *Child & Youth Care Forum*

<sup>16</sup> Koller, D., & Stoddart, K. (2021, August). Approaches that address social inclusion for children with disabilities: A critical review. In *Child & Youth Care Forum* (Vol. 50, pp. 679-699). Springer US.

- Consult with Autistic children and their families/carers and therapeutic team on appropriate accommodations/adjustments/modifications for the Autistic student.
- Include strategies for reducing physical barriers that create sensory overload for Autistic students such as cluttered classrooms, bright lighting and strict uniform policies.
- Include guidelines for education and therapist settings that follow the lead of Irish system, with a recent report stating “Behavioural interventionist therapies are ultimately founded on modifying disabled people's behaviour to meet goals decided by others; often to conform more closely with neurotypical communication, behaviour and/or norms and therefore the Committee believe cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment.”<sup>17</sup>
- Emphasises the importance of focusing on the Autistic person’s goals, desires, interests and preferences for social inclusion and skills development - rather than addressing skills deficits.
- Address the overrepresentation of disciplinary processes such as suspension and exclusion amongst Autistic children, especially the higher rates of punitive disciplinary processes and exclusion that occur for First Nations Autistic children.
- Outline strategies for comprehensive and transparent data collection on suspensions, expulsions, segregation, attendance, as well as passive engagement (i.e., children present in the classroom but not meaningfully engaged in class activities)
- Acknowledge the harm, including trauma that many Autistic people experience due to exclusion, ableism, stigma and therapeutic practices not designed to meet the needs and preferences of Autistic people.
- Support greater flexibility in various settings – for example class sizes & teacher workload when supporting Autistic children in mainstream classes.
- Improve teacher and support staff training for supporting Autistic children.
- Outline strategies (including navigational support) to improve access and equity issues – it is extremely difficult and time consuming for Autistic people, their families and carers to research and navigate their way into inclusive activities.
- Address lack of transparency and siloing of support between NDIS and Education

***We also agree strongly that there are significant gaps in intersectionality and support provided to First Nations autistic people. We believe that First Nations people and First Peoples disabled-led organisations are best placed to advise this issue, and strongly advocate that the National Autism Strategy be co-designed where appropriate to ensure that it is culturally responsive.***

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[https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint\\_committee\\_on\\_disability\\_matters/reports/2023/2023-02-23\\_report-on-aligning-disability-services-with-the-united-nations-convention-on-the-rights-of-persons-with-disabilities\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/reports/2023/2023-02-23_report-on-aligning-disability-services-with-the-united-nations-convention-on-the-rights-of-persons-with-disabilities_en.pdf)



## How can we improve community attitudes toward Autistic People:

We strongly agree that in all areas of society and our community, there is a fundamental lack of understanding around autistic identity and autism as a disability. Autism is more than a clinical diagnosis. Autism is increasingly being recognised as a social identity; Evidence indicates that a stronger sense of Autistic identity improves Autistic people's sense of wellbeing.

Popular messaging and discourse focus on a deficit-based, medical model; this example is typified in media messaging and the reporting of stories that discuss Autism. Reporting on autism alongside NDIS and education, in the media continues to perpetuate the narrative of Autism as a burden on society.

### Recommendations

The strategy must

- include a community-based campaign around increasing Autism **acceptance** – *not awareness*. It is vital that this campaign is co-designed by Autistic people, applies a strengths based but realistic view of autism that recognises the strengths and capacity of the autistic community, whilst also acknowledging the challenges faced by autistic people when engaging with the community, and the ways that members of the community, and its organisations, can best support Autistic people.
- Must include media guidelines developed by Autistic people for responsible reporting around Autistic individuals and Autism. These guidelines should be circulated and upheld to ensure that the media supports the important work of the National Autism Strategy, instead of undermining its aims.
- acknowledge the strong influence of media representations of Autistic people and autism on societies understanding and acceptance of autism.
- emphasise the importance of diverse representation in the media of Autistic people provides guidelines for representation in the media, to avoid narrow representations of Autistic people
- Include stigma reduction strategies – including how to increase public awareness of neurodiversity in the wider community without placing the onus on Autistic people themselves
- Outline a strategy for shifting the concept of 'fixing' / 'treating' autism in childhood and adolescence – which perpetuate interventions designed to make the autistic person more like a non-autistic person to addressing knowledge and attitudinal barriers in the wider community.
- In any community awareness campaigns attend to the subcomponents of autism and the over-conflation of behaviour with disability
- outlines guidelines for increasing the voice of Autistic people, to redress the dominance of non-autistic people, altruists, positivists, health professionals and educators speaking about autism in the media – Greater social representation of the Autistic voice is needed.
- Outline a research framework which includes examining societal attitudes and environmental impacts on Autistic people's experiences to address the gaps in research due to the dominant focus on interventions supporting tenets of medical and behavioural models

of disability which perpetuates underlying assumptions that Autism needs to be ‘fixed’ or reduced (re)producing deficit and exclusionary practices. Include a research agenda for understanding the perceptions and experiences of people with experiences of autism (autistic person, carer of autistic person, or close relative of an autistic person) and the non-autistic population. Research of this nature is scarce <sup>18</sup>. *There is also need for further research into the lived experience of exclusion and isolation, including longitudinal research to assess the impact of awareness and acceptance campaigns on societal attitudes.* Research teams must include Autistic researchers.

- Highlight the need for further research on areas of autism such as PDA to ensure supports are better tailored to the diverse needs of Autistic people

## Key Theme 2: Economic Inclusion

We strongly believe that economic inclusion (particularly educational inclusion) is a fundamental issue that needs to be central to the National Autism Strategy. We note the significant discussion given to education by the Discussion Paper, but wish to provide the following general comments on education inclusion for Autistic children.

It is our view that the Australian school system fails Autistic students on many levels, and that whilst some progress has been made states (we especially commend the efforts of the SA government), far more needs to be done in order to improve education equity for Autistic students nationally.

As an advocacy group, we hear time and time again of discrimination and inequity in Australian schools. Feedback from our own members and research tells us that support for Autistic students in schools is lacking. The deficits can be categorised into the following key areas:

- 1) Segregation and integration instead of inclusion
- 2) Use of behavioural practices, in particular Applied Behaviour Analysis (ABA)
- 3) Overrepresentation of autistic students in exclusionary discipline figures
- 4) Informal segregation and removal from either school grounds or the classroom
- 5) Ableism and Inaccessibility.

In our discussions, we will address the following questions from the discussion paper:

- 1) Are there any other issues experienced by autistic people that affect their economic inclusion?
- 2) How do you think we can better support the economic inclusion of Autistic people?
- 3) How can we better support Autistic people in education, employment and the workforce?

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<sup>18</sup> Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2021). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people’s experiences. *Journal of Autism and Developmental Disorders*, 1-12.

We will do so by addressing the key deficit areas stated above.

## Segregation and integration instead of inclusion

Many Autistic students are separated from their allistic peers to receive their education. This is done through specialist schools or units, or via “specialist” Autism programs delivered within a wider school environment.

Prior to and following the release of the Disability Royal Commission’s *Final Report and Recommendations*, there has been an outpouring of support from the disabled community for the ending of segregation, including the recommendation made in [recommendation 7.14](#), which calls for a phasing out of segregated schools.<sup>19</sup> Despite this call for inclusion, not one Australian state has committed to phasing out special schools. Some have explicitly stated they will not be doing so – without consultation with disabled stakeholders.<sup>20</sup>

Many powerbrokers in education – including those with a vested interest in maintaining segregation – maintain that the maintenance of segregated special schools is an essential part of retaining “parent choice” to choose their child’s education.<sup>21</sup> One media piece went so far as to assert – “It is important to keep providing choice for families to enrol their child in a school that fits their needs and values. In that way, the option to enrol your child in a special school is no different from a parent wishing to enrol their child in an independent or religious school.”<sup>22</sup>

The perpetuation of this narrative is both harmful and misleading, and it is vital that the National Autism Strategy does not fall at the hurdle when discussing inclusive education.

While human rights laws recognises a limited liberty of parents to choose for their children education that conforms with their religious and moral convictions, this does not extend to either a right of parents to choose education models that contravene human rights standards nor does it impose on a government an obligation to provide such choice.

In his legal opinion for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability (DRC) about the rights under international human rights law of students

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<sup>19</sup> See for example: <https://pwd.org.au/pwda-calls-for-a-radical-response-to-end-segregation-and-discrimination/>; [Segregation-Position-Statement-Easy-Read-1.pdf \(wwda.org.au\)](#); [42 disability rights and advocacy organisations call for an end to the segregation of disabled people in Australia - Disabled People's Organisations Australia \(DPO Australia\)](#)

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<sup>21</sup> [‘She is cared for and feels that she belongs’: what parents think of special schools \(theconversation.com\)](#)

<sup>22</sup> *ibid*

with disability to inclusive education, Professor Andrew Byrnes found that there is no international right or obligation to support “parental choice to segregate”.<sup>23</sup>

The United Nations Committee on the Rights of People With Disability has also stated in its General Comment No.4 (Right to Inclusive Education) about Article 24 of the UNCRPD that “education is the right of the individual learner and parental responsibilities in regard to the education of a child are subordinate to the rights of the child” (paragraph 10).<sup>24</sup>

The CRPD Committee also made it clear that segregated settings for students with disability are a form of disability discrimination and are incompatible with inclusive education, stating that “the right to non-discrimination includes the right not to be segregated and to be provided with reasonable accommodation” (paragraph 12).

In their joint statement in 2022, the CRPD Committee and the Committee on the rights of the Child reaffirmed that “the right to quality inclusive education is not compatible with sustaining two systems of education: a mainstream education system and a special/segregated education system”.<sup>25</sup>

In its recent “Guidelines on deinstitutionalization” the CRPD in calling on governments to end all forms of segregation, including institutionalisation, and said that governments should refrain from using “choice” arguments to justify segregation on the basis of disability and that being forced to choose between services and support option that do comply with the UNCRPD is not a real choice.<sup>26</sup>

Being given the choice of local schools that are not inclusive and do not provide children with disabilities with the environment and supports they need to thrive and segregated settings that may provide more supports but in an environment that separates students on the basis of disability and perpetuates discrimination are not real choices.

As parents who wish to ensure that our children’s fundamental rights are realised, we emphatically reject not only the idea that parental preferences about education settings should abrogate a child’s own fundamental right to inclusive education, but that the maintenance of discriminatory segregated settings is being done in our name.

It is our passionate belief, developed based on human rights conventions, legislation and international human rights law, that inclusive education is the human right of all students, including Autistic children. We desperately hope that a National Autism Strategy upholds these human rights by supporting a human-rights based model of education that aligns with the CRPD position on inclusive education.

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<sup>23</sup> p.2-3, see <https://disability.royalcommission.gov.au/publications/public-hearing-24-andrew-byrnes-2020-analysis-article-24-crpd-and-note-travaux-preparatoires>).

<sup>24</sup> Reference - article 4 crpd

<sup>25</sup> [https://www.ohchr.org/sites/default/files/2022-03/CRC-CRPD-joint-statement\\_18March2022.docx](https://www.ohchr.org/sites/default/files/2022-03/CRC-CRPD-joint-statement_18March2022.docx)).

<sup>26</sup> <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>

## Behavioural Practices

The latest neuroscience based evidence, and the critical evidence of autistic and neurodivergent students experiences in the classroom, show that the current approach to behaviour management in public schools are both ineffective and inappropriate.

To appreciate the paradigm shift necessary, a full understanding of the status quo approach to behaviour management is needed, including an understanding of behaviourism and how it has permeated the Australian school system.

Our member advocates have shared stories (a sample of which are included within this submission) of the impact of the current behaviour management approach on their children. These stories are frequently heartbreaking, and paint the picture of neurodivergent (frequently autistic) children labelled as having “challenging behaviours” or being “non-compliant.” These children, who exhibit what Dr Ross Greene identifies as “unlucky behaviours”<sup>27</sup> are frequently subjected to disproportionate discrimination and inequity. They are more likely to experience restraint, seclusion, isolation and exclusionary discipline. They are among those students that fuel the school to prison pipeline, who experience school can’t (previously known as school refusal) or who leave the education system at the earliest opportunity.<sup>28</sup>

In the majority of Australian schools, the public education system relies heavily on Positive Behaviour Support (or Positive Behaviour for Learning), usually implemented at a whole school level, and under the guise of a multi-tiered system of supports and interventions. This approach is underpinned by operant conditioning, and frequently (often unintentionally) privileges neurotypical ways of being that autistic students can only emulate at significant personal cost. This is explored further in the section on “inaccessibility and ableism” below.

The fundamental premise of the current system is an emphasis on rewards and consequences, where compliance is obtained by coercion and expectations are adult-imposed and universal, regardless of student diversity and disability. Multi-tiered systems of support have instead become a series of escalating consequences, culminating in suspension or ultimately exclusion.

We know that behaviourism-based compliance approaches, including ABA and PBL are traumatising for neurodivergent students<sup>29</sup>. Our understanding of the research supporting behaviorism-based compliance has changed. It is no longer ethical to call the approaches “evidence-based”, as it excludes the opinion of the autistic person in preference of that of the carer<sup>30</sup> and it completely misses or ignores the difference between behaviors that are willful and behaviors that are automatic (stress behaviors)<sup>31</sup>. Furthermore, there are approaches and

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<sup>27</sup> Dr Greene Quote reference

<sup>28</sup> Do we really have a frightening school to prison pipeline in this country? Only one way to find out | EduResearch Matters (aare.edu.au)

<sup>29</sup> [H Kupferstein, “Evidence of increased PTSD symptoms in autistics exposed to applied behaviour analysis”, January 2018 4\(3\) \*Advances in Autism\*](#)

<sup>30</sup> [Neuroclastic - On ABA: Evidence-based Doesn't Mean Good Therapy](#)

<sup>31</sup> [Alliance Against Seclusion and Restraint - Questioning the evidence behind evidence-based approaches](#)

therapies that are trauma-sensitive and are as effective as behaviourism-based compliance approaches in helping to achieve outcomes.<sup>32</sup>

*“Disability isn’t a behaviour. Disability can’t be behaviour managed out of a child. When the behaviour goes away, it means you are supporting the disability. Don’t be surprised when the supports are removed and the behaviour returns. Behaviour is simply communication or indication that a child has a problem they can’t solve. Can we please have Ross Greene’s programs in all WA schools!”*

*Parent to SPRW*

## Applied Behaviour Analysis & Autistic Students

We are especially concerned by the heavy reliance on techniques and interventions from Applied Behaviour Analysis within the Australian school system. Applied Behaviour Analysis is deeply embedded within the way the current system approaches autistic students. Several states have specialist (segregated) Autism programs, units or schools, as well as Early Intensive Intervention Programs that utilise segregated learning approaches to deliver applied behaviour analysis to autistic students in lieu of the education being provided to their allistic peers.<sup>33</sup>

Applied Behaviour Analysis has come under intense scrutiny in recent years, with many researchers, experts and autistic advocates calling for a move away from behavioural interventions altogether. Despite this, the majority of state school systems offers no alternatives for autistic students, with almost all public systems drawing upon ABA techniques when advising on how best to support autistic students.<sup>34</sup>

*When SSEND was called in by my child’s school, we were presented with a new IEP. For the first time, on the advice of SSEND, verbal communication was incentivised and eye contact was added as a goal to be rewarded. I can’t even begin to explain how inappropriate this is for an autistic child with situational mutism.*

*Parent to SPRW*

The cost-benefit of ABA as an intervention has also been explored recently with doubt cast over its effectiveness. TRICARE, the United States of America's health care program for service members and their families, conducted an extensive investigation into ABA service offerings for beneficiaries diagnosed with Autism. The study<sup>35</sup> is one of the largest ever conducted into ABA effectiveness. Of particular note it found that over a five year period, program costs increased 129 percent whilst participation increased only 39 percent. Furthermore, a quarterly report<sup>36</sup> found that the majority of participants had little to no change in symptomatic presentation over

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<sup>32</sup> [Autism CRC - A review of evidence for interventions for children on the autism spectrum \(Summary 2 of 2: Umbrella review\)](#)

<sup>33</sup> [Department of Education - Specialised Learning Programs for Students with ASD](#)

<sup>34</sup> *ibid*

<sup>35</sup> [Annual Report on Autism Care Demonstration Program for FY 2020](#)

<sup>36</sup> [TRICARE Comprehensive Autism Care Demonstration Program 2 2019 \(1\) Autism Report](#)

the course of 12 months, with a small percentage worse off. Of the participants that did record improvement, it was not statistically significant.<sup>37</sup>

Across the two reports, conclusions were drawn about the effectiveness of ABA services, specifically:

1. "... the delivery of ABA services is not working for most TRICARE beneficiaries in the ACD."
2. "... the Department remains very concerned about these results, and whether the current design of this demonstration, as well as ABA services specifically, is providing the most appropriate and/or effective services to our beneficiaries diagnosed with ASD."

With costs growing disproportionately to participant uptake and the lack of demonstrated benefit among beneficiaries, the longevity of ABA services as a therapeutic support is questionable. The cost-benefit of the provision of ABA is not in the best interest of participants nor its financiers, and as such it is imperative to adopt other programs and therapies. There are alternatives that are financially more economical and provide trauma-sensitive support to autistic people.

It is our view that the Australian education system must follow the lead of Irish system, with a recent report stating "Behavioural interventionist therapies are ultimately founded on modifying disabled people's behaviour to meet goals decided by others; often to conform more closely with neurotypical communication, behaviour and/or norms and therefore the Committee believe cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment."<sup>38</sup>

## Exclusionary discipline

Our member advocates have shared stories of repeated suspensions (often multiple suspensions per term in children as young as kindy age) and in a couple of cases, expulsions.

The overuse of suspensions as a disciplinary response is a key factor in the current issues facing autistic students in Australian schools. This discrimination also reflects wider inequities within the school system. First Nations and Disabled students are significantly disadvantaged by school discipline, and this is disproportionately so in all states. Disabled students are approximately twice as likely to be suspended than their non-disabled peers, and First Nations students are more than 300% overrepresented in suspension figures.<sup>39</sup> These suspensions are often directly discriminatory and a result of a lack of accommodations and supports, as well as a fundamental lack of understanding of dysregulation and the needs of autistic students. Time and time again we are approached by our member advocates, telling us of suspensions imposed for disability related behaviour, in direct contravention of disability discrimination laws.

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<sup>37</sup> [Therapist Neurodiversity Collective - ABA is NOT Effective: So says the Latest Report from the Department of Defense](#)

<sup>38</sup>

[https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint\\_committee\\_on\\_disability\\_matters/reports/2023/2023-02-23\\_report-on-aligning-disability-services-with-the-united-nations-convention-on-the-rights-of-persons-with-disabilities\\_en.pdf](https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint_committee_on_disability_matters/reports/2023/2023-02-23_report-on-aligning-disability-services-with-the-united-nations-convention-on-the-rights-of-persons-with-disabilities_en.pdf)

<sup>39</sup> Data reference

*“Our school acknowledges to me verbally that my child should not have been suspended at age 5 when he had an imputed disability. (but it certainly enraged and deteriorated our family's trust and relationship with the school and compelled me to seek a diagnosis )”*

*Parent to SPRW*

We have also heard from our members that suspensions are frequently used as a bargaining tool. Schools will not accept a student back after a suspension unless the parent agrees to a previously rejected strategy, such as planned use of restrictive practices or part time attendance.

*“Suspensions or exclusions - school have said if we choose to send out child to more school (child is actually requesting to attend) they will have no supports or accommodations and will be subject to the school's standard disciplinary code.”*

*Parent to SPRW*

## Informal segregation and removal

All children have the right to appropriate and meaningful education. Our member advocates, because of their belief in inclusive education, most frequently have children who are enrolled in mainstream public schools. Preference for children with disability attending mainstream school is also reflected in enrolment statistics which indicate, 89% of children with a disability attend mainstream school<sup>40</sup>. Despite this, children with disability are still denied an inclusive education. Autistic students are often subject to informal segregation, through alternative learning arrangements.

These can include reduced attendance at the insistence of the school, impromptu requests for students to be collected early from school or being taught by an EA in a separate area to the rest of the class, often alone. They are refused attendance at school events, camps, and excursions, frequently under the guise of “what’s best for the child” or “being unable to cope.”

These strategies, although often well-meaning, act to reinforce difference, compound isolation and deny autistic students the school education that their non-disabled peers experience.

*“Current school level 3 funded child goes to school 9-1pm for the last 12mths. Collaborative decision. Child would now like to attend more schooling and the school has said they don't have the funding/resources. Basically no. You can not attend.”*

*Parent to SPRW*

The experiences of our member advocates' children are not dissimilar to the experiences of students and parents who gave evidence in the Brisbane hearing of the Disability Royal Commission. In the Report on Public Hearing 7 - “Barriers experienced by students with disability in accessing and obtaining a safe, quality and inclusive school education and

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<sup>40</sup> [People with disability in Australia 2020: in brief, Education - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://www.aihw.gov.au)



consequent life course impacts”<sup>41</sup>The Royal Commission heard lived experience from students and their parents about a teacher who ‘tried to manage [a students] behaviour by separating him from the rest of the class’ and ‘prolonged part-time enrolment’.

The Royal Commission acknowledged the disproportionate use of exclusionary discipline against students with disability in the recommendations for further inquiries in the Report on Public Hearing 7. It stated, “The Royal Commission will give further consideration to the policy and regulatory levers available to address the disproportionate use of exclusionary discipline against students with disability, particularly in respect of First Nations students with disability and very young children with disability.”

Further, the lack of data and transparency in recording exclusionary discipline and compounded by informal practices, was addressed in the finding ‘The NSW and Queensland state school systems do not routinely record and use data and information about incidents of denial or discouragement of enrolment, bullying, exclusionary discipline and restrictive practices experienced by students with disability.’ Our research of national data shows that generally, states do not disaggregate students with disability in exclusionary discipline data.

Where data was available, we identified clear and dramatic disproportionality in the use of exclusionary discipline against students with disabilities and First Nations’ students.

*My child was suspended twice before the end of term one, Kindy (he was four). During one suspension, the deputy spoke to his classmates in his absence, telling them that ‘he was absent today because he needed to learn not to be naughty’. No wonder he never made any friends in the playground – after that, they all thought he was a bad kid.*

*Parent to SPRW*

## Inaccessibility and ableism

Member advocates frequently ask for advice on how to navigate inaccessibility and ableism at their child's school. Through the compiling of this submission, members have recounted their experiences of inaccessibility and how this has hindered their child's ability to participate in courses or programs on the same basis as a student without disability as protected by the Disability Standards for Education.

*"My child preferred to wander the classroom and listen during mat time rather than sitting and listening to the teacher. It was never disruptive and they could always answer any question about the lesson. I was told that my child couldn't have that as an accommodation as their wandering was distracting to the other students."*

*Parent to SPRW*

The barriers to accessibility identified by our members include:

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<sup>41</sup> [Report on Public Hearing 7 - “Barriers experienced by students with disability in accessing and obtaining a safe, quality and inclusive school education and consequent life course impacts”](#)

- Blocking therapists from entering school grounds to conduct therapy that aligns with student outcomes
- Using funding, or lack thereof, as an excuse to refuse support or accommodations to an autistic student
- Not consulting with the student, students carer, or therapeutic team on appropriate accommodations and supports
- Refusing accommodations or supports based on perceived impact to other students in the class or the insistence of equality over equity
- Suggestions from school that an autistic student may be better placed at a segregated specialised school or learning program instead of mainstream schooling
- Physical barriers that create sensory overload for autistic students such as cluttered or bright classrooms and uniform policies

Autistic students' neurology is different to that of allistic students. Placing expectations on them to learn, play and interact in ways that are not congruent to their neurotype is traumatic and exhausting for autistic students. Typically, autistic students who are not included and accepted for their neurotype will either; mask their traits to appear neurotypical resulting in burnout, or exit the schooling system.

*When you say we need to look into PDA (Pathological Demand Avoidance) supportive alternatives, we get eyerolls because the kids “just need a kick in the pants” -  
Teacher to SPRW WA*

Ableism in schooling practices needs to be stamped out in order to appropriately support autistic students. When considering if schooling practices are inclusive of an autistic student, care should be given to respect their preference or style for listening, speaking, social interactions, play, learning and work. Examples include the revised whole body listening program<sup>42</sup>, augmentative and alternative communication (AAC), removal of tone policing, respecting autistic play styles and universal design for learning (UDL).

*“My 7 year old last year kept getting sent to the office for ‘not listening with his ears’ despite having a diagnosis of ADHD and Autism, and despite me telling the school teacher that my son was listening even if he was doodling on paper at the time”  
Parent to SPRW*

*“Every time I tried to talk to my child’s teacher about their school work, the teacher would tell me about another child who could do it perfectly, and why couldn’t my child just be like them?”  
Parent to SPRW*

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<sup>42</sup> <https://www.everydayregulation.com/>

## Challenges facing Educators

Research indicates that the majority of teachers lack the training, time and/or patience to try and understand the specific and often complex needs of autistic children. This issue is further compounded by attitudinal and dispositional characteristics of staff that contribute to discrimination and marginalisation of autistic children.

As part of our work to create this submission, we sought the input of those member advocates who are also teachers and education professionals, asking them to share the issues or challenges they faced in supporting their autistic students. A selection of this feedback is included in the appendix to this submission, however the two major problems that appeared consistently through many comments received were:

1. Class sizes & Teacher Workload
2. Lack of quality, relevant training

We were told of teachers who have literally hundreds of students to cater to, and of many of these students requiring differentiation or additional support. In all but early childhood classrooms, education assistant support is either minimal or inefficient (due to school policy directing assistants to teach students 1:1 rather than through teacher support or whole class assistance).

Despite the increasing complexity of classrooms and higher demand on teachers, many feel ill equipped and uninformed due to a lack of quality, up to date and useful training. Teachers felt that training made a fundamental difference, not only to their knowledge and understanding, but also to the attitudes and ability to connect with their autistic students.

Teaching staff who are also parents of autistic and neurodivergent children felt frustrated and upset by the way their own children are treated by the education system, particularly given their own attitudes, commitments and dedication to handling those students themselves. They attributed much of this to the lack of training and ongoing development available to their colleagues in the public education system.

*“In my experience as a teacher and parent of a neurodivergent child - training! Different teachers’ experience and understanding plus ability to connect with the student makes the difference between A and E grades. Class sizes also has a huge impact on this, in my opinion.*

*The (unintentional?) discrimination in the verbal and written feedback given to students over the years makes a huge difference I think. The amount of feedback we’ve had that pretty much says “be less adhd” is... just gross. I feel that if classes were smaller, teachers would have more time to provide formative feedback along the way, especially with group tasks or ongoing project based tasks”*

*Teacher to SPRW*

## Lack of appropriate direct educational advocacy (contribution from ACE WA)

*The following contribution was provided by Accountability for Children in Education WA (ACE WA), a grassroots advocacy group that offers a direct volunteer advocacy service to WA families.*

Here at ACEWA (Accountability for Children in Education WA) we offer direct volunteers advocacy to families navigating the public education system, in our day to day operations the distinct lack of available advocacy services are apparent and especially when requiring specialised neuroaffirming advocacy who support the needed adjustments and accommodations required by neurodiverse students and their families.

The public education system can be difficult to navigate due to the lack of transparency and global policies, with many policies being at the discretion of the school to implement or vary as needed and with no consistency there is a profound understanding of inadvertent discrimination occurring where families, carers and students can not access reliable, consistent or regulated procedures but are instead able to be discriminated against through the individual opinions and choices of each individual school or principal.

The majority of advocacy requests we get relate directly to the struggles of inclusion of neurodivergent students into the education system, where their options are limited and often the only adjustment or accommodation the department can offer is to refer them to the home education arm of their operations.

With the lack of neuroaffirming education and practice entrenched into the school system at each of these levels, we see more and more students who can not access a safe, appropriate and supportive education system.

We feel that with a uniform approach to inclusion and adjustments that is regulated and based on best practice rather than personal discretion we could hope that schools would adopt accommodations that were reasonable, safe, trauma informed, person centred and that allowed more neurodiverse students to access the education they deserve

## How can we support the economic inclusion of Autistic people

It is SPRW's strong belief that improving accessibility, inclusion and equity for Autistic children in school is an essential precursor to improving overall economic inclusion.

For this reason, in addition to the education related recommendations noted under Key Theme 1: Social inclusion, we also recommend the following:

- Inclusive Education:

An inclusive education can only become a reality for autistic students with a gradual shift away from segregation towards full inclusion. This transformation is an integral component of improving outcomes for Autistic, neurodivergent and disabled students in Australia. In addition, it will also ensure that all students receive the quality inclusive education that is their human right, and which is the obligation of government to provide in accordance with the CRPD. As referenced earlier, Square Peg Round Whole endorses the Australian Coalition for Inclusive Education's '*Driving Change: A roadmap for achieving inclusive education in Australia*<sup>43</sup>'

There is substantial evidence indicating that both disabled and non-disabled students benefit from an inclusive education system.<sup>44</sup> For students without disabilities, academic outcomes improve, or, at worst, remain neutrally affected, because of the inclusion of their same aged disabled peers.<sup>45</sup>

Further, substantial positive impacts on social attitudes and beliefs of non-disabled students occur within inclusive systems.<sup>46</sup>

For students with disabilities, the benefits of inclusion are clear. Full inclusion directly correlates with higher levels of academic achievement, social and emotional wellbeing and higher lifelong economic outcomes and independence.<sup>47</sup>

For these reasons among others, it is our strong belief that a National Strategy must include provision for the development of a transition process to ensure that Autistic students and their allistic peers have access to a fully inclusive education system, as is their human right.

- Neuroaffirming approaches to replace PBS and ABA

One of SPRW's core aims is to promote the adoption of Collaborative Proactive Solutions (CPS) in the Australian education system. We share this aim with many other organisations and groups nationally.

CPS was proposed as an evidence-based solution in a number of submissions to the recent Senate Inquiry into School Refusal [SPRW prefers the terminology School Can't] as well as the Senate Inquiry into "The Issue of Increasing Disruption in Australian school classrooms." SPRW's National submission to this inquiry gave significant exploration to CPS, its uses in

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<sup>43</sup> <https://acie.org.au/acie-roadmap/>

<sup>44</sup> [https://alana.org.br/wp-content/uploads/2016/12/A\\_Summary\\_of\\_the\\_evidence\\_on\\_inclusive\\_education.pdf](https://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf)

<sup>45</sup> Ibid, p.8

<sup>46</sup> Ibid, p.12

<sup>47</sup> <https://allmeansall.org.au/research>

other systems and countries and its evidence base.<sup>48</sup> Notably, we draw the attention of the strategy group to the fact:

- There are already multiple Australian schools who have commenced implementing CPS successfully – for example, St Phillip’s Christian College (SPCC) DALE and Mosman Church of England Preparatory School

-CPS model has been proven to drastically reduce discipline referrals, detentions, suspensions, restraint and seclusion in schools, as well as in mental facilities and juvenile justice centres. All research is available on the Lives in The Balance website – [www.livesinthebalance.org/research](http://www.livesinthebalance.org/research)

CPS is a cost-effective alternative to PBS and ABA; Lives in the Balance has a number of existing teacher and education professional resources and programs that are freely available, with formal training available at a reasonable cost. To date, Dr Greene has met with education departments in SA, NSW and WA.

We also draw your attention to the SA Department of Education’s free Interoception curriculum.<sup>49</sup> This is an example of an excellent, universal design for learning, neuroaffirming approach that can benefit autistic and allistic students alike. Interoception is a pre-requisite skill for self-management and self-regulation, which assists individuals to identify emotional and bodily responses, and the skills to manage these responses. Explicitly reaching interoception is widely considered to be neuroaffirming for autistic people, and has significant benefits for students abilities to regulate, engage and build connections.

- SPRW have long advocated for improvements to teaching conditions and more robust support for teachers to provide quality teaching experiences to Autistic students and their peers. We will not elaborate on these in this submission, as it falls outside the scope of the discussion paper, beyond noting that without making substantial improvements to working conditions, including workload, planning time, additional support staff and higher quality training and development that is delivered accessibly with no cost to teachers themselves, limited improvements in the education experience of Autistic young people can be expected. We recommend, where possible, that a national strategy recognise the invaluable role teachers play in determining the life outcomes of autistic students, and promotes the necessary changes to make these life-changing professionals more supported and recognised.

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<sup>48</sup><https://www.aph.gov.au/documentstore.ashx?id=59f99491-360c-4bda-af8b-80a8b5e9dbea&subId=736437>

<sup>49</sup> <https://www.education.sa.gov.au/schools-and-educators/curriculum-and-teaching/curriculum-programs/applying-interoception-skills-classroom>

## Key theme three: Diagnosis, services and supports

### Relevant themes from the lived experience of our members:

Broadly speaking, the experience of our members is that:

- Understanding of Autism and its many and varied presentations is severely lacking in society generally, including amongst medical professionals, psychologists, school counsellors, teachers, and other professionals.
- Access to diagnosis is prohibitively expensive and challenging. Public system waitlists are often years, forcing parents to spend thousands out of pocket (even with Medicare rebates available) on private assessment – which also often have months (or sometimes even years) long waiting periods to access. This creates a massive stressor for autistic children, their carers and their families as frequently, attempts to access diagnosis only come once things are approaching crisis point at home, or in school.
- It is frequently unclear and inconsistent exactly what is required for a diagnosis. Whilst the [National Guidelines for Assessment and Diagnosis of Autism Spectrum Disorders](#) have provided welcome clarity on the diagnostic process, some states education systems and the NDIS often do not clearly align with these guidelines, leaving students underfunded and children with barriers to NDIS access.<sup>50</sup>
- Members report significant feelings of gaslighting in the period leading up to a diagnosis by medical professionals. This can come from schools, community agencies or allied health therapists – as well as from innumerable other areas. For example, parents are frequently extremely competent and very engaged in their parenting, however the regular parenting advice (which is designed around neurotypical children) often does not work for these families, and it is implied by the professionals involved that the issues families experience are because of poor parenting practices, lack of discipline or other parent-based issues. Members who are “in the thick of it” often struggle massively with this; members who are further along in their journey can often retrospectively see that other children respond to this typical parenting advice far more readily than autistic children.
- It is very common for an Autistic person to have other co-existing “conditions” such as anxiety, ADHD, dyslexia, dysgraphia etc. This makes our children complex people who need highly skilled and attuned professionals around them to provide them and their families and carers the most appropriate care and advice. Such professionals are difficult to find and to access.
- There are many health professionals and therapists who do not practice in a trauma-informed, neuroaffirming way, and appear to lack appropriate knowledge and skills in their interactions with and assessment of Autistic children and families. For example –

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<sup>50</sup> [Australia's First National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders | Autism CRC](#)

Applied Behavioural Analysis (ABA) is often recommended as a best-practice approach to “treating” autistic children despite the fact that it is widely considered as abusive by Autistic people.<sup>51</sup> Considering the consistent evidence and testimony from neurodivergent people who have experienced ABA, SPRW believes that ABA and related behaviourist approaches to interventions should not be funded by the NDIS or the governments of Australia, let alone recommended by them. It is worse than simply a waste of money, it is actively paying for Autistic children to be traumatised and it exacerbates the very behaviours it attempts to erase. Our members report having to experience this and work this out for themselves, as they often initially follow the popular advice and initially engage with ABA services. Many of them do so unwittingly, as we have frequently come across ABA providers who advertise themselves as strengths-based and neuroaffirming. This leads to families trusting that the providers will provide strengths-based and neuroaffirming supports, when in reality, their children end up actively traumatised and suffering. This realisation often comes after thousands of dollars have been sent, and their children’s self-worth, emotional and self-regulation capacity and confidence in their own minds and bodies have been seriously damaged.<sup>52</sup><sup>53</sup> There is also increasing evidence highlighting a range of implementation issues with ABA interventions.

- It is commonly understood in the Autistic and neurodivergent communities that Autistic people have experienced some level of trauma in their lives, including in the short lives of children. This can be as simple as having been the subject of constant discipline for things they can't control from a young age, the need to mask their autistic identity to avoid difficulties in schools, home and the community, or always feeling as if they don't fit in and are different from their peers, yet never understanding why. Being autistic influences learning, social, emotional and behavioural regulation at school<sup>54</sup>, as does exposure to adverse childhood events<sup>55</sup>
- Furthermore, behaviorist interventions more strongly align with medical approaches, placing emphasis on disability, rather than socially oriented models, premised on a

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<sup>51</sup> See for example H Kupferstein, ‘Evidence of increased PTSD symptoms in autistics exposed to applied behaviour analysis’, January 2018 (4(3) *Advances in Autism*) <https://www.researchgate.net/publication/322239353> Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis ; Alex Kronstein, ‘Treating autism as a problem: The connection between Gay Conversion Therapy and ABA’ (2018) <https://nsadvocate.org/2018/07/11/treating-autism-as-a-problem-the-connection-between-gayconversion-therapy-and-aba/?fbclid=IwAR2yzbyrDcHI5dNKD4afHtO5vtz3TMD7JcEbW1khCwlyz6FGDP7fy5nTw> ; By apreneraquererme, NeuroClastic, ‘On ABA: Evidence-based Doesn’t Mean Good Therapy’ (2019) <https://neuroclastic.com/on-aba-evidence-based-doesnt-mean-good-therapy/>

<sup>52</sup> See McGill, O., & Robinson, A. (2020). “Recalling hidden harms”: Autistic experiences of childhood applied behavioural analysis (ABA). *Advances in Autism*, 7(4), 269-282.

<sup>53</sup> Wilkenfeld, D. A., & McCarthy, A. M. (2020). Ethical concerns with applied behavior analysis for autism spectrum disorder. *Kennedy Institute of Ethics Journal*, 30(1), 31-69.

<sup>54</sup> Kasari, C., & Smith, T. (2013). Interventions in schools for children with autism spectrum disorder: Methods and recommendations. *Autism*, 17(3), 254–267.

<sup>55</sup> Berger, E., D’Souza, L., & Miko, A. (2021). School-based interventions for childhood trauma and autism spectrum disorder: a narrative review. *Educational and Developmental Psychologist*, 38(2), 186-193.



rights-based approach to disability, through which people with disabilities are recognised as 'active subjects with rights and not passive objects of assistance'<sup>56</sup>.

Our member discussions also reveal that many families are actively seeking out neurodivergent professionals, therapists and support providers. This is because these providers and professionals understand neurodivergence and its nuances, and have actively undertaken training in neuroaffirming practices.

We also note the following points:

- The complexity of accessing a diagnosis, participating in the assessment process and engaging with diagnosing professionals puts a huge strain on families (many parents of autistic children are also neurodivergent themselves). The complexities of diagnosing co-occurring conditions are innumerable, and many families spend years flailing when health professionals don't recognise the seemingly conflicting signs; for example, the presentations of Autism and ADHD. Many professionals are also unable to recognise and allow for the impact of masking, and many assessors are particularly unhelpful when their patient is an adult person, or non-typical presentation.
- The ability to access the NDIS (or indeed any other support services) is, by definition, extremely challenging for Autistic people. As stated earlier, Autistic children often have Autistic parents (frequently undiagnosed), and the executive functioning challenges they themselves experience are a significant hindrance when applying for, engaging with and communicating about access to support.
- It is important to note that if intersectionality is accounted for, such as adding to this already complex situation, that the family is Indigenous, then all other barriers to accessing healthcare, support or services come into play. Families being gaslit on their parenting approaches, assumptions of poor parenting and personal and systemic racism are issues that heighten the challenges for First Nations families with Autistic children. Add to the mix the trauma, including the intergenerational trauma, in First Nations families and communities, and it is clear that a service-provider or public sector employee who is not well-trained and well-practiced in trauma informed and culturally responsive approaches can do immense damage to the very people they are intended to support. If you add socioeconomic disadvantage into this mix, both Indigenous and non-Indigenous families experience huge obstacles to access, because of the significant costs associated with accessing timely assessment and supports.
- The impact of education for Autistic children cannot be overstated. Education is a fundamental human right, and it is acknowledged to be one of the most significant influences on the lifelong health, economic and social outcomes of an individual. Despite this, Autistic children and their families in Australia face deeply entrenched education inequities, and many face discrimination in almost every aspect of their school life. Autistic children are excluded, disadvantaged, restrained, secluded, pushed out and isolated in Australian schools and the ongoing disadvantage these children face set the

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<sup>56</sup> Autism-Europe. (2013). Charter of rights, international congress. ASD-EUROPE, 26–28 September. Budapest Hungary. <http://www.ASDEurope.org/publications/rights-and-ASD-2/charter-of-rights-4/>

path for a lifetime of disadvantage. It is imperative that the National Strategy confronts and addresses this devastating reality that was documented extensively in the recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, and provides a starting point for systemic educational reform to ensure that all students (including Autistic students) are able to access the high quality, appropriate and inclusive education that is their human right.

## How can we better support health and mental health outcomes for Autistic People?

The challenge of improving health and mental health outcomes for Autistic people is a formidable one, and Square Peg Round Whole believes that this is the responsibility of experts and professionals working in this area (in co-design with Autistic people and led by Autistic experts and professionals).

However, from a community perspective, we suggest:

- Addressing the substantial obstacles facing families and carers seeking assessment and diagnosis for their autistic children. This should include ameliorating the financial barriers, significant waitlists and challenges accessing neuroaffirming diagnosticians, familiar with non-typical presentations of Autism and the impact on masking.
- Incorporating within the National Strategy (in particular, in relation to education) actions that recognize that for significant numbers of Autistic people, diagnosis is inaccessible or unavailable, and that many autistic people throughout the entire life stages remain undiagnosed. Such individuals should not be excluded from accessing supports or resources necessary, and school funding should not be weaponized as an excuse to avoid providing appropriate supports and services necessary to undiagnosed young people, or those whose diagnosis has not been revealed to the school.
- Diagnostic processes should be culturally responsive, and measures must be implemented to mitigate the intersectional barriers faced by First Nations Autistic people when accessing supports, services or assessments.
- It is imperative that the Australian government urgently ceases to provide government funding for the delivery of ineffective, harmful interventions including Applied Behaviour Analysis.
- There should be particular measures taken to encourage and support autistic, neurodivergent and disabled people themselves becoming professionals and service providers, given that they are particularly placed to provide neuroaffirming, intuitive and empathetic care.