

SUBMISSION FOR NATIONAL AUTISM STRATEGY RESPONSE

October 2023

Every single parent/carer of a young autistic child that I know has a school "horror" story. It is no exaggeration to say that the education system with its one-size-fits-all approach with little consideration of environmental factors is failing our autistic children. Creating the appropriate sensory environment, being less rigid about sitting in a classroom for hours on end, not forcing unwanted group socialisation and welcoming input from a child's therapists would assist in creating a more favourable experience. These types of changes would likely help all children.

An example: My 5 year old autistic daughter is starting school next year. As part of the enrolment process, I had to complete an 'adaptive functioning' questionnaire. The purpose of the questionnaire was to understand what additional supports she may require for school and was requested by the school as per (I believe) NSW Department of Education procedure.

The questionnaire was like something out of the 1980s! There were lots of questions such as 'Does the child lie?', 'Does the child self-harm?', 'Does the child hurt others?', 'Is the child toilet trained?'. I understand the need to ascertain if there are over-and-above issues and obviously things like being toilet trained and harming self or others are important to be aware of, but the questionnaire was solely deficit based with an overriding premise that the child is broken and has many issues.

Where are the questions about the child's strengths? Where are the questions about sensory needs to better understand how a child is impacted by lots of people, lots of noise, sitting still for long periods of time? Why are we only questioning the autistic child and not the environment which they are in?

Instead of focussing on understanding a child's needs in order to create a favourable school environment, this questionnaire was a scaling device to rank how much of a problem my child may be. This shows an appalling lack of understanding by the NSW Department of Education of what it means to be autistic. The classroom has evolved so much since the 1980s but it appears that our understanding of autism has not. This needs to change!

Early intervention is meant to encourage utilising the skills/strategies learnt in therapy sessions in "real world" community environments. Very little capacity building will occur if early intervention is solely formal sessions in a clinical setting, but this is precisely what the NDIS encourages via its restrictive funding model. As long as it is clearly linked to a child's goals, why can't parents use NDIS capacity building funds on

things like swimming lessons, gymnastics, yoga classes, dancing, craft groups etc. These types of activities help build gross motor skills, fine motor skills, communication skills, social skills etc. We don't enrol our kids in these activities for frivolous reasons - we do it because they provide our kids with invaluable real-world opportunities to practice and capacity build. The existing rule of the NDIS to not fund activities that "typical" peers would do, robs our children of the opportunity to learn and grow alongside their peers in a community setting. It's meant to be capacity building which can happen in many different settings, so

why does the NDIS only support overpriced therapy which typically happens in a boring, clinical setting with little resemblance to the real world? Allowing a more flexible approach would also result in saving money - I would happily reduce OT or physiotherapy sessions at \$193.99 each for a swimming, gymnastics or dancing session at \$20-\$25 each.

Once again in terms of Early Intervention, there should be strong integration with early childhood education. Pre-school is a critical early intervention environment and the biggest influence outside of the home. Universal access to pre-school for autistic children would reduce the need for multiple overpriced weekly therapy sessions. A simple, rather crude example - if a child currently does 3-4 therapy sessions a week, that same funding would pay for a week of pre-school access. Arguably a full week of pre-school under the guidance of qualified educators, with peer interaction and a large variety of stimulating activities would have a greater impact on capacity building. It defies logic that pre-school is not considered a core early intervention programme.

Being a carer is a VERY time-consuming role due to the significant over-and-above tasks and advocacy we need to undertake. It can be difficult to maintain paid employment or do typical household chores, with self-care an elusive dream. We don't expect the government to financially support us, but why not make it easier for us to support ourselves by allowing support services such as cleaners, nannies and gardeners to be tax deductible for carers.

Autistic people often have difficulty accessing spaces that others take for granted - shopping centres, museums, airports, hospitals, Centrelink offices, Medicare offices - the list is long. The overwhelming sensory nature of these environments (lots of bright lights, lots of noise and announcements, lots of people) make them overwhelming spaces for autistic people. If public places such as shopping centres, museums, government offices etc. had regular 'quiet appointment times' at which the environment was adjusted and crowd control was managed with minimal or at least controlled wait times, then accessibility would be vastly improved for autistic people. They could do the sorts of things that neurotypical people take for granted.

We quite rightly have ramps to improve the accessibility of those in wheelchairs - let's provide autistic people with their "ramp".

Thank you for taking the time to read my submission.