

Letter to the Editor

Accepting Autism and Neurodiversity

Antonio D'Costa, MD*

Bai Jerbai Wadia Hospital for Children, Mumbai, Maharashtra, India

*Corresponding Author: Antonio D'Costa, Bai Jerbai Wadia Hospital for Children, Mumbai, Maharashtra, India.

Received: August 10, 2022 Published: September 19, 2022

Dear Editor.

I'd like to share with you an interview I recently had with a neurodiverse individual with Autism and ADHD. As an allistic myself, we seldom get the experience of talking to people who think differently than us. I personally feel a lot of residents and physicians seem to miss an understanding of the individual and their lives, focusing more on the "technical" aspects of our craft- the diagnosis and the treatment. But to be a holistic practitioner, it is of utmost importance that we understand the people we treat, and how they experience their lives, and how our "interventions" may affect them and their personal needs. As paediatricians we sometimes forget that the children we treat and inspire, will one day be members of our society as adults. With this write-up, I hope the readers can delve into the world of a neurodiverse individual, and build an understanding and acceptance for the same. The interviewee is someone with diagnosed Autism level 1, and ADHD. I've tried my best to keep the interview as pristine as can be, so as to not taint the mind and thoughts of someone with ADHD(and Autism) which I personally feel would give the best insight for the reader. My sole purpose with sharing this is for the reader to grasp a renewed appreciation and acceptance of a world of thought processes alternate to what we're normally used to.

Hi. So, since I'm new to neurodiverse thinking, I would love for you to start, and if need be, I'll ask you specific questions to elaborate. For now, I'd prefer to not interrupt you. So to begin, what are your thoughts about Autism and ADHD?

In my opinion, it's important to just give both ADHD and Autism exposure. Be it positive or negative exposure because they are both still not widely known, both lack awareness in many societies across the world, and so I'm more than happy to invest time into this.

I believe that a few questions to guide the flow of information would definitely be beneficial for a more efficient exchange of information since I can easily get lost and tend to over explain some things in order get my points across.

Anyways let's get started!

A few things that I'd like people to understand or rather would like humans in general to utilize is the nature of the human being in itself. I'm talking about the curiosity that is inherited in all of us. Only by asking questions, not leaving the (metaphorical) table of diplomacy and willingness to tolerate one another would go a long way for inclusion of autistic as well as people with ADHD.

Both predispositions are definitely having a huge effect on the individual, be it a single diagnosis or the combined case. People with ADHD are being generalized into being loud, uneasy, hyperactive(as the H in ADHD implies) and also lazy. Many people hear about an ADHD person talk about their struggles with regularly doing their household work such as washing the dishes, doing laundry and other tasks and quickly get labeled as lazy, though if one would make an effort to try and understand, you'd probably quickly hear about executive dysfunction which is a very real struggle. It's very difficult for a neurotypical (NT) human to even imagine the concept of executive dysfunction since it sounds like laziness.

Not doing a task that isn't fun not being done? "Oh yeah I don't like to do it either but it has to be done. Not doing it is just lazy"- Is a typical reaction that I've encountered on numerous occasions and it makes you question yourself, it cultivates doubts in yourself and your self worth. It's taken me a long time to get diagnosed with ADHD (and autism for that matter), even though I've been to various specialists in my childhood. They've all missed my obvious signs and I was led to believe that I'm just an incapable human being until 29 years of age.

Being an ADHD (and autistic) patient it's very difficult to figure out how to handle yourself. Odds are that in your social environment you have many more neurotypical humans that you inevitably compare yourself with and you ask them questions- "Is this normal/do you know the moment when X happens.." and most of the time, if you don't know about ADHD/autism you're not asking the right questions that'd show you how different you really are from the majority of humans. Even if you ask the right questions you probably would still not end up realizing that you're inheritedly different from others which can lead to self doubts and which will over time become a harmful habit of doubting yourself.

For autism specifically it's seen as a disability, whereas ADHD is "just" a predisposition. Yes, I'm aware it's also labeled a disorder but I like to think of ADHD that it's not just bad, especially when identified, treated and reacted to by the social environment at an early age. Back to autism though.

For people to be more inclusive of autistic people we need to take a closer look at it and not ignore it. Exposure is the name of the game, raising awareness for the difficulties can go a long way. One of the most important things that I've come to learn has been said by a wonderful nurse in my latest stint in a clinical institution where I was diagnosed with ADHD and autism. The nurse has previously worked in a special social pedagogical environment. In the years at her previous job she also guided autistic children in school for special needs and she was tasked with ensuring to show to the autistic child the ways of the neurotypical- "our world" as she expressed it, but she came to the conclusion that it's actually a lot better to leave that autistic child in their world.

The discrepancy in understanding of how things work, how they (autistics) experience the world can be beautiful on its own and at times it's not even possible to teach autistic people how the neurotypical (NT) world functions. It's mostly an obstacle due to a lack of tolerance for "different ways" and also a lack of understanding each other.

Obviously it's very difficult to even try to imagine how someone perceives the world they live in without actually being in their body, this goes for everyone but making an effort can only benefit us all.

So that's what I believe would be instrumental in the advancement for integration of people who suffer from said conditions, making an effort to understand, trying to comprehend and respecting their ways by practicing acceptance and tolerance.

I can use myself as a prime example. I'm very, very high functioning. I was able to hide my autism for 29 years from various specialists and only got "caught" by my latest doc. I've made people believe I'm NT because I mastered the art of observing and copying behaviors in order to adapt to a world that is neither created/catering to me and my needs.

It can only be beneficial for humanity if we find a way to co-exist and accommodate one another. That way we are all able to grow on our challenges and increase the likelihood to evolve into the best version of ourselves. It's a Utopian thought because many people have all their mental resources occupied to deal and cope with their own business/life but I like to keep that thought of a perfect world in my heart shaped box because I find comfort in positive thoughts when adversity hits.

Hmmm... Thank you for sharing that. You did mention that you "hide" your autism to blend in with other people. Could you please elaborate on that?

Strategies to hide my autism.

It wasn't until my most recent stint in a clinic where I encountered a person that has worked with special needs people before that I was confronted with showing autistic behavior. That is due to many factors but the greatest factor here was that my mental resources were occupied with dealing and coping with my traumas and issues that I have developed over the years that my subconscious routines to hide weren't functioning properly anymore.

How exactly do I hide my autism? As I have mentioned before, I have mastered the art of observing and copying behavior. I am a very adaptable human being and have managed to survive in many social environments. I was always odd, different or unique, you name it but I always managed to fit in.

I don't have a natural understanding of how the world around me works. I think in patterns. Patterns for social interaction, patterns for how I have to carry myself and handle expectations, patterns for literally everything. That in itself is very autistic as I was told, behaving like a machine where every action that I am witnessing is causing a reaction not based on the circumstances but from observed behavior in the past with the most basic example being when someone tells me "have a good day" I cannot leave the conversation without wishing them a great day as well.

This actually has led to a few issues in my past where people think I always have to have the last word in whatever is being said. I just simply struggle heavily when I do not react to something being said. It's a big conflict because I am unable to identify when its appropriate to respond or not respond. I don't want to be impolite or ignorant for not answering or awkward for remaining silent so in order to handle that I have gotten used to always replying, which leads to me having the last word most of the time- which is problematic to many people and can cause negative emotions towards me or give them the idea that I love to hear myself talk/me being a narcissist; Which is far from the truth.

These patterns exist for about every interaction that I have. Another small example for something not related to social interaction would be my time in art therapy. My motor skills are limited in the fine motor department. It takes a lot of time, effort and practice for me to become decent (I am aware that a judgement like decent is always very subjective but generally speaking I am not talented in this department) at these skills.

I struggled to come up with something that I could do in order to express myself and give the therapist something to work with. Our options included working with clay, soapstone and all sorts of drawing or painting utensils. I always had to be guided in order to do something. When I talked about my struggles with my therapist (not the same as in the art therapy sessions) he told me to sit down, take a blank paper and just let it flow. Paint whatever would come to mind, use the colors that I am feeling like. That in itself would imply that I am able to function without a pattern and just act on creativity alone.

Now taking into account that I am absolutely broken as a human being these days I tend to rely a lot more on these patterns and during art therapy I felt challenged, probably even overwhelmed with the confrontation of said patterns. I sat down with said white paper. I had pencils, all sorts of colorful pens, brushes and what else there is for creating art on a white paper but I could not move. I was attempting to "let it flow" for over 10 minutes but my hand doesn't move without an order from my brain. I simply can not comprehend how to naturally do something. I was pretty much incapacitated when I sat there. My mind was racing through so many thoughts at once as if someone was playing multiple audio tracks at once so I could not even grab a single thing.

So these patterns that I developed over time made me appear somewhat normal on the surface but after enough negative experiences, which resulted in traumas, weren't able to sustain that appearance.

I am also very adaptable to certain "classes of society". I need to preface the following information with a short explanation of how the school system works here in Germany.

The first 4 years of school (age 6-10) you have elementary school and with the conclusion of that you get recommended one of 3 possible further educational paths. It's basically an evaluation of your abilities (This has changed by now).

Then, depending on what level is recommended, you either spend 5th-9th grade, 5th-10th grade or 5th to 12th grade in their respective schools. The latter is usually the school diploma you need in order to go to college.

I was recommended to the middle one.

So getting back to my experience- 1st through 4th grade I spent my life on the countryside. Very unique way of life as many can imagine, though the German countryside is vastly different from the US countryside of course. Then when I entered 5th grade I changed schools and my living situation also changed to city life. As a matter of fact we moved to one of the biggest cities in Germany in Hamburg. I was one of only 2 Germans in my class and the other 24 students were all with an immigration background.

It was an absolute culture shock for me. Suddenly the calmness of the countryside was gone. The way that school worked was you have 2 lessons, 8 am to 9:30 pm, followed by a 30 min break. then 3rd to 4th lessons 10 am to 11:30 am, followed by another 30 min break, leading to 5th to 6th lessons from noon to 1:30 pm.

During those breaks the whole school was on break. All the students ranging from 1st to 10th grade were all wilding out during those breaks. It was like I moved from one planet to another and it was super overwhelming. People physically fighting, having to be separated, students smoking cigs in secrecy, people playing sports like soccer amongst other things were common scenes to be found. I was not used to it at all but learned the ways to not get bullied and be subject to physical violence quickly. My vocabulary also went from an attempted eloquence to utter slang. Using all the bad words as well which caused a lot of stress at home. I learned to get along with all types of people- criminals, educated ones, people barely able to speak German and many more types of humans.

I also learned to be around higher educated people when I went to attempt the higher education degree later in life (which I did not execute to the end, I stopped it half a year before graduation). I also learned to adjust to a high school in the USA when I was an exchange student in Corpus Christi, TX. So I have been exposed to many different levels of education, cultures and layers/levels of society.

Like a machine I am able to switch programs that run internally on how to interact with people, adjusting to their level of intelligence and articulation in order to connect with them.

I have to put on a disclaimer, many autistic people absolutely despise being thought of or associated with being a machine because that is an existing stereotype, especially for people affected by Aspergers or Autism level 1 as it's called these days. I on the other hand made this machine-like thing my strategy to survive. I made use of the observatory gift that I have and utilized the memory capability of my hard drive to keep my programs saved so I can make use of them at will.

Ah. That was an interesting tale into how you've managed to blend into "our" world, as you put it. I have come across neurodiverse individuals who seem to prefer a more "liberal" view of gender and sexuality, some even preferring to be agender, or are demisexual. What would your take on this be?

As its factually the case, ND (neurodivergent) people have a higher tendency to not identify with their assigned gender at birth/sex. I have not had the struggle. Though as a recent development has happened inside me I am currently starting to question my sexuality but let's start this from the beginning...

Very early on in life I realized I am into women (again I am AMAB -Assigned Male at Birth). I am also hypersensitive, so sex always felt really good. With that being said, these days I am on a medication for ADHD which is called Atomoxetin, Strattera and this medication is a combined ADHD and antidepressant. This has almost reversed my sex drive. As a matter of fact sex often felt so good that I wasn't able to have sex for longer periods of time. This led me to question what's going on and I am currently in the process of checking whether its a medical issue since there are a few more issues that came along with this change or whether this is actually me discovering I might not be heterosexual as I thought and lived all my life. It is not a side effect of my medication and there are a few more details going into this but those are not relevant for the question itself so I will not mention them, unless you want me to.

I have also been an exchange student in the USA (as I have mentioned) where I actually lived with a gay host family. I had two host dads and that experience really opened my horizon for the homosexual culture that they practice and open mindedness and tolerance in general. I saw their way of life but never felt like I identify with any of it. I never had the urge to explore how it is to make out with a man or anything that comes along with homosexuality. Obviously there are many more things to consider like bi-sexuality, a-sexuality, transgender and many more but as of now I feel like those do not apply to me. That is obviously subject to change at any point in time since I am not denying any of those preferences, I just don't feel them if that makes sense.

Another thing where I don't know whether this is relevant for this topic is my idea of tolerance. I do have few friends these days (by choice) but they share about all my values and live them freely. Notably for this is tolerance, inclusion and acceptance for all sorts of ways of living ones life so I can't tell if this is just my microcosm or whether this is actually part of my autism.

I don't view people in sexes or gender identification. I purely view a human being as a human being. There is not much reason to differentiate, in my opinion. I accept everyone the way they are, which doesn't mean that I have to interact with them. One of my patterns is that I have basically a template or blueprint which is applied to every human being that I interact with where I try to identify whether they are worth initiating more conversations with. If they don't fit, I don't ignore them or dislike them, I just don't bother investing energy into them, unless they seek my help in a respective way.

I have a subconscious mechanism due to my traumas where I basically have my emotions in a castle with lots of defense and security measures and for every security measure there is a template for it. If a person fits the template they get to move in closer until they eventually reach their end of the journey, either at a security measure or inside my castle where I then can open myself without holding back anything, which is also dangerous for me but unfortunately that's how I function at the moment. I felt like I have to clarify this because I am not ignorant of people, I just made the experience that certain requirements have to be fulfilled in order to interact regularly in a positive fashion.

So whatever you want to be identified with I will be accommodating you with it. I do not see the need to identify with all the terms that exist these days but I absolutely respect them.

The only difference that I noted in my social interaction when it comes to any kind of gender is that I have trouble interacting with feminine women. I absolutely struggle with social interactions (which is obviously autistic) to find any similarities with them.

Even talking about the weather is difficult for me, when talking to a feminine woman. This also mostly applies to younger ones since more experienced feminine women tend to be able to adjust to me better, this is purely from my subjective experience of course. I have no compatible programs in me that satisfy interactions with all kinds of feminine women.

I tend to be overly polite and respectful to people I am not accustomed to in order to not cross any boundaries which is often interpreted or viewed as a negative characteristic, surprisingly. These women tend to think that I behave like that because I have underlying issues and deep down I am a psychopath so they tend to avoid me after a while. This is very frustrating in many ways. I have been socialized mainly with males so I have no issue talking to men of any kind or age even more manly women are not an issue since I can just run the bro program (superficially said) and we get along great but feminine women are a mystery that I have not solved yet.

Other than all this, I do not have any input on gender. I accept everyone for who they are and/or want to be and everyone is well within their rights to practice their identity as long as it is within the rules/laws of their respective country/area.

As you may know, following rules that make sense to me is a big part of my life as an autistic + ADHD affected person.

On a side note: My ADHD always had me going with a strong sense for justice. Equality is very important to me and when I see issues I usually act on it in order to restore or achieve it.

Could you share some experiences in your life where you've been misunderstood?

This is purely me and I do now know if other autistic people feel the same. I take things very literal and sometimes talk very literal. I am by no means sexist but I had an issue recently with a young woman who has a masters degree in social studies. This also happened during my last stint in a clinic.

She was walking a short path outside from her room to the gym in a very short skirt. It was decently cold outside so impulsively (thanks ADHD) I just said "Aren't you cold in this short skirt?". You have to imagine her skirt as in a tennis outfit bottom.

Unfortunately I did not take into consideration everything that I had to in order to make a good judgement of the situation. It was a situation where I sat with two others in a few chairs, while she was about 10 meters away from us so I had to raise my voice a bit and other people caught it as well. Her reaction as you might imagine wasn't all too positive. She thought I meant that in a sexist way referencing that one could almost see her butt. To me, I sat there with two hoodies on, it was just cold and I was wondering whether she really isn't feeling it. I have had experiences in the past where I saw people with short sleeved shirts in freaking winter with some shorts on! I also asked those people whether they feel the cold and it was literally just me asking her the same, without any sexist intent. I would have asked the same to a man walking across in, let's say, a tank top. I would have asked him in the same way I asked this woman because my intention is exchange of information, nothing else.

I found NT people to often talk between the lines or to imply something when they speak. To me, it's very difficult to read between lines to the point where I just gave up and made sure that I communicate as straightforward to people in hopes of them responding with the same to me. Pretty much, treat other people the same way you want them to treat you.

Taking things literal and having a conversation simply for the case of exchange of information is something that other autistic people also have experience with. There is a stereotype about autistic people being rude due to a lack of empathy. Whether the latter is true or not is not in my realm to judge. My take is that we simply use the tool that is language often times in a different way that many people aren't accustomed to. Just like the love languages that exist (like one person "sees" someone loves them when they do the dishes for them, whereas someone else doesn't care about that but needs the verbal affirmation with the classical "I love you". Exchange of information is something that is very important for me, looking for solutions when someone is telling me about their misery is what I would want someone to do with me. I don't just say things to have them said and have the other person just listen.

So you feel that there is a barrier in communication between Neurodiverse and Neurotypical individuals?

Communication in itself is very fascinating and very difficult even for NT people when they talk to each other. Adding in a disability like autism makes the product of communication that much more challenging. I hope one day people will be open to accept autistic people in their way of communicating how they naturally are. Just like the story I used earlier. Leave them in their world and learn another's language, don't try to make the other speak your language, maybe even find common ground to create a language together?

That to me would be the dream, that I have gotten to experience once in my life with a woman that I will love to the end of my days. Unfortunately she is no longer with me but my interaction with her was by far and away the most loving I have ever felt from someone else (my friends can't love me like that but they accept me the same way she did).

You know, I am aware that people with ADHD have issues talking to NT people because their brains tend to "jump" in conversations making a connection that is not easy to follow for others. It might not even be clear how they jumped from one topic to another while the ADHD person believes its easy to comprehend. Same actually is for autistic people, I have read experiences where Aspie Group meetings finally give them some sense of being understood. They don't need to over -explain in order for the other to follow them.

Those were some wholesome thoughts, indeed. I personally believe that if Neurodiverse people are diagnosed earlier, it'll help them in being understood better and not be "forced" unnecessarily to conform with our NT world, which would create undue mental distress. As a paediatrician, that sits close to me. Would you be able to address the gaps that need to be filled to aid with this regards?

The gaps that need to be addressed for children to get diagnosed earlier are very difficult to cut down to a tee. This is more of a process of raising awareness so for now it is about exposure.

The way to fix this issue in a nutshell is more knowledge about autism in the general public and more research being done. The latter is especially true for any female human being. Most research always favors the counterpart to the female, the male. If you look up some statistics of males and females being diagnosed with autism (or ADHD for that matter) will always show that autism is more often diagnosed for males. According to the latest research autism is even more likely to be developed in male humans (was gonna say fetuses since autism is inherited but that sounds weird). The ratio is 4 (M) to 1 (F) if I recall correctly. I'd look it up to be exact about it but I have not ordered that book since I've read it in my last clinic. I've borrowed it from the senior doctor while I was there.

Anyways, research is really the key to earlier detection so at least the specialists get to do their job correctly. It's shocking that there is still no confirmation as to how ADHD and autism are actually "created" (for a lack of a better term). The current assumptions, to my knowledge, are that autism is due to genetic issues and ADHD can be genetic and also be developed due to socio-biological factors. I stress the word assumption again while also putting out a disclaimer for autism, not 100% certain if that is the latest research development.

The other factor that I've mentioned is the exposure and creating awareness. The following will be a bit of a difficult comparison and might not be fair ultimately but it should get the point across.

Autism and ADHD face a similar issue which is that you'll find a lot more people absolutely clueless as to what they are. Autism gets confused with down syndrome all too often. You can see examples when people mention phrases like "you don't look autistic" (in depth there is more detail, the quote is just most relevant for my point).

Autism awareness is probably at the stage where social justice was a long time ago. People have heard it exists but they don't see it. They don't know exactly how autism works, what the signs are and how you identify it. Most people that have a bit of knowledge about autism know about eye contact and difficulties in social interactions and you can compare that to the earlier days of social justice or equality (for females) movement where there were sole who denied it at first, then slowly started seeing discrimination and racist acts or wage gap issues with the first statistics publicized to now (also thanks to social media) a wide spread awareness with outrageous cases being made available to the public and these days most people know just about how racist acts work and when inequality is actually taking place because people have been exposed to it, awareness has been raised and the general public can now identify and differentiate and I'd like to see the general public at some point reach the same quality knowledge about autism so the children of our future have a fighting chance in their life's and don't have to suffer countless traumas that will render them ad broken as I (or others) am today.

A caring family that tries to cater to a child's needs goes a long way in having autistic humans being great additions to society and for their own quality of life of course.

Therefore I'm very thankful that humans like you exist and do the work I could not possibly do myself in the current time.

Just a quick word about ADHDs struggles. Many people just say ADHD symptoms are excuses for laziness, ADHD is still not universally accepted as a disorder(some say it's just fantasy) and ADHD just like autism is often evaluation on the basis of males. Females have it a lot more difficult to get a diagnosis because of it so we need equality here as well (in the research department). So the same two processes that autism needs to go through also apply to ADHD. ADHD is also perception changing with differences in stimulus processing amongst others (similar to autism in terms of different stimulus processing from neurotypical people but in their own unique ways).

To wrap up, I have one last question: How do you feel people could understand Neurodiverse individuals better?

So to answer your final question...

The answer to it is pretty simple actually. You can't. Just like I will never be able to comprehend how a neurotypical brain functions, how it feels and especially what it doesn't do that my brain does. There are countless examples that I could tell you about but that'd be too derailing. All we can do is try to become more accepting of other worlds. Neurodiversity really includes many disorders and disabilities. I share the opinion that it may not be generalized other than an umbrella term that is used to describe that the brain development and function differs from the typical/normal/healthy human being. Even though one neurodivergent disorder usually doesn't come alone but in packs- Down syndrome, dyscalculia and epilepsy all also belong to neurodiversity and as you probably know these disorders you can tell that they are all unique.

Gun to my head, if I had to try and make a universal statement on this I'd say that neurodivergent human beings need treatment and accommodations in order to survive in a world that is not primarily designed for them. They are humans, like every other human, they have the same rights and should be treated as equals. As it is the case with neurotypical humans as well, everyone should bring a certain amount of curiosity, tolerance and acceptance towards one another in order for us to live a good life which is something that I believe is in everyone's interest.

I have a small group of friends where I can live my Utopian ideals and I can confirm that I am indeed not burnt out after interacting with them. Then it goes to show that autistic people, who suffer from heavy depressive episodes, are affected by traumas and disorders can function. We/I can live a normal life once certain requirements are fulfilled but unfortunately I do not see that happening in my lifetime. Humans are too selfish by nature and it's truly a shame. The latter is based on my life experiences and is not a judgment of every individual I am encountering. Every person is given a chance to prove me wrong. As a matter of fact, neurodiverse people probably know better than the average human that having to deal with your own business sometimes is more than you can handle so no offense to anyone just minding their own business and not caring about someone else's struggles. It's just that, that history has shown that if we all try to help each other out and work together we can make something "magical" happen. There are large examples like the JWST (James Webb Space Telescope) which is a masterclass in international cooperation and smaller scale examples like humans caring for the elderly. We are able to support one another and when we come together to do just that we can thrive to heights that previously may not have been imaginable. To wrap this off I'd like to say that a team is only as strong as its weakest member, so lets make sure we help the ones that need it and quite frankly neurodiverse people often need extra assistance and consideration as well as others.

{**Disclaimer:** Kindly note that the interviewee is 3 months into his autism diagnosis, and his opinions and thoughts are as of the interview. They are subject to change with time and further understanding of his diagnosis.}

Citation: D' Costa A. "Accepting Autism and Neurodiversity". SVOA Paediatrics 2022, 1:5, 109-115.

Copyright: © 2022 All rights reserved by D' Costa A., et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.