Autistic NDIS participants and the AAT

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Originally, I was going to write a detailed report about experiences of autistic people and their families in who ask the Administrative Appeals Tribunal (AAT or The Tribunal) to review NDIS decisions. However, the issues have recently escalated and I only have the capacity to make a brief report.

Much of my advocacy in the AAT has related to families fighting to access early intensive behavioural intervention (EIBI) for young severely autistic children. EIBI uses Applied Behaviour Analysis (ABA), which is the practice of behaviour science, to help severely autistic children gain functional skills that improve their lives. I have been helping a severely autistic adult access ABA based behaviour supports when the previous behaviour support plan (from a prominent PBS-based service) was not working.

The application of behaviour science in disability supports is a contentious and highly politicised issue. It is not an issue that should be examined on a case-by-case basis in the AAT.

<u>A recent ABC 4 Corners story</u> made ABA especially topical when it showed video of a premeditated attack on an Autistic child at <u>Irabina Autism Services</u>. Note that <u>Irabina's behaviour support service webpage</u> says it uses positive behaviour support; it does not mention ABA.

The ABC story says:

The Severe Behaviour Program is purported to be based on a model used in the United States and is a type of Applied Behaviour Analysis (ABA) therapy.

This is clearly not the case; the ABAI statement on restrain is available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3089400/ - the video is clearly contrary to ABA practice described in the statement. The video shows that a program that clearly was not ABA.

In response to the ABC 4Corners story, one member of the IAC (who has no discernible expertise in behaviour support for autistic children) posted the following ...



This is an unacceptable response when the video in question had nothing to do with ABA and was one specific program that clearly was not being monitored by the NDIS Q&SC or the Victorian Senior Practitioner.

Note that clinical and expert medical opinion agrees that Early Intensive Behavioural Intervention (EIBI) for young children with DSM-IV Autistic Disorder has the strongest evidence; it was the *only* early intervention rates as *evidence-based* in the 2011 Roberts (ASfAR) research review for HCWA. This was reaffirmed in the Roberts & Williams (2016) research review for the NDIS, a review that the NDIA chooses to ignore.

It is unacceptable that the membership of the NDIA's Independent Advisory Council (IAC) is strongly biased against evidence-based early intervention for autistic NDIS participants and chooses to ignore the Autism DRO¹ and the NDIA's own expert witnesses (see Maclean's statements below; E/Prof Einfeld gave similar advice).

I have not seen autism advocates advising about wheelchairs and other issues outside their expertise; it would help if the disability sector left advocacy and advice about autism to people with relevant lived experience of autism, and if the spectrum of voices relating to severe and profound autism were heard and respected.

At this stage, I have personally helped about 50 autistic individuals with their AAT Reviews of unsatisfactory NDIS Plans. So far, most of the families I've helped have achieved all or most of what they requested; the outcomes are very like those reported in https://a4.org.au/node/2566. Though hearings started in Dec 2022, Mr Hill's matter (see below) still awaits a decision from the Tribunal. And several matters are still in progress.

I should point out that, other than small personal satisfaction from having helped desperate families, I have no personal benefit from this effort. It is not part of my work for A4, even though I use my A4 email account, other than the information it contributes towards A4's systemic advocacy.

In my view, the fundamental problem is that the NDIA and the government choose to misunderstand autism in Australia. The Autism Spectrum today is complex and increasing in numbers. It requires far more attention from government than it is getting. This is best demonstrated by the failure (and refusal) of government to recognise, respect, and address the repeated reports from the Australian Bureau of Statistics that outcomes for Autistic Australians in education and employment were especially poor compared to other parts of the disability sector. The authors and administrators of the National Disability Strategy 2010-20 (NDS) and Australia's Disability Strategy 2021-31 (ADS) chose to ignore data showing especially poor outcome for Autistic Australians. The consequence is that the government is now trying to develop a National Autism Strategy, while the bureaucrats are trying desperately to minimise its impact and avoid the commitment and responsibility that it might bring.

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¹ See Annex A in A4's submission to the NDIS Review on 5 Key Questions.

At the NDIS level, autism spectrum disorder:

- has emerged as the overall biggest primary disability in the NDIS; yet
- is still, after a decade of development and operation, left without practices and policies that recognise, respect, and meet the needs of autistic NDIS participants.

The NDIS has repeatedly failed to:

- consult effectively with the autism sector, especially the more severely affected (and harder to reach) part of the spectrum;
- implement policy, programs and practice relating to autism; and
- provide a spectrum of solutions for the spectrum of needs that Autistic Australians bring to the NDIS.

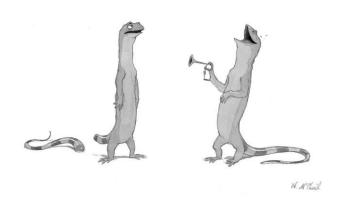
EIBI and ABA are among the most contentious issues for autistic children and the NDIS. There is a substantial body of evidence that children who meet the criteria for DSM-IV Autistic Disorder benefit from evidence-based early intervention. As is shown repeatedly in every ABA related matter for young autistic children before the AAT, numerous research reviews identify evidence-based early intervention for these children that meet the s34 requirements of the *NDIS Act 2013*.

It is not surprising that more recent research reviews get different results for children diagnosed with DSM-5 Autism Spectrum Disorder. DSM-5 ASD is a bigger population that DSM-IV Autistic Disorder so I would be surprised if the results were the same. I am not aware that clinical professionals advised children with DSM-IV Asperger's Disorder be treated with EIBI, or that that changed when the DSM-5 was published. I would be surprised if autistic children who met criteria for DSM-IV PDD-NOS got the same results as those who meet criteria for DSM-IV Autistic Disorder.

I am aware that researchers have reported that as yet they are not good at recommending what treatments and interventions best suit which autistic children. I have not seen research that tests whether the decisions that families make when they are well informed are in any way better or worse than other approaches.

I am concerned that few families are fully informed about their options. The NDIS's annihilation of HCWA Autism Advisors was a very backwards step.

My biggest concern is in relation to the NDIS's current <u>AAT Case Management</u> <u>Guide Applied Behavioural Analysis</u> (<u>ABA</u>) In my view, this policy targets many of the most severely-effected autistic children and their families making accessing essential evidence-based early intervention for their autism as difficult as possible. The policy makes



"You know what doesn't grow back, Susan? Trust."

autistic children, whose clinicians advise they need evidence-based early intervention, that experts advised repeatedly must be intensive ASD-specific as difficult as possible for them to access individualised early intervention, have to fight the NDIS through the quasi-legal AAT for supports that qualified clinicians advise them are what their child needs.

The policy says

The NDIA is likely to fund up to 20 hours per week of ABA therapy where it is considered likely to be effective and beneficial.

Where more than 20 hours of ABA is requested, the NDIA is likely to run the matter to hearing."

The NDIA is likely to fund up to 20 hours per week of ABA therapy where it is considered likely to be effective and beneficial. Evidence from a meta-analysis of clinical studies indicates that it is unlikely that more than 15 hours per week of ABA will be effective and beneficial.

This all appears to be based on a relatively recent single <u>piece of research</u> that's abstract says:

Results

Neither style nor intensity had main effects on the 4 outcome variables. In terms of moderating the effects of initial severity of developmental delay and of autism symptom severity, neither moderated the effects of treatment style on progress in any of the 4 domains. In terms of treatment intensity, initial severity moderated effect of treatment intensity on only 1 domain, namely, change in autism symptom severity; in a secondary analysis, this effect was found in only 1 site.

Conclusion

Neither treatment style nor intensity had overall effects on child outcomes in the 4 domains examined. Initial severity did not predict better response to 1 intervention style than to another. We found very limited evidence that initial severity predicted better response to 25 vs 15 hours per week of intervention in the domains studied.

There are several very important things to note about this research.

- 1. It was conducted on very young children, "mean age 23.4 months". This age group in younger than the subjects in much of the previous research (which possibly relates to the ESDM target group).
- 2. It was conducted "for 12 months" only half as long as is recommended in previous reviews that advised intervention for at least 2 years. This may contribute to there being only an average gain of 12 DQ points, lesser gain than others have reported.
- 3. Most (if not all) children in Australia who are advised need 20+ hours of intensive intervention would likely fall in the 2 domains where a difference between 15 and 25 hours per week was observed in this research.

- 4. The subjects in this study needed to agree that their child would be randomly assigned to either 15 or 25 hours per week. Parents who felt their child needed more than 15 hours would not have made an informed choice to be in the study. Sandbank, Maclean and the NDIA ignore this potential bias.
- 5. The authors of this paper tackle the question of previous 20+ hour recommendation (Dr Rogers is an author of both) and says

Does our finding indicate that 12 to 15 hours per week of comprehensive intervention is sufficient and that the National Academy of Sciences (2001) recommendation of 20+hours is not supported? It does not, because, for at least 1 important variable—namely, degree of autism symptoms—25 hours of intervention was found to be more efficacious than 15 hours for improving core autism symptoms in 1 site. Furthermore, the study focused on toddler-aged children, and it is possible that different findings could emerge for preschool-aged children or those with more years of intervention. Finally, because this is the first study to address these questions in a controlled fashion, replication is necessary before practice alterations might be addressed.

So in her reports to the Tribunal, the NDIA's expert (Sandbank) contradicts the paper's own assessment on this key issue.

The reality for families of severely autistic children is that they have to understand the complex research and present arguments like this to the Tribunal without funded support from either a disability advocate or legal support. At the same time, they have to manage their severely autistic child without essential supports while the matter drags through the process. The challenge is greater for single mothers or where the family has multiple severely autistic members.

Maclean, the NDIA's "expert" in his report to the Tribunal and quoted in <u>the VXGN decision</u> para 114 said

Long term outcomes and response to therapy are typically less in children with moderate to severe disability. VXGN has moderate or above global developmental delay, level 3 ASD and severe speech and language delay. Children with severe ASD, severe behavioural disturbance, severe language delay and GDD, which correlates with IQ (but is not a direct measure of IQ) tend have lesser gains'.

Similarly, the HHRQ decision says:

115. His clinical opinion that HHRQ has several predictors of achieving lesser gains with early intervention having regard to research of Dr Sandbank.[159]

This is repeated at [para 150]. Note that Dr Sandbank did not research the subject; Dr Sandbank authored a review of others' research. One of the main pieces of research Sandbank and Maclean rely on, the Rogers RCT quoted above, said

"In terms of moderating the effects of initial severity of developmental delay and of autism symptom severity, neither moderated the effects of treatment style on progress in any of the 4 domains."

The research that Sandbank and Maclean rely on says the opposite of what the AAT's decision says, that "HHRQ has several predictors of achieving lesser gains with early intervention" apparently based on their evidence.

The Rogers RCT describes changes in DQ from Time 1 of DQ 64 to Time 4 DQ of 78; these are very substantial changes for autistic children who receive this type of early intervention. These findings are consistent with previously published research.

In his report on RKYH, Maclean wrote (without any supporting reference) ...

There is some evidence that ABA may have a lesser effect in children with severe impairments, based on data from well conducted RCT trials, systematic reviews / meta-analysis and expert review.

In relation to autism spectrum disorder (ASD), Maclean also told the Tribunal

116. Dr Maclean considered that ABA is an accepted EIBI therapy endorsed by both US and Australian guidelines. [127] Further, that 'ABA is the principal EIBI with the strongest evidence base'. [128]

. . .

[127] R2(d) page 33 as evidence given in respect of VXGN's sister HHRQ. [128] R2(d) page 28; R5(d) page 2.

Presumably, advice like this is the basis for the AAT's consistent decisions in favour of EIBI in these matters. The strength of the evidence may also be the reason that

Autism Partnerships Australia (APA) told the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) the agency was "getting the planning decisions wrong" for 100% of the autistic children in its early intensive services

and

100% of the children who proceed to appeal [in the AAT] are ultimately funded for intensive service

See https://a4.org.au/node/2566

My experience is similar.

The problem is that the NDIA and its governance do not understand autism. It seems that they do not want to understand autism. The NDIA needs to develop an autism spectrum taskforce to:

- understand the research, evidence-base and outcomes across the whole autism spectrum, not just women & girls and autistic self-advocates.
- be prepared to recognise that the autism spectrum is distinct from other parts of the disability sector but also issues co-occur with other disability and health sector issues.

• recognise that Few "autism experts" are expert across the whole autism spectrum

data

I do not have data about how many autistic children get an internal review or progress to an AAT review of their requests for ASD-specific early intervention. I know I have helped over 45 families though only one of those cases (involving two severely autistic children) went to hearing (see below). In this regard, my experience is similar to the recent description given to the NDIS Joint Committee where all children eventually have their request met (albeit belatedly). Unfortunately, the NDIS does not provide the data that is needed to properly understand this aspect of autism supports and how they relate to the AAT.

I am keen to know how many autistic participants:

- 1. apply to the NDIS multiple times, and how many go to the AAT. We can only see those that go to hearing.
- 2. request an internal NDIS Plan review (s48 & s100 ... s47A) and how many reviews are done.
- 3. Have their review request satisfied via the internal review? And how many requests are partially met?
- 4. get a review decision that upholds the original NDIS decision?
- 5. proceed to an AAT review for each category partially met or original decision upheld?
- 6. Progress to AAT hearings?
- 7. What is the breakdown of needs being requested at the AAT? What is the autism profile?
- 8. Have AAT matters relating to autistic NDIS participants relate to ABA, PBS and other behavioural supports?

AAT review is inaccessible for most families

Many people simply will not challenge the government in a quasi-legal process like the AAT, especially families of newly diagnosed autistic children. Many of these families are families with previously undiagnosed and very vulnerable adults.

The AAT process involves the implicit decision in favour of the Respondent until a decision is made. This is clearly unjust in the matters being discussed here.

Contest of experts

It is unreasonable to expect an AAT Member to adjudicate a contest of experts especially when the evidence is presented by a NDIA lawyer and the parents of an autistic child.

In any case the so-called "expert" witnesses for the NDIA are often not expert.

Unreasonable delays

A4 has raised concerns about the delays in AAT matters relating to early intervention.

The AAT promised A4 that it would review the issue and consult with A4. I believe the AAT reneged on its commitments. BTW, A4 was not consulted in the government's review of the AAT. Our input was avoided.

Adversarial approach

Annihilates any future relationship the family has with the NDIS.

Model litigant

The NDIA is not a model litigant. MLO complaints are ignored ... we simply don't bother any more.

Examples cases

VXGN & HHRQ

These matters were a "contest of experts" between two very experienced clinicians, one of whom is particularly expert, for the Applicants and a paediatrician and researcher for the Respondent.

When the matter went to hearing, VXGN was 4% years old.

In relation to VXGN, the VXGN v NDIS decision document (5/9/2023) says:

32. The evidence overwhelmingly supports, and it is not disputed, that VXGN has diagnoses of autism spectrum disorder - level 3 (ASD), global development delay and severe speech and language impairments.

The Tribunal observed numerous recommendations for intensive early intervention for VXGN.

paragraph	Clinician	Role	recommendation
41	Dr Garg	Paediatrician	"the ABA program continue for 15- 20 hours per week"
43	Dr Puusepp- Benazzouz	Paediatrician	"A minimum of 20 hours per week of intensive behavioural therapy"
89	Ms Verstappen	founder and Clinical Director of 'Aspire'.	"20 hours per week of EIBI with Aspire"
119	Dr Maclean	Paediatrician	"7-8 hours per week, equating to two sessions per week"

Para 104 says "Dr Maclean is a paediatrician and a geneticist" appearing as an expert for the Respondent. He has no discernible clinical experience providing

early intervention for children's autism. He is a paediatrician so it would be very unusual for him to be involved and experienced in intensive early intervention for an autistic child; there is no evidence that he has that experience.

Similarly, other "independent assessors" and "independent medical experts" that I have come across in these matters did not have relevant clinical training or experience; their main qualification for the role was having an opinion that suited the NDIA's anti-ABA agenda.

The Respondent (NDIA) obtained reports, one for each child, from Dr Maclean. The reports contain many errors, some basic and some much more substantial.

- The address of the household he said he attended was wrong.
- The description of the father's autism was wrong: his diagnosis is for "Level 2" but the Maclean's report and the Tribunal's decision [para 33] say "Level 1".
- His report says intervention has less effect for more severe autism, however the primary research he cites, the Rogers et. Al. RCT paper describes an average 12 point DQ improvement for all subjects, not just the less severe.
- He describes highly cited research as "low quality" and unreplicated. The research has been replicated numerous times; this replication is discussed in documents that he cites.

The Tribunal accepted documented errors in Maclean's evidence as facts.

Clearly, the Tribunal rejected factual evidence from the Applicant.

His advice on VXGN's intervention needs are substantially less that the recommendation of VXGN's treating clinicians. There was no evidence before the Tribunal that to support his recommendation of 7-8 hours per week, or that fewer than 12-15 hours of EIBI meets the legal requirements of s34 of the NDIS Act 2013 for a child such as VXGN.

In relation to HHRQ, the Tribunal's decision was handed down on 10/8/2023.

The Tribunal ignored evidence and recommendations from the family and HHRQ's treating clinicians, again preferring flawed advice from the Respondent's "expert", Dr Maclean.

The Tribunal's assessment of Ms Verstappen and Ms Taylor and their evidence is available in the decision. Most notably, as well as rejecting the mother's evidence about her children, the Tribunal rejects *all* the applicant's clinical evidence on treatment approaches for both children.

Advice from multiple clinical sources that HHRQ needs intensive ASD-specific treatment for her eating disorder is ignored. Instead, the Respondent and their "expert" repeatedly referred HHRQ to a clinic whose website clearly states that it does not treat autistic children.

The mother clearly stated that she had been to one of the clinics. The clinic provided a few tip ... that did not work for her child. It seems the clinics took a mostly dietary approach while HHRQ's issues are behavioural and possibly sensory. Ms Taylor, whose evidence was ignored, appears to be a world

authority² but the Respondent's "expert" and the Tribunal dismissed her evidence.

The NDIA espouses a "family-centred" approach for early intervention, but their treatment of families in the AAT is completely the opposite. Their lawyer dismissed the mother's views suggesting that service providers, acting primarily in their own commercial interests, mislead her.

The Tribunal's decision disregards professional opinions other than those of non-clinical "experts" that the Respondent paid for their one-sided opinions.

The Tribunal's inadequate understanding is shown clear in its decision: rather than fund the 22.5 hours of intervention from a mix of therapy technicians and clinicians, the Tribunal funded 15 hour per week at the clinician rate (at a higher cost).

M Hill v NDIS

Mr Hill was accepted into the NDIS 14/2/2017. His first NDIS Plan is dated 26/09/2017. His second plan, resulting from an undocumented plan review is dated 30/11/2017. It was for only 6 months before it reverted to the previous inadequate plan.

From the outset, Mr Hill's NDIS Plans were inadequate. It took two reviews, one of which was never documented, the failure of Mr Hill's day program (and the urgent transition to a home-based program), and a request that the AAT review his plan before most of his NDIS-funded supports were made workable. His current plan started on 6/05/2020. He also had to change all his service providers.

At this stage, his home-based program operates week about from the two homes of his divorced parents. His support remains in this state while the matter before the AAT drags on indefinitely.

The remaining matter before the Tribunal relates to transport funding. This was an issue with the NDIS from the outset. Shortly (2 months), after becoming an NDIS participant, Mr Hill's plan was reviewed and some supports were increased. The plan increased the amount of transport funding (though it did not fully fund transport as the law required) but in a manner that could not be accessed. To this day, not one dollar of the "increased" transport funding in his 6 month plan has been paid – in effect, transport funding was cut to zero. A small amount of transport funding was restored at the next NDIS Plan review.

Mr Hill's NDIS Plan funding was insufficient so the service provider cut services. Mr Hill's divorced parent had to cobble together a new program for him that ran from their homes. The new program required the purchase of a modified vehicle so that Mr Hill's support workers could drive him as he required.

While they were setting up Mr Hill's home-based program, they were unable to also require a NDIS Plan review.

² Based on the research evidence she provided.

At the next scheduled plan review, Mr Hill's supports were again cut. The requested an internal review. This increased funding ... but not enough to meet Mr Hill's needs. They asked for an AAT review. An NDAP advocacy service and NSW legal aid assisted Mr Hill initially.

A much more appropriate level of funding was negotiated and a new NDIS Plan was implemented via s42D of the AAT Act. The one remaining issue that is still before the Tribunal is funding for Mr Hill's driving needs.

Shortly after the s42D new Plan, the Respondent made an offer of an moderate increase in transport funding on the condition that Mr Hill was kept in his bed overnight and was not allowed to roam the house; and that he could not have alcohol and/or sugary food before bed. Mr Hill parent advised that:

- a) Mr Hill will not be restrained (kept in bed or prevented from roaming the house at night); and
- b) he rarely, if ever, partakes of alcohol or sugary food while he is at home.

They regard these conditions as inappropriate and violation of Mr Hill's human rights.

Because Mr Hill's parents did not accept these conditions, both NSW Legal Aid and the NDAP advocacy service withdrew their support for Mr Hill. Clearly, they had no interest in protecting Mr Hill's human rights in this matter.

In this matter, the NDIA have accused Mr Hill's parents of lying to the Tribunal about transport payments, how Mr Hill is driven (this is especially hurtful since both his parents are proudly pathologically honest). The NDIA claims that there is no evidence Mr Hill is less agitated when he's in their care ... despite his needing 2 support worker at all times when he is not in their care, but either parent can support him unassisted for extended periods (overnight, weekend and over holiday periods) and support him on their own in public. The NDIA claimed first that Mr Hill's parents lied about driving him in their own cars. Then the NDIA claimed offensively that the parent's practice of driving with Mr Hill seated beside them in their own car was unsafe; that it put people at risk.

Hearing in this matter started in December 2022. As yet, there is no decision from the Tribunal.

Mr Hill's IER process failed; it demonstrated that the legal system ignores facts and evidence provided by autistic people, their families and their advocates. Legal systems in Australia are prejudiced.

RJTY

I became involved in the third AAT review for RJTY. RJTY is a child with very high support needs who lives in a regional centre with little or no local support for profound disabilities like RJTY's.

After a 6 month plan arising from the previous settlement while at the AAT, the NDIS again cut RJTY's plan savagely. RJTY was removed from the NDIS's complex needs supports. The impact on RJTY's support services were massive and stress and support burden imposed on the family was cruel. It put their health and well-being ... and the family unit at extreme risk.

The AAT process demanded that the family provide detailed and complex evidence after just 6 months. The legal process initially ignored the existence of the two previous cases and all the associated supporting evidence.

RJTY has a rare genetic condition with huge impact. Her profound autism is only part of the support needs. The lack of NDIS funding meant that RJTY's mother was constantly recruiting and training support staff. She also had complex negotiations with school to contend with.

The AAT process expected that the mother could somehow run an extremely complex matter in the AAT while she provided active overnight support for her child every night ... and go to work during the day.

The IER was given to an "independent" reviewer with uninformed ideological objection to the ABA supports that were advised by international experts (there are no relevant specialists in Australia). The IER process failed RJTY.

I suspect that RJTY's matter also had a heavy toll on some of the NDIS staff involved.

This matter was eventually settled. It showed that the AAT is extremely inappropriate process for matters like this. There needs to be an informed and sympathetic negotiation process instead.

Recommendations

- 1. Stop making the AAT decide on access to professionally provided EIBI and ABA on a case-by-case basis; the NDIS and other government agencies need properly developed and clear policy. And service standards that are enforced.
- 2. The NDIA needs to engage with the full autism sector. It needs to recognise, respect and address that autism in the NDIS is a spectrum with a spectrum of opinions and needs. It needs to engage with the more severe & profound parts of the spectrum, not just self-advocates and the voices of non-autistic human rights activists. It needs to disengage from its "independent medical experts" and their uninformed medical model of autism.
- 3. The NDIS should instigate a replacement for the HCWA Autism Advisors.
- 4. The NDIS needs a comprehensive process for negotiating, not imposing, complex NDIS plans and plans that involve EIBI and/or behaviour support. The AAT process delays access to intensive early intervention for young children; the detriment to the child, the family and long-term cost to the NDIS are substantial. For young children, the negotiation process needs to be quick.
- 5. The NDIA and the NDIA Q&SC need to fix the behaviour support workforce issues. They need to engage with the autism sector and internationally registered professionals, the Behaviour Analysts Certification Board and ABAI to establish a strong professional organisation in Australia. This work may also require a substantial effort to establish professional standards for Positive Behaviour Support (PBS) practice in Australia.

6. The Australian government must develop a formal position on the application of behaviour science. Its development must involve all parties interested in clinical level behaviour management. And that means voices for all parts of the autism spectrum must be respected and included.

3/10/2023