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WA Education and Health Standing Committee
Inquiry into support for Autistic children and young people in schools
Reframing Autism Submission

Reframing Autism thanks the Committee for the invitation to make a submission to its inquiry into support for Autistic children and young people in schools. Reframing Autism is an Australian, Autistic-led charity, with a particular focus on Autistic wellbeing across the lifespan. Our aim is to offer the Autistic and autism communities access to lived experience knowledge alongside and augmented by respectful, inclusive research.

We have a deep interest in the conditions required for the provision of inclusive, neuro-affirming education to Autistic children and young people, and in the barriers and enablers which would allow Autistic children and young people to thrive in schools.

In our submission, we have addressed those questions within the Inquiry's terms of reference that are within our field of knowledge and expertise.

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Co-CEOs

[redacted]

The Reframing Autism team would like to acknowledge the Traditional Owners of the many lands on which we have the privilege to learn, work, and grow. We are committed to honouring the rich culture of the Aboriginal and Torres Strait Islander peoples of this Country, and the diversity and learning opportunities with which they provide us. Sovereignty was never ceded: always was, always will be Aboriginal land.

1. The prevalence of Autism in WA and projected demand for support in schools

Is Autism more prevalent across certain demographics than others?

Disparities in Autism prevalence across demographics are less likely to result from intrinsic factors, and more likely related to (a) access to knowledgeable clinicians and services (or lack thereof), (b) cultural and linguistic factors, including in research, and (c) behavioural characteristics. These factors are most likely to explain assumed under-identification of particular demographics. For example, whilst it remains true that more boys are formally identified as Autistic than girls (a 4:1 ratio of male-to-female diagnosis is generally accepted), it is likely that this discrepancy is more related to behavioural characteristics than gender (Duvekot et al., 2017). It may also stem from a lack of research about or including Autistic females, so that our understanding of the many factors that might shape Autistic girls' experiences and expression of Autism is lacking (Nordahl, 2023).

Whilst Australia is a western high-income country, we do not adequately understand how cultural and contextual factors impact various intersectional populations in seeking and obtaining Autism diagnoses for their children or themselves (including but not limited to First Nations people, culturally and linguistically diverse communities, and financially disadvantaged populations). De Leeuw, Happé & Hoekstra (2020) proposed a framework to map out such cultural and contextual factors that can affect the identification, help-seeking and diagnosis of Autism which included accounting for "cultural norms of typical and atypical behaviour, culture-specific approaches to parenting, mental health literacy, cultural beliefs, attitudes and stigma, as well as the affordability, availability, accessibility, and acceptability of services". In Australia, access to affordable and knowledgeable diagnosticians and diagnostic teams should not be assumed, especially for CALD and First Nations families, and those located in remote and regional areas.

2. Current support available for Autistic students in WA schools

2a. Positive Behaviour Support

Our understanding is that WA schools, both primary and secondary, very often rely on schoolwide (or whole school) Positive Behaviour Support (PBS) as their primary evidence-based framework, as endorsed by the WA Education Department. Whilst a focus on social-emotional learning, deep partnerships with parents, clear behavioural expectations, and individualised support can be integral to some PBS programs, so too is a reliance on award/reward systems to recognise and promote "positive behaviours".

The risks of PBS to Autistic students are many, not least of which is that individual school implementation varies greatly and is deeply dependent on the knowledge and skills of each school's leadership and staff. Nevertheless, discussions around classroom and schoolwide behaviour management rarely address the risks of PBS (especially when poorly implemented), or the pedagogical implications for Autistic students.

PBS assumes that some behaviours are categorically "good" or acceptable (and should be positively reinforced, recognised or rewarded), while others are categorically "bad" or unacceptable. While some obvious examples (e.g., bullying) may well fit into this simple binary construct, many Autistic behaviours, which are authentic expressions of Autistic processing or Autistic needs, are categorised as unacceptable or negative behaviours that need to be "managed" using PBS. Autistic children and their parents cite stimming (self-stimulatory behaviours), sensory differences, differences in processing, and differences in social communication as frequently being managed as "unacceptable behaviours" that need explicit behaviour management. These are not recognised within PBS models as authentic Autistic behaviours, but rather as behaviours that challenge the neuronormative assumptions of what "positive" behaviour entails.

In the work that we do with parents, very rarely if ever do we hear of examples of schools who have worked with Autistic and otherwise neurodivergent young people and their families to understand how positive and authentic Autistic behaviours can be captured respectfully in PBS models. Instead, Autistic children and young

people are often subject to behaviour management through PBS if they cannot follow deeply neuronormative constructs of "positive" behaviour.

Moreover, when more classic or universally accepted "challenging" behaviours are at play, PBS is not shown as efficacious in managing such behaviours in the Autistic population (see Hassiotis et al., 2018).

More deeply, the prevalent issue at the core of PBS, is that its implementation usually relies on a transactional contract of "positive" behaviour for reward (for which there are many models, with varying complexity, which can be targeted at an individual, group, and/or class level). In implementation, PBS effectively substitutes punishment with reward; the motivation for offering the reward, however, is consistent with that of administering punishments (child compliance and operant conditioning), which means that ultimately the reward has a punitive effect. In effect, when an Autistic child or young person can only be "rewarded" through their compliance with prescribed "positive" behaviours (that may very well not be positive to them and may undermine their Autistic and authentic ways of processing and learning), we must acknowledge the latent threat of withholding the reward (whether tangible or abstract) for Autistic non-compliance.

The core business of educational institutions is not to teach compliance, and yet this is most often the focus of PBS in schools. For Autistic students, the effect of PBS is often that their basic needs are misinterpreted or unacknowledged, their internal realities and neurocognitive experiences are ignored, diminished or dismissed, and their internal motivation is decreased (Kohn, 2020). PBS sacrifices the relational ethics of care that should be the cornerstone of strong pedagogical relationships, often diminishing feelings of safety and trust upon which all genuine learning is dependent.

As a compliance-based intervention, PBS "serves as a way to label, punish, and surveil students" (Kim & Venet, 2023), which is antithetical to best practice in trauma-informed, attachment-based educational paradigms which are more appropriate to Autistic learners.

Whilst we do not wish to engage with the broader issues associated with Applied Behavioural Analysis (ABA), as a compliance-based intervention that promotes Autistic masking and camouflaging through the provision and withholding of rewards, PBS is open to the same criticism and concerns as ABA, which we articulate here.

When schools engage with models that promote Autistic masking and camouflaging (i.e., when schools reward the suppression of authentically Autistic expressions and experiences), they run the risk of causing long-term mental harm. Autistic masking is associated with higher prevalence of anxiety (Cage & Troxell-Whitman, 2019; Hull et al., 2021), exhaustion and burnout (Bargiela, Steward & Mandy, 2016), depression and low mood (Cage et al., 2018; Hull et al., 2021), and (most concerningly) suicidality (Pelton et al., 2020). Indeed, since masking is one of the strongest predictors of suicidality in Autistic adults (Cassidy et al., 2020), educational institutions have an immediate duty of care to their Autistic students to adopt approaches that eschew masking.

We advocate for WA schools to understand deeply the lifelong risks of masking (e.g., Bradley et al., 2021) before implementing any strategies such as PBS which – for Autistic children and young people – often result in increased masking behaviours.

2b. Zones of Regulation

We understand that the WA Department of Education has adopted the program, "The Zones of Regulation", as their preferred approach to improving self-regulation in students, and that this program has been widely adopted in schools. The Zones of Regulation program (and related strategies such as behaviour thermometers and feelings registers) are often linked with de-escalation strategies and are utilised in contexts and environments in which there is an expectation that Autistic children should exercise connection, interaction and emotional regulation.

In our experience, and given feedback from Autistic people and their parents, the "Zones" program is often implemented poorly, and has been used by teachers in WA as a compliance-based model in which "being in the green zone" is rewarded. Not only does this undermine the principle of the "Zones" program (which is not

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designed to prioritise one "zone" above others), but the program is exclusionary to many Autistic students of all ages.

Most concerningly, the "Zones" program rarely accounts for the many Autistic children who present with co-occurring alexithymia, with interoceptive differences, or with anxiety sensitivity, and may in fact contribute to the distress and exclusion of Autistic students who present with any of these.

In essence, alexithymia is a condition that stems from altered emotional awareness, including challenges in processing, interpreting, and expressing emotions both in self and others. That is, alexithymia is not an inability to experience emotion, but is rather associated with challenges with describing, labelling and recognising feelings. There are high rates of overlap between alexithymia and Autism, and this very often presents as a dynamic interplay between alexithymic and Autistic traits. It is estimated that almost half of all Autistic individuals are also alexithymic (Poquérusse et al., 2018).

Interoception is "the perception of sensations from inside the body and includes the perception of physical sensations related to internal organ function such as heart beat, respiration, satiety, as well as the autonomic nervous system activity related to emotions" (Price & Hooven, 2018). Significant differences in interoceptive awareness (i.e., experiences that differ from expected, typically developing norms) is a prevalent Autistic sensory processing experience and should be as recognised as more familiar Autistic sensory differences (like auditory or tactile differences), with many Autistic children and young people finding it difficult to recognise and interpret their internal bodily signals.

It is important to remember that many Autistic children (and their families and allies) may not know or recognise these alexithymic or interoceptive traits explicitly.

The "Zones" program requires a sophisticated level of emotional and interoceptive awareness that is often inappropriate or inaccessible to Autistic students with alexithymia or interoceptive differences. The program operates on the assumption that the student has the interoceptive and emotional perception available to them to recognise their emotional zone.

Autistic adults report that programs like the Zones of Regulation can be ineffective at supporting their emotional regulation at best, and actively damaging at worst. Autistic people report feeling a deep sense of failure and prevalent confusion because their experiences of alexithymia and/or interoception preclude them from even identifying which zone they are "in". Indeed, this confusion and sense of failure can *exacerbate* emotional regulation challenges, rather than mitigate them.

Additionally, Autistic students may possibly be experiencing what has been termed "anxiety sensitivity". Anxiety sensitivity was first described by Reiss and McNally in 1985 as the fear of anxiety-related bodily sensations (see, e.g., Rodriguez et al., 2004). As individuals who often have distinct somatosensory reactions to anxiety, and for whom sensory input can often be interpreted as pain, many Autistic people of all ages experience fear of the bodily feeling of anxiety itself. For those Autistic children and young people with anxiety sensitivity, the Zones of Regulation program can itself be triggering, since the visual analogue scales can indicate to a child that their anxiety is increasing ("entering the yellow zone"), which can actively trigger and further increase anxiety. For these children, the Zones of Regulation program can be counter intuitive, contributing to emotional dysregulation.

We advocate for the removal of the Zones of Regulation program from schools, and for more respectful, inclusive, and universal approaches (as we outline below) to be instead adopted.

3. Strategies in other jurisdictions that support school systems to respond to the needs of Autistic students

The following discussion captures what Reframing Autism advocates should underpin the education of *all* children and young people, but are especially apposite for Autistic students to thrive in educational contexts and for them

to experience success, engagement, and connection in school environments. This discussion should be understood within the context of a human rights model of education, as is captured in a genuine commitment to the UNCRPD Article 24, and especially General Comment 4 (2016).

Australia has voluntarily ratified The United Nations' Convention on the Rights of Persons with Disability (UNCRPD), which means that we are bound by its articles and are obliged to implement its content in our legislation and policy decisions.

General Comment Number 4 to Article 24 of the CRPD was adopted in 2016. General Comment Number 4 built on what was already in the CRPD that required signatories to recognise "the right of persons with disabilities to education" and bound them to "ensure an inclusive system at all levels" (CRPD, 24.1). Whilst Article 24.2 defines some of the criteria of inclusive education (including not being excluded from general education, access to education on an equal basis, and the provision of reasonable accommodations to support education), not being excluded is not the same as experiencing inclusion; access to education does not dictate its inclusiveness or quality, and "reasonable accommodations" are open to interpretation and are subjective.

General Comment Number 4 was thus adopted to provide more specific guidance on what defines inclusive education.

The following General Comment Number 4 paragraphs should inform all WA educational decisions:

- Children with disabilities (and therefore, Autistic children) and their families are partners and not merely recipients of education (para 7), which means that parents and caregivers "can serve as partners in the development and implementation of learning programs, including individualised education plans. They can play a significant role in advising and supporting teachers in provision of support to individual students" (para 70).
- Inclusive education requires a transformation in culture, policy and practice to realise genuinely inclusive education and to dismantle or eliminate the barriers to achieving inclusion (para 9).
- Educational structures must distinguish exclusion, segregation, and integration from inclusion (para 11), where inclusion is defined as involving "a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of relevant age range with an equitable and participatory learning experience and environment".
- The nine core features of inclusive education should include (para 12)
    - Whole systems approach
    - Whole education environment
    - Whole person approach
    - Supported teachers
    - Respect for and value of diversity
    - Learning-friendly environments
    - Effective transitions
    - Recognition of partnerships, and
    - Monitoring
- Inclusive education will apply the Universal Design for Learning (UDL) approach (para 25).
- In-classroom support measures (like teachers' aides or learning support staff, for example), must strengthen opportunities for inclusion, not contribute to marginalisation (para 33).

- Children with complex communication needs are able to express themselves and learn using alternative or augmentative communication (or AAC) (para 34), since communication is an inalienable human right.
- Governments should transfer resources from segregated environments to inclusive education environments (para 68).

To deny an Autistic child access to inclusive education as defined by these principles constitutes discrimination against that child.

Moreover, we advocate for the adoption of the following models and principles:

- *A relational ethics of care, grounded in trauma-informed and attachment-aware teaching*.

  Developing quality, individual, and deep relationships with Autistic students is vital to their feelings of belongingness in schools, and to their educational success (Anderson, 2020; Hodges et al., 2020; Makin et al., 2017). The benefits of responsive and profound care in schools are well established, but we strongly advocate for teachers to commit to Noddings' (1984) model of educational care (Fernandes, 2019). As we advocated in recent research:

  Autistic students report having better school experiences when they feel greater school connectedness and a sense of belonging (Anderson, 2020; Hodges et al., 2020), especially when fostered by deep connections with their teachers and other school staff (Makin et al., 2017), who celebrate their students' unique differences and meet their needs with innovative, strengths-based approaches (Hodges et al., 2020). Indeed, Brede et al. (2017) found that a mutually trusting student-teacher relationship was perceived to be the strongest predictor for educational re-engagement for a group of Autistic learners who had been repeatedly excluded from school.

  The importance of an educational process that is responsive to each individual child, and of having teachers and school staff that care deeply for the children who they teach, has been well articulated for neurotypical children (Noddings, 1984; Owens & Ennis, 2005). In the context of the classroom, 'caring' goes beyond the interpersonal pragmatics of a caring personality to imply a "space where teachers are invested in meeting the needs of individual children and where children are able to take responsibility for themselves and their own experience" (Wood, 2015, p. 260). This relational view of education is especially relevant for Autistic children, given its attention to fulfilling needs (Murray, 2002; Noddings, 2010) and to valuing autonomy, interdependence, community, equity and inclusion (Tichnor-Wagner & Allen, 2016; Wood, 2015).

  Heyworth et al. (2021).

  That such care is trauma-informed and attachment-aware builds on necessary factors of responsivity to the Autistic experience, given the prevalence of trauma in the Autistic population, including in Autistic children and young people. Developing attachment-aware and trauma-informed relational models of educational care is evidenced in Australia, Canada and the UK (e.g., the Attachment Aware Schools pilot from the UK and see Diggins, 2021; Jacobsen, 2020), and could be referenced moving forward (e.g., Brighton & Hove Schools, 2018; Brooks, 2020; Colley & Cooper, 2018).

- *Dr Ross Greene's Collaborative and Proactive Solutions (CPS) model*

  Whilst Greene's CPS model (see https://livesinthebalance.org/educators-schools/) has not had sufficient input from neurodivergent populations to be entirely responsive to all Autistic (and otherwise neurodivergent) students' needs, this CPS model of relational collaborative problem-solving is an existing, evidenced, accepted, and feasible structure for WA schools to adopt, and one which aligns to trauma-informed, attachment-aware principles of education. It is also predominantly free and tailored for educators. The above website includes links to training, Facebook groups, podcasts, surveys, and testimonials, as well as multimodal information about the CPS model and how to implement it. Importantly, the CPS model answers many of the charges laid against the current reliance on PBS as a behaviour support model.

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- *SA Department for Education interoception program*

  The South Australian Department for Education has developed and implemented a universal design approach to support students' emotional regulation that has its focus on interoception. This program, which could replace the current reliance on the flawed Zones of Regulation program, can promote psychological, emotional and physical health and wellbeing, as documented here. We note the findings that:

  The Department for Education in South Australia has trialled teaching interoception as a strategy for developing self-regulation and decreasing challenging behaviour for two years and is now rolling this strategy out statewide, with over 250 schools currently implementing interoceptive awareness teaching as a proactive positive behaviour management strategy. These schools teach students Siegal's (2010) 'Hand model of the brain' and a regulation scale based on the link between the expression of their autonomic nervous system and the hand model of the brain. Educators were also taught how interoception relates to the mindfulness part of the brain, to explain why students can move into a state of being 'ready to learn' through using the variety of interoception activities provided free via resources from the Department for Education's website, that educators can use together or separately to introduce and teach interoception:

  - *Ready to Learn – Interoception Kit (2019) for preschools and primary schools, families and allied health professionals;*
  - *Interoception Activity Guide 301 (2019) for upper primary, intermediate and secondary schools, families and allied health professionals;*
  - *YouTube videos about interoception and managing behaviour (Healthy Possibilities, 2019); and*
  - *Linking Interoception to the Australian Curriculum, General Capabilities and Embedding in Classroom Practices (Goodall & McAuley, 2019).*

  Initial data from a range of schools, confirmed observations of a significant decrease in challenging behaviour over 8-10 weeks of implementation, with pro-social behaviour increasing after 16-20 weeks (Goodall, 2016). Data analysis demonstrates that after one year, these decreases are sustained with suspensions and other negative behaviour consequences dropping significantly in both primary and high schools. Qualitative data, collected over three years, suggests that once teachers have committed to implementing interoception two to three times a day, they see positive impacts within a term: "Students will even ask when we are going to do our interoception if I have forgotten. They really feel the benefit of it." ... In summary, the Department for Education's interoception trials implemented a universal design approach to decreasing challenging behaviour. This approach focused on the theoretical link between self-regulation and interoception and how these can be targeted through teaching to promote psychological, emotional and physical health and wellbeing. Results clearly demonstrated that students being taught interoceptive awareness activities, increased their self-regulation and pro-social skills over time. Effects were statistically significant in both primary and high school, with improvements equally observable in preschool settings.

- *Learning About Neurodiversity in Schools (LEANS, UK)*

  The Learning About Neurodiversity in Schools (LEANS) program was developed and piloted by the University of Edinburgh to introduce the concept of neurodiversity into primary school settings. This participatory research project produced free educational resources about neurodiversity to introduce children aged 8-11 years to the concept, and to how it impacts their own and their peers' experiences at school. The LEANS program promotes inclusive actions and attitudes in teachers and students alike and, since it is for all members of the school community, it "upskills all pupils and staff members, focusing on capacity for positive future changes" (Alcorn et al., 2021), including understanding concepts of equity and individual, specific needs.

Whilst the LEANS program is not a specific model of educational care, we advocate for the need for school and department wide access to respectful, affirming information about neurodiversity to foster welcoming and inclusive educational environments which support Autistic children and young people to thrive.

4. Conclusion

It is clear to us that an overall philosophical framework shift to one that is trauma-informed and prioritises relational safety grounded in care and attachment (rather than compliance and reward) is vital to support the wellbeing and academic outcomes of Autistic students in WA.

However, such a shift can only be successful if there is appropriate and robust investment in the resources and infrastructure to make sure this work is done properly, deeply, and with adequate support for new ways of operating. Such investment would avoid previous mistakes where PBS and Zones of Regulation programs have been adopted and rolled out without proper training to support a behaviourist framework, resulting in implementation difficulties and fidelity issues.

A move towards any of the principles and projects noted above simply cannot be implemented successfully by giving teachers handouts, mandating short CPDs, and/or leaving implementation to individual school leadership and staff. Ideally, every WA school – both primary and secondary – would include specialist officers (who are themselves neurodivergent and are immersed and trained to support neurodivergent members of the school community in these ways) who would then provide consistent, trauma-informed, consultancy support for the staff and students, and could ensure that the implementation of programs is done properly and consistently.

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