For the WI Autism Treatment Symposium Series

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Thank you, and I am honored to be here today to advocate for the rights, fair opportunity, dignity, and personal growth of people on the autism spectrum.

Legislation has never been a specialty of mine, so the perspectives I am about to share must necessarily be about the broader sociocultural context of adults on the autism spectrum, and how childhood autism services impact their lives. Children are future adults, and as I see it, a respected, meaningful adulthood is the ultimate goal of autism supports during childhood and adolescence.

I strongly endorse maintaining and expanding a wide range of supports for children and adults on the autism spectrum. Under no circumstances, within reason, do I endorse reducing or eliminating the *amount* of support available to people on the autism spectrum. However, the *kind and quality* of that support, not only its quantity, is key, and is something I will address today.

Neurodiversity:

Before I go further, I must provide you with context for where I'm coming from.

As both a mental-health professional and a person on the autism spectrum myself, I’ve been in a rare position to observe how the historical and cultural assumptions of neurotypical society have shaped the American approach to autism, and how this impacts the experience of living on the autism spectrum. This has taught me that the medical-and-behavioral model, which sees autism as a pathosis to be reduced or eliminated, contributes to an overwhelming sense that people on the autism spectrum are not legitimate, not valued, and to be pitied, appeased, or scorned rather than accepted or embraced. In particular, the notion that autism should be "cured" is profoundly dehumanizing, because it says to people like me that others think we would should never have been born, and that it would be better if people like me were prevented from being born in the future. If that attitude were applied to any other marginalized identity, we would – I hope – be horrified. Therefore, my starting point for all autism advocacy is this: how can we on the spectrum live well, be confident, have dignity, and thrive in a society that often implies we're not really supposed to exist? I will not sugar-coat the very real and serious challenges, yet we must assert our right to be who we are.

In most ways, I see autism as being a difference of identity. This is the neurodiversity model. Autism is neurologically and socially more complicated than many other minority identities; this is why I favor using multiples lenses as needed to better understand autism. Overall, I strongly favor the neurodiversity lens, but I acknowledge that it is not perfect, and that the medical-and-behavioral lens does sometimes have relevance. In my autism work I also use cultural, historical, and existential lenses to provide a much more complete, robust, well-rounded, and adaptable understanding of autism. These lenses are unfortunately not widely used or appreciated in professional autism supports. The fact is that adults on the autism spectrum are still quite poorly researched, and the long-term impacts of childhood autism treatments are, likewise, not well-understood. Therefore, we have to lean more heavily on the self-report of adults on the spectrum than we otherwise might.

ABA Therapy is Widely Reported to be Traumatic or Abusive:

Those self-reports are often grim, painting a picture of perpetual difficulty in an indifferent or antagonistic society. In particular, I am compelled to report on the passionate and often bitter controversy regarding ABA therapy. A disturbing fraction of adults on the autism spectrum who went through ABA therapy report it to be traumatic or abusive (1, 2). I was diagnosed at age 15, and I never had any such "treatments," so I consider myself an outside observer in that sense. Yet I am haunted not only by the sheer number and vehemence of ABA therapy survivors, but also by how their voices have comparatively little political influence in the face of the ABA therapy industry, which is a two-billion-dollar industry in the U.S. (3), and of its nonprofit supporters. With any group impacted by a policy, it's essential to listen to the affected people themselves. It is beyond disheartening that adults on the autism spectrum are still treated as a fifth wheel compared to the complex of parents, advocacy organizations, researchers, and "treatment" providers – most of whom are good and sincere people, but their voices usually drown out ours, and that is a distressing position to be in.

This very symposium, as originally planned, included no adults on the autism spectrum. I'm glad that was addressed when it was challenged, but the fact that it had to be challenged is sadly representative of these issues. However well-meaning other stakeholders may be, they are not us on the spectrum, and though I welcome thoughtful non-autistic voices on these issues, they can never be a substitute for our own voices or our own lived expertise. This is borne out by research: for example, a 2014 study called <u>Autistic expertise: A critical reflection on the production of knowledge in autism studies</u> (4) states, quote, "autistic people have often become distrustful of researchers and their aims, and are frequently frozen out of the processes of knowledge production" (end quote), and further that, quote "The involvement of autistic scholars in research and improvements in participatory methods can thus be seen as a requirement, if social research in the field of autism is to claim ethical and epistomological integrity." In other words: Nothing about us without us.

Some former practitioners of modern ABA therapy have gone on record as saying that what they did was a form of child abuse (5, 6), yet there are some adults on the spectrum who report being helped by ABA therapy, so I am not dogmatic about this – I'm a fan of taking things on a case-by-case basis. In fact, there are many forms of ABA therapy, not all identical, and it has even been said that many therapies that are not ABA *call* themselves ABA in order to be covered by insurance (6). However, because of the extensively self-reported potential for disproportionately negative impacts on mental-health outcomes for adults on the autism spectrum, I cannot in good faith endorse or condone ABA therapy without much more extensive investigation, debate, and addressal of the issues brought up by ABA therapy survivors in the adult autism community. There are also good alternatives to ABA therapy, and I maintain that they should funded much more extensively than they are today.

The Autistic Self-Advocacy Network (ASAN), the world's largest advocacy organization run exclusively by and for people on the autism spectrum, has this to say (7):

> Many therapies can be helpful for autistic people, like physical therapy, speech therapy, occupational therapy, and AAC (Augmentive and Assistive Communication). We think these therapies should be easier for autistic people to get. But there are some therapies that focus on making autistic people seem "normal" or appear "less autistic". The most common type of this therapy is Applied Behavioral Analysis (ABA). ABA uses rewards and punishments to train autistic people to act non-autistic. ABA and other therapies with the same goals can hurt autistic people, and they don't teach us the skills we actually need to navigate the world with our disabilities. (End quote.)

In 2017, ASAN published a report called "First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities." (8) That report quotes one adult on the spectrum who received ABA therapy, saying:

> "The therapeutic goal was presented as learning social behavior - in retrospect, this was learning to mimic NT [neurotypical, or non-autistic] social behavior. It resulted in corrosive damage to self-esteem and deep shame about who I really am. No effort was made to explain autism to me or to explain the role of sensory overload in issues like meltdowns, shutdowns, etc. (End quote.)

The report goes on to say:

> Participants preferred treatments to focus on skills that would help them understand their own disabilities and coping with sensory overload, as opposed to therapies that made people look less autistic on the surface. Therapies that participants considered helpful included occupational therapy to help with sensory integration, play therapy, social skills groups for children, job coaching, mentoring, and mindfulness to help with anxiety.
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> All the therapies suggested were aimed at encouraging self-determination and self-care, rather than indistinguishability from their peers. On the other hand, participants thought that therapies designed to make them appear superficially non-autistic did more harm than good. For example, "stimming," or repetitive movements that many autistic people use to calm down or focus, should not be suppressed if there is no physical harm to others. (End quote.)

I agree, and my work with fellow adults on the spectrum strongly corroborates this. Even those adults on the spectrum who have not received any kind of treatment – and that is many of us – tend to be trained by society to reject or doubt themselves and to internalize stigmas about autism. In contrast, I know that it's possible to be on the spectrum and to have a healthy identity that accepts or embraces these neurological differences.

Training for Conformity Versus Teaching for Complexity:

A large number of adults on the autism spectrum report that not only ABA therapy, but the medical model overall, trains them how to conform to questionable cultural assumptions, and that it does not teach them how to assess, prioritize, or pursue their own unique needs, goals, or self-expression. In my work, I’ve seen that this leaves a great many adults on the autism spectrum very prepared to go with the flow of society no matter what, and very unprepared to make mature, confident, enlightened decisions about their own best interests. I’ve seen this over and over in my work with adults on the spectrum - people who have been taught to suppress their individuality, and who therefore are timid, passive, and uncertain about how to be fully engaged members of society. They know that their way of being is devalued, and in response they mask their struggles (9).

In fact, there is a terrible irony that, whether through formal treatment or informal social pressure, people on the spectrum are told that they must hide their symptoms in order to appear normal and respectable to not be rejected or discriminated against. Yet, when those hidden struggles finally become overwhelming, and such an adult on the spectrum seeks help, they are too often told “Well you look very normal – so either you’re not actually autistic, or you are but you don’t deserve the help.” How gruesome to be trained to keep up appearances and then be told that your pain and your problems aren’t significant because you have succeeded at looking normal like other people insisted you must do.

In contrast, those adults on the spectrum who were taught to balance self and society tend to be much more emotionally successful in my experience. As a state and a nation, we can do far better than this – and the best time to head off these psychosocial problems is in childhood, when both autistic *and* neurotypical children can be taught that autism should be accepted and supported rather than hidden, overridden, and kept in the obscurity of shame.

Supports Must be Far More than Training for Skills:

If you think that teaching communication, self-care, and conformity is good enough, you are deeply mistaken. In my professional development over the past decade, I have grown increasingly frustrated by the lack of humanity in many or most professional approaches to autism. What I have seen in these approaches is a persistent focus on skills, with very little fluency in teaching cultural context, personal values, healthy identity, and the vital questions of human existence. Again and again, I encounter clients on the spectrum who have been taught or browbeaten to seem normal yet who have no healthy answers to questions like "Do I have worth?" "Do I have a legitimate place in society?" "Will I always be alienated?" "Can I be loved?" If we teach social skills for a society that is going to reject these souls anyway, how can we claim to be "treating" their condition? What about their human condition? In my view, supports for adults on the spectrum, starting in childhood, must include identity development, exploration of cultural values, and self-advocacy skills if we are to expect people like me to navigate a society that is not designed for us and which continues to be basically opposed to our natural perceptions, interests, and self-expressions. Adults on the spectrum have potential that is worth every penny that society invests in them, yet that potential is deeply undermined by the mental-health pressures imposed by a society that mostly does not understand and often does not care.

Whether informally due to the stigma, rejection, and punishment by family members and society at large, or formally, as with ABA therapy and other therapies that emphasize training toward a neurotypical standard rather than supporting toward an autistic standard, I end up encountering adults on the spectrum who feel worthless, alienated, confused, and frustrated, *even when* they have strong communication skills, social skills, and are well-educated, whether or not they had childhood treatment. In fact, at least 50% and perhaps 80% of adults on the spectrum have clinically significant anxiety, depression, or both, largely due to challenges needlessly imposed by society. The fact that outwardly successful adults on the spectrum are so often wracked with struggle and inner turmoil tells me that existing treatments and training alone are not sufficient for psychosocial well-being, and that supports for the whole person are woefully absent and desperately needed. I see it as crucial that such supports begin in childhood, so that, rather than counselors like me helping to manage autistic emotional trauma later in life, those emotional traumas can be avoided and healthy autism identities can be built up from a young age.

Culture is As or More Important Than Neurology:

One of the core messages of my autism advocacy is that culture plays an enormous role in interpreting and acting upon neurological differences, which in turn plays a huge role in determining opportunities and outcomes for us on the spectrum. Interpret autism as a medical condition, and everything about it will look like a symptom to be targeted. Interpret autism as a problem of human relations, and suddenly it looks very much like a matter of social inequality and cultural prejudices unfairly holding back the well-being of a group of people. Supports for both children and adults on the spectrum should reflect this.

Most people on the autism spectrum face some serious neurological challenges; all people on the spectrum face challenges that are created or worsened by cultural factors. The bottom line is this: *we are devalued.* We are told that we are not good enough by the standards of society, so the dominant "treatment" regime attempts to make us "good enough." Yet change those cultural standards, and you may change how we are interpreted by others.

Autism is addressed not only by changing the person, as in the medical-and-behavioral model, but by changing how society reacts to the person – the social model. If typical autistic behaviors like self-soothing, unusual interests, and communication differences were truly accepted by society, rather than subjectively labeled as “undesirable behaviors” to be trained out of the person, that would go a very long way toward making autistic lives far more manageable and far less confusing, threatening, and exhausting. It would certainly not solve every issue, but it is my position that support services that don’t consider the need for societal change are merely a bandage on the social wounds rather than genuine social healing.

I endorse legislation for autism programs and supports that empower personal choice and personal meaning, not conformity to arbitrary neurological or cultural standards. And we as people on the autism spectrum should have an important and clear role in defining and refining childhood autism therapies - nothing about us without us.

In 2019 I cofounded the INTEGRAL Autism Conference. I defined and wrote its mission, vision, and value statements, and my goal in doing so was and is to get adults on the autism spectrum in the same room with parents, providers, researchers, and other stakeholders of the autism community - so that we can all learn from each other, and so that we as adults on the autism spectrum can converse, and engage, and not be easily dismissed. This year's INTEGRAL conference is coming up on October 24th, and this time around is focused mainly on the impact of the COVID-19 pandemic. I extend my personal invitation to everyone involved in these proceedings to attend INTEGRAL this year and in future years, so that you can directly interact with adults on the spectrum and hear from *them* about the challenges they face and the strategies that they are seeking. Our website is **integralautism.org**.

Thank you for this opportunity to address the broader horizons and farther trajectories of autism in American society, and Wisconsin in particular. I leave you with eight words: Please listen to us; please listen to us.

References Cited

All webpages cited herein were most recently accessed on 09/29/2020.

(1) The Autistic Community does not support Applied Behaviour Analysis (ABA).
https://abacontroversyautism.wordpress.com/2017/06/27/aba-autism-discussion/

This blog post includes an extensive set of links to research articles, commentaries, and other documents that address and explain the adult-autism community's overwhelmingly negative response to ABA therapy.

Highlight:

> "It is a sad state of affairs that there was even a need in 2017 to publish research evidence that supports the stance that autistic adults should be considered as 'experts' and involved in matters relating to autism, but clearly there was. Despite this the alternative of autistic people being ignored, dismissed or silenced by others remains a common occurrence, experienced by many activists who wish to do nothing more than help autistic children have their needs met and grow up accepted for who they are, feeling safe and competent. One example we hear over and over is the classic rhetoric used by ABA proponents "do not listen to autistic adults as they are able to communicate, use social media so are not like your 'low-functioning' 3 year old child".
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> This article starts off with a reference to the 2017 research article about autistic adults as 'experts' and other evidence supporting the involvement of autistic people, it then sets out evidence that the autistic community does not support ABA and finishes with what ASAN, the largest organisation run by and for autistic people have to say about ABA."

(2) Invisible Abuse: ABA and the things only autistic people can see
https://neuroclastic.com/2019/03/28/invisible-abuse-aba-and-the-things-only-autistic-people-can-see/?fbclid=IwAR3_slgyD2fUgBXvp80Bxych8DhcubHP8030sTb2-m3JwNUwTPkIbOcqApM

This blog post by a mother on the autism spectrum provides some background and examples of how ignoring autistic perspectives inadvertently leads ABA therapy to be a form of abuse.

Highlights:

> "The reason parents and ABA therapists can't see it as abusive is because they can't see it from an autistic point of view."
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> "ABA is not designed to consider the child's feelings or emotional needs."

(3) The U.S. Autism Treatment Market is Expected to Reach 2.23 Billion by 2022
www.businesswire.com/news/home/20180501005785/en/The-U.S.-Autism-Treatment-Market-is-Expected-to-Reach-2.23-Billion-by-2022

Self-explanatory, although the COVID-19 pandemic has reduced the profitability of ABA therapy.

(4) Autistic expertise: A critical reflection on the production of knowledge in autism studies
https://journals.sagepub.com/doi/abs/10.1177/1362361314525281

This research article explores the role of adults on the autism spectrum in autism research.

Highlight:

> "The field of autism studies is a highly disputed territory within which competing contradictory discourses abound. In this field, it is the voices and claims of autistic people regarding their own expertise in knowledge production concerning autism that is most recent in the debate, and traditionally the least attended to."

(5) Why I Left ABA
https://sociallyanxiousadvocate.wordpress.com/2015/05/22/why-i-left-aba/

This blog post by a former ABA practitioner lays out the serious ethical problems inherent to many, if not most, forms of ABA therapy.

Highlights:

> "I thought that because I cared about the kids' well-being, because I had a strong desire to help them, everything I did must therefore be in their best interest. In my mind, it gave me a special immunity to making mistakes."
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> "A lot of kids may make progress through ABA therapy, but that doesn't necessarily mean that it's not harmful to them emotionally and psychologically. They may be learning very valid skills, and yet still feel devalued or invalidated for who they are in the process."

(6) I Abused Children For A Living
https://madasbirdsblog.wordpress.com/2017/04/03/i-abused-children-for-a-living/?iframe=true&theme_preview=true

This blog post by a former ABA practitioner lays out in stark terms the professional and ethical problems inherent to many, if not most, forms of ABA therapy.

Highlights:

> "You see, I was an ABA therapist. My official title was 'Behavior Technician' which in itself is really telling. I was hired off the street with no background in child development, no knowledge of autism or ABA, and no experience working with children, let alone autistic children. I. Literally. Did. Not. Know. What. Autism. Is. And I wouldn't find out what autism is in the years that I worked there either."
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> "The ultimate objective of ABA is to make the child 'indistinguishable from peers.' This in itself is abuse because you are teaching the child that the only way that they will be tolerated is if they pretend to be like everyone else."

(7) ASAN Position Statement on Autism Research and Therapies
https://autisticadvocacy.org/about-asan/position-statements/

This is the Autistic Self-Advocacy Network's current position statement on autism-related research and therapies, including ABA therapy.

(8) First-Hand Perspectives on Behavioral Interventions for Autistic People and People with other Developmental Disabilities. ASAN of Greater Baltimore.
https://autisticadvocacy.org/wp-content/uploads/2017/07/First-Hand-Perspectives-on-Behavioral-Interventions-for-Autistic-People-and-People-with-other-Developmental-Disabilities.pdf

This whitepaper reports on the perspectives of adults on the autism spectrum regarding their preferred therapy modalities.

(9) When SLP Meets ABA
https://leader.pubs.asha.org/do/10.1044/leader.FTR2.25102020.52/full/?fbclid=IwAR3ar9gnspO_t_z-2oCUVrOIQ7HUC40KksuicJzmX-pVGIdp6xqWY1GI4Vk&

This article reviews the history and premises of ABA while comparing and contrasting them to the perspectives of speech-language pathology regarding autism therapy.

Highlights:

> "Meanwhile, not all SLPs [speech-language pathologists]—or adults with autism—agree that ABA-based interventions are beneficial. Julie Roberts, founder of the Therapist Neurodiversity Collective and owner of Bayou City Speech and Language in Houston, is ethically opposed to ABA interventions. 'ABA is disrespectful of human rights,' Roberts says. 'ABA interventions don't look at the cause behind the behavior,' she says. 'Is there a sensory issue? Is the child

traumatized? Are they tired? Angry? Sleepy? Asking "why" is just a compassionate way to deal with another human being, especially a child.'

"The concept of 'training' children with autism to present as neurotypical is artificial and unnecessary at best, and traumatic at worst, says Roberts. '"Training" social skills means that neurodivergent people must conform to unrealistic, obscure, and often confusing neurotypical standards through masking,' Roberts explains. (See "Putting Autistic Voices at the Forefront of Care" on page 8.

> 'ASHA tells us there are three pillars of evidence-based practice [scientific evidence, clinical expertise, and client values/perspectives], and one that I feel we often overlook is the pillar of client perspective. The perspective of the autistic community is that ABA is abusive and controlling.'"

Further Reading

In Print

(1) ***Uniquely Human: A Different Way of Seeing Autism***, by Barry M. Prizant. Simon & Schuster, 2016.

The amazon.com page for this book includes extensive samples from its chapters, and the customer reviews are also worth a serious look: https://www.amazon.com/Uniquely-Human-Different-Seeing-Autism/dp/1476776245?fbclid=IwAR1iQAhPDigP2mO9DClmqmZm3jfWxq_4n1R3eeYa5TpHwmFYfhnhMrhw8Qo

On the Web

From self-advocates:

(2) ASAN Resources on Coverage for Autism-Related Services

https://autisticadvocacy.org/policy/toolkits/healthcoverage/

This page includes ASAN's documents regarding coverage for various autism-related services, with something of an emphasis on alternatives to ABA therapy.

(3) Appearing to enjoy behavior modificiation is not meaningful

https://www.realsocialskills.org/?offset=1439325350000

A short blog post explaining why videos of seemingly happy children in ABA therapy don't prove that the ABA therapy is not harming the child.

(4) Not being believed

https://www.realsocialskills.org/?offset=1432051323000&reversePaginate=true

A short blog post describing the experience of not being believed about the harm inflicted by ABA therapy.

From researchers and scholars:

(5) Harris, H., Israeli, D., Minshew, N. et al. **Perceptual learning in autism: over-specificity and possible remedies**. Nature Neuroscience 18, 1574–1576 (2015). https://doi.org/10.1038/nn.4129
(also: https://www.nature.com/articles/nn.4129)

A research paper in a high-level scientific journal that presents evidence suggesting that the highly repetitive treatments in ABA therapy may impair learning rather than promote it.

(6) Aileen Herlinda Sandoval-Norton & Gary Shkedy. (2019) **How much compliance is too much compliance: Is long-term ABA therapy abuse?** Cogent Psychology, 6:1, 1641258
https://doi.org/10.1080/23311908.2019.1641258

Self-explanatory.

***(7) "Autonomously Autistic*: exposing the locus of autistic pathology**," Canadian Journal of Disability Studies, vol. 7, no. 2, pp. 60–82. [2] *Williams*, R. M., (2019)
file:///C:/Users/SCOTTA~1/AppData/Local/Temp/423-Article%20Text-1381-1-10-20180719.pdf

An argument in favor of seeing autism-related disabilities as being in the intersection between the autistic person and their environment, not within their autism.

(8) Simpson, Jessica Nashia, **Toward a Sociology of Autism**. (2018). Masters Theses & Specialist Projects. Paper 3072.
https://digitalcommons.wku.edu/theses/3072

This paper explores the socially constructed nature of the concept of autism (and stigmas about autism) from a sociological perspective, rather than a psychiatric one.

(9) Distorting Psychology and Science at the Expense of Joy, by Kathleen P. Levinstein. Catalyst: A Social Justice Forum, 2018 Vol. 8, Issue 1.
https://trace.tennessee.edu/cgi/viewcontent.cgi?article=1105&context=catalyst

A mother on the autism spectrum (thus, also a self-advocate) writes about ABA therapy in memory of her son, who died due to injuries sustained during ABA therapy.

A final note and invitation: Many, many other insightful and heartfelt blog posts by adults on the autism spectrum about virtually all aspects of autism therapies – including a wide diversity of perspectives – can be accessed through links in the various blog articles that I have shared in this document. I strongly encourage anyone with any interest in the well-being of people on the autism spectrum to read at least a dozen such posts, articles, etc. to get a better feel for the conversations that have been unfolding in the adult-autism community for the past decade or more. – Scott Allen, 09/29/2020