

Below is a version of Scott Allen's remarks, prepared by him from his original outline of notes for this discussion.

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Regarding my personal background, I have a Master's in counseling, and currently work at both Westside Psychotherapy, LLC, where I specialize in work with fellow adults on the autism spectrum and also work with a similar number of non-autistic clients, and at the UW-Madison McBurney Disability Resource Center, where I co-facilitate an empowerment group called AS WE ARE for college students on the autism spectrum. I have also been a board member of the Autism Society of South-Central Wisconsin since 2018, am the facilitator for our chapter's AUSome Adult support group and social nights, and am co-founder and planning-committee leader for the INTEGRAL Adult Autism Conference, established in 2019. I was diagnosed with Asperger's Syndrome in 2001 and have been actively engaged in autism-spectrum advocacy, mainly through public speaking, since 2002.

Remarks:

I see that the autism community as a whole can be said to include the specific autism community, which is everyone who is considered to be on the autism spectrum, whether diagnosed or not, and the general autism community, which is the specific autism community plus everyone who is not autistic and has a stake in the specific autism community – in other words, any non-autistic parents and professionals who are involved in supporting, understanding, researching, or simply caring about the autistic people in their lives.

In an ideal world, all these groups would form a single, natural, extended community built on dignity, respect, mutual curiosity, good faith, good logic, high ethical standards, and where appropriate, emotional bonds. But in reality, there are deep and often unacknowledged divisions both within and between the general and specific autism communities.

In particular, there is a division between adults on the autism spectrum and the rest of that general autism community. What I've observed is that autistic adults have the most experience and wisdom about what it means to live a life on the autism spectrum, and yet, they are not regularly or systematically sought for that wisdom. Non-autistic parents and professionals mostly do not make a concerted effort to seek or benefit from the life experience of autistic adults. (I mean that strictly as a systemic observation, not as a value judgement.) And so I had to ask myself both, "why is that?" and "what can be done about it?"

Divisions like this exist, among other reasons, because the way in which autism used to be defined did not include a large fraction of the people who are recognized as autistic today. The older narrative was a wholly medicalized narrative of pathological disorder, deficiency, pity, and a desire to eliminate the neurology that was perceived as causing suffering. It was based on an outmoded assumption that the suffering in autism is located within the person, rather than between the person and their environment, whether the physical, social, or conceptual environment.

In contrast, my position, and that of many other adults on the autism spectrum, is that it is entirely possible to be physically and mentally healthy and to have autism/be autistic at the same time.

It is often the culture around us that problematizes our differences, usually by insisting that our neurologies must be judged by moral and economic values that were not designed with our rights, well-being, or dignity in mind. I try to avoid moralizing and financializing people, and I instead focus on practicalizing solutions to personal, interpersonal, and systemic problems.

The system we have in place now was built around that older narrative of medical pathology, yet today, because of the diagnostic expansion of who is included under the label of autism, there is a large proportion of adults on the autism spectrum who do not match that older narrative – and in fact, who deeply challenge that older narrative. Yet the system continues to promote that older narrative even simply through its structure, which may or may not be anybody's fault, but it is a problem. And the adult autism community has recognized it as a problem for about twenty years, which is an indication of the inertia that has been built into this larger system of how autism is defined and supported.

This situation a problem because it has led to artificial divisions within both the general and specific autism communities. At best, those divisions are accidents of history. At worst, they are engineered and avoidable political splits built around wedge issues. Autistic adults are almost always on the losing end of those political calculations because we are the minority and, with rare exceptions, we are not the ones who built, maintain, or derive status from that system.

There is no inherent, natural reason for these divisions to exist. For example, there is a division between many autistic adults and parents of autistic children. There are legitimate grievances by adults on the spectrum against the way the system, as created and supported by many parents and some researchers, has attempted to define them as pathological. Yet it is also true that, in the vast majority of cases, autistic people are raised by non-autistic people. That's how it works, that's unavoidable. So for there to be a split between autistic adults and the parents who are raising *future* autistic adults is an artificial split, resulting, at the very least, from historical forces that have divided what should be a single natural community into camps that, in some cases, can't even agree on the basic dignity of autistic people and our right to exist as we are.

It wasn't until 2017 that I saw a formal call by autism researchers to seek out and listen to autistic people as a standard part of the research process. It was only within the past year or so that some researchers finally, finally began publically challenging ABA quote-unquote "therapy." I am a strong supporter of science both as a set of principles and, usually, in practice, so it's unsettling for me to know that it took this long for the voices of people on the autism spectrum like me to be consistently sought for our input, even when accounting for the timing of diagnostic expansion. I can't imagine wanting to understand and help a group of people without regularly consulting that group of people about how and why *they themselves* want to be helped.

For those not aware of the disputes about ABA therapy, this will be a simplification on my part, but the general position in the adult-autism community is that ABA "therapy" is a frequent source of trauma (sometimes profound emotional trauma) to autistic people because, in essence, it trains them to rotely imitate uniquely American social standards while giving them neither 1) an understanding of why those standards exist (or are or are not legitimate standards to begin with) or 2) a sense of being legitimate people in and of themselves; their worth is implied to be conditional on complying with the social standards they are being trained to imitate. Even when performed in an outwardly affectionate manner, ABA "therapy" functions to make natural, inherent autistic behavior seem unacceptable and

less worthy than the behaviors common in mainstream American culture. However, I acknowledge that some autistic adults have reported that ABA practices provided them with some relevant skills. Yet overall, occupational therapy and speech-language therapy offer superior alternatives to ABA “therapy.”

In my experience, there are also large numbers of adults on the autism spectrum who are not even aware of these divisions or these disputes – they haven’t been exposed to them. How are they being served by this situation? I don’t think they are. There are groups like the Autistic Self-Advocacy Network, which is run of, by, and for autistic people, that are doing some really great policy work and developing great materials to help autistic people, and yet almost none of the adults on the autism spectrum that I’ve worked with professionally or on a volunteer basis in our area have heard of their organization. Their work is really important and it’s not penetrating into the public consciousness of much of the autism community, whether specific or general.

All of that is difficult enough on its own, but it also intersects with a wide range of ongoing and emerging problems with our American system overall. Our socioeconomic system as a whole is strained, broken, or breaking. It’s not working well even for most neurotypical people, and that’s exponentially harder for autistic adults to manage or navigate. Things are different now. The system is not what it once was. It is not enough to continue seeking support from an ailing system; new approaches and repairs are needed. This is our opportunity to revise the autism-support system before it resolidifies for the next 20-30 years.

In much of the country lately it’s hip to criticize our political system, to criticize capitalism, and for a lot of obvious and usually justified reasons. But amid that criticism I don’t hear a lot of serious attempts at staking out solutions. Within the disability community and within the autism community, we know that an approach that is based only on reacting to deficits does not work for the whole person – there has to be a strengths-based approach. And I see the flaws in our American system the same way – let’s be honest about the deficits, and let’s use a strengths-based approach to figure out solutions to those challenges.

Attempting to resolve these divisions and other problems is the driving purpose behind the INTEGRAL Adult Autism Conference, for which I am the co-founder and team leader. (Our website: <https://integralautism.org/>)

INTEGRAL is intended to be a community-focused, strengths-based, inclusive approach to bringing all the stakeholders of the general autism community together to learn from each other, with the goal of autistic adults being heard, respected, supported, and able to engage mutually with non-autistic parents, professionals, and policy-makers. Most of all, I want to break down the artificiality of the us-versus-them mentality that has gripped various parts of the general autism community as a whole, and to forge healthy, intellectually valid, morally legitimate, sensibly practical connections, ideas, and potential solutions to the enormous challenges faced by people on the autism spectrum - especially adults, whose circumstances and experiences are poorly understood on an official level.

Please let me extend my personal invitation to INTEGRAL 2021 to all of you on the autism spectrum and to all of you non-autistic stakeholders in the autism community. I want all of you there. Let’s break our

bubbles and have a conversation with each other rather than with ourselves. INTEGRAL will be virtual this year, on Saturday, November 6th – I hope to see you there!

I strongly encourage autism-advocacy groups beyond our local chapter of the Autism Society to establish regularly scheduled opportunities for various stakeholders in the general autism community to interact with each other in a relatively open and relaxed manner, and above all for adults on the autism spectrum – of all developmental levels, abilities, outlooks, and so on – to interact with non-autistic parents and professionals, so that autistic adults can truly be considered fully active participants within their own communities at large. At the same time, having times and places where autistic adults can gather with few or no neurotypical people present is also of great value, so we can simply be ourselves among ourselves. Both outreach and looking inward have merit, and they complement each other.

Remember also that there are plenty of parents and professionals who are, themselves, on the autism spectrum, and they should not be explicitly or implicitly excluded from those communities. Break down the stereotype, and the power dynamic, that says non-autistic people are the helpers and autistic people are the helped; it's another artificial divide that doesn't exist in reality, and is enforced by commonly held false assumptions. Challenge passive acceptance of neurotypical norms and look for where autistic norms can be upheld and uplifted in healthy, fair, and mutual ways, rather than being stigmatized, suppressed, defensive, or self-isolating. Build bridges where possible, fences where necessary, and think in terms of people on the autism spectrum as being complete people who deserve to be complete members of society.

Relevant links:

Autism Society of South-Central Wisconsin: <https://autismsouthcentral.org/>

INTEGRAL Adult Autism Conference: <https://integralautism.org/>

Autistic Self-Advocacy Network: <https://autisticadvocacy.org/>

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