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Mental Health Issues in Autism

and some things that can help.

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By WolfSpirit

- **Anxiety seems to be inherent in autism.** Biologically, as well as environmentally caused. A lot of it is related to Sensory Integration Dysfunction, and the problems related to not being able to understand what's going on around you. The difficulty with change and need for sameness is largely related to sensory issues, and the uncertainty and confusion of not being able to understand what's going on around you.
 - I read something about dementia in 2019 that commented on the confusion and scariness of not being able to understand what you hear, or recognize where you are, or who the people around you are, or what's expected of you, and I thought "they could be talking about autism!"
- Another problem for some autistics is being able to **recognise or identify emotions**. Naming them, distinguishing them from thoughts, that kind of thing.
- Some autistics also have a hard time dealing with the intensity of their emotions, and/or have no skills in coping with them.
- Another major source of stress is **unreasonable expectations by the Neurotypicals** around the autistic person, and/or intolerance by Neurotypicals. **The "cure" mentality is still, unfortunately all too alive and well.** The idea that there is something inherently wrong or "defective" about being autistic, that needs to be "fixed". **"Acting autistic" is still criticized and denigrated, and "acting normal" is rewarded,** and seen as the goal, **no matter what the cost to the autistic person.** Dave Spicer discusses this eloquently in his articles "Autistic and Undiagnosed, My Cautionary Tale" (Spicer, 1998), and "Self-Awareness in Living with Asperger Syndrome" (Spicer, 1997, August 17-20). Jim Sinclair also discusses the topic compellingly. Particularly in his "big three" articles, as he refers to them: "Don't Mourn for Us" (Sinclair, 1993); "What Being Different Means" (Sinclair, 1992a); And "Bridging the Gaps: An Inside-Out View of Autism" (Sinclair, 1992b).
- Needless to say, **depression is also a huge issue in the autistic population** because of this kind of intolerance.
- **Bullying occurs** also because of this prevailing societal attitude, and the notion that there is something wrong with being different. That being friends with someone who is different is "not cool".
- Contact with other people on the spectrum, where the autistic person can be seen as 'normal', and realize they are not freaks, or anything, is incredibly important. Contact with adults on the spectrum for children and adolescents can show them what it's like to grow into an autistic adult and that there is a future for them. See Jim Sinclair's "Cultural Commentary: Being Autistic Together" (Sinclair, 2004).
- Reading **positive literature about autistic characters or about changelings** (as many autistics identify with) can also really help autistics' self-concept, as it gives them someone they can relate to. Someone "like me". It is huge to be able to see one's self reflected elsewhere. In literature, in movies, in TV, in real people, wherever. To be able to relate. To not be the only one.
- Getting a diagnosis, at any age, for one's difficulties, is huge. It allows a person to stop feeling like everything is all your fault; that your differences are somehow a result of "not trying hard enough", or attitude, or "being difficult", or whatever the Neurotypical (NT) excuse of the day is for why the person's differences are their fault. Why their differences are something that person, by themselves, needs to fix, despite not knowing how, having no tools, and trying 150%, 24/7, often for *years* to no avail.

- **Being able to explain why you are different**, and that **it is not your fault** helps to alleviate the guilt of not being able to “win”, or “succeed”, or even really manage, at the NT game; at life, at being human. No wonder so many of us turn to the explanation that we’re aliens, or changelings, or members of some lost tribe, or... anything else we can come up with that is an alternative to “defective.” After all, no one wants to be considered defective. Much better to find a different explanation for being “Other”.
- “Autism Speaks” is a **hate group** and yet also the most vocal/prominent autism group in the media. It is a **parent** group whose primary goal is to raise money for a “cure”, and which outright **rejects adult autistic perspectives**, never mind involvement, and claims that anyone on the spectrum who can articulate their experiences isn't very autistic and therefore doesn't count.
- One of the best things that helped me was my autism specialist's regular reassurance that there was **nothing wrong with being autistic**, and that I was okay just the way I was, and that I had a valuable contribution to make to society the way I was. Particularly when the world was telling me just the opposite. Often rather strongly.
 - My autism specialist's being impressed with how functional I was, given all that I was dealing with, even when I was barely functional, really helped to change my perspective! She really helped me change my viewpoint, and stop the whole self-condemnation thing I had going on. Rather than focusing on the messages I got from the rest of the world about “you should be able to do this, you should be able to do that” I could focus on, “I managed this, and that, and the other thing, despite x, y, z stressors” and how impressed she was with me.
- **Having someone understand** the things that stress autistics out that NTs don't seem phased by, or *autistic stress* (Shah, 2019), really helped. Shah describes autistic stress below:

I prefer to refer to the stress experienced by autistic individuals as autistic stress as their experience of stress, factors which cause them stress and their reaction to stress are specific to autism and related sensitivity and difficulties. [...] Autistic people are extremely vulnerable to becoming anxious, distressed and easily overwhelmed in situations which cause them stress. This vulnerability is due to their underlying autistic characteristics, which include social and communication difficulties, sensory sensitivity, and cognitive style of focusing on detail rather than the whole. Due to these characteristics, they often experience the world around them as invasive, chaotic, overwhelming and unpredictable. The psychological distress and autistic stress experienced by autistic individuals often relates to fear, social and general anxiety, demand overload, frustration, fatigue, confusion, misunderstanding and misinterpreting and non-coping. (pp. 79-80)

- Having someone understand the ways stress affects autistic functioning (i.e. often drastically!) was also invaluable.
- Having someone who understood how autism works and manifests, and who could explain it to me in a non-judgemental manner, was equally vital.
- Again, being able to have **reasonable expectations** of myself, and realize that my **functional level could and would fluctuate, sometimes wildly**, by things NTs could take in stride, (as well as things that

would also stress them out) really alleviated a lot of stress, and guilt! It allowed me to dispel a lot of self-condemnation and criticism I had had previously.

- Being taught the ideas identified in the previous three points was essential. Nobody in the NT world teaches you this stuff. They expect you to be like them and to figure things out for yourself.
 - That's another thing. As Jim Sinclair says “being bright only means I'm good at learning; it doesn't mean that I'm good at knowing things without having to learn them first.” (Sinclair, 1992b) And also, that in essence, being autistic means having to learn things other people take for granted (Sinclair, 1992b). **Things NTs learn by osmosis, or know by instinct, autistics often have to learn.** Teaching autistics this stuff means starting a lot farther back than most NTs realize.
- **Being able to see things in a way other than they are can be a difficult thing for many autistics.** Imagination can be a hard thing for some autistics to understand. Alternative possibilities can be difficult to comprehend, and need to be pointed out. **Optimism, and hope, may need to be taught.** Both in words and through actions. The cliché “actions speak louder than words” applies here. Following through on promises, and demonstrating that more beneficial outcomes are achievable, will have more effect on a logical, concrete autistic mind than any words possibly could. Especially when they have learned from experience that people often say things they don't mean, or if they have overlearned that not only is life not fair, but that it predominantly works against autistic needs and desires.
- **A great deal of reinforcement** was needed to get me out of my catastrophizing and cynical viewpoint. Particularly when the world around me was so intolerant, and problematic. It took copious demonstration that things really could be better than they were, and that perhaps, there was a reason to hope before I started to change my perspective. Later, I became able to realize that there was reason to potentially even expect that things might work out in a beneficial way for me. A profuse amount of counteracting the NT world's negative views of autism and autistics was required.
- In addition to positive reinforcement and encouragement by the neurotypicals in one's environment, the neurodiversity movement, despite its problems, is equally important, if not more so, in getting the concept out that **autistics are people too**, and just as important to the world as NTs, or any other disability group. Autism is perhaps the **last disability group to be seen as people**, and as credible, with the same human rights as anyone else. Society is still working on that one. Currently, it is **still considered acceptable to terrorize and torture autistic children (and more severely affected adults) in the name of “treatment”**. Namely ABA behavioural “therapy”.
- To that point, **teaching behaviours without teaching the reasons for that behaviour**, or for the sake of “fitting in”, **is pointless**. Again, **it teaches the person that being “normal” is the only acceptable way to be**. It teaches the person that there is something wrong with being the way they are.
- Additionally, **trying to “eliminate” behaviour because it “looks weird”, or “isn't normal”, or seems to serve no purpose, without taking the time to find out what purpose it does serve, causes just as much or more damage**. Of course, if a behaviour is dangerous, or disrupts others from doing what they need

to do (see “Is Cure A Goal”; Sinclair, 1998) then certainly, another course of action needs to be found. However, understanding why such a behaviour is happening, and how better to fill that need must be discovered first. (Also discussed in Prizant, 2015).

- **Self-advocacy skills are important and need to be taught and practised early.** Ideally, as early in life as is practical, given the person’s developmental level and capabilities. (not presumed capabilities, or lack thereof, but actual capabilities).
- The book *Text, Don't Call* (Caycedo-Kimura, 2017) about life as an introvert could also be applied to autism. In fact, it could almost be argued that autism is an extreme form of introversion. Almost.
- **People are hard to deal with.** Socialization with NTs is often overwhelming, exhausting and confusing. They are loud, talk too fast, engage in rapid-fire changes in body movements, don't say what they mean, or mean what they say. They ask several questions at once, talk about nothing meaningful, expect you to keep up, know what they are saying/doing, know what they don't say (essentially mind read), and change topics in rapid succession. They also prefer to do all this in noisy, crowded places with overwhelming fluorescent lighting, or otherwise sensorily noxious environments. And when you get tired or overwhelmed by all this stuff, their solution for fixing the problem is to socialize more! My autism specialist was the first person in my life, (and one of the few professionals at the time, to my knowledge), to realize and suggest that **sometimes the best solution when an autistic is stressed is to have them socialize less, not more.** To realize that some things that are adaptive for NTs, are actually maladaptive for autistics.
- Of course, **different autistics have different levels of interest in other people.** There are many reasons for this. Some of it is hard-wired, some is developmental, and subject to change, some sensory, and some of it may be trauma related – people are too overwhelming, (see above) or have been too negative, or hostile, or rejecting, or downright dangerous. The whole idea of other people being useful in any interactive sense can take a very long time to develop. It just isn't necessarily a natural thought for those on the spectrum.
- **Even if someone on the spectrum wants relationships,** and wants to interact, **that doesn't mean they know how to,** or can even be taught how by “standard” neurotypical means. Again, it goes back to differences in how autistics learn, and perceive the world. **Basic neurotypical assumptions may need to be questioned** because they may not be so basic to the autistic person (Sinclair, 1992b). Or even comprehensible, for that matter.
- Other autistic people may have a pretty strong **aversion** response even to the **idea** of other people, due to negative experiences with them. Still others may be **oblivious, or indifferent.** I'm just starting to figure out the whole concept of what people are for - maybe. It's only been in the last couple of years I've started to have actual interest in the concept of “people in general”, rather than in certain, specific people. Hell, I was practically 20 before I started to think people could occasionally be rather useful objects.
- Sometimes direct instructions from people who are important to the autistic person about what to do or not do with regards to upsetting, or counter-productive thought patterns or beliefs etc. can be helpful. E.g. “Tell your brain to shut up when it's spewing garbage” when it is being overly negative or

full of NT “shoulds” or other stuff that just doesn't fit where a person is at, at that point in their life. Or “Call me/come talk to me when you're having problems”, or... instructions to stay away from emotional minefields, that sort of thing.

- Just **the knowledge that someone cares enough to provide such instructions**, or to honestly want to help **in a way that works for the autistic person**, and is willing to do so in a concrete enough fashion that it makes sense to the autistic person, can make a big difference. This is true whether or not the autistic person expresses or demonstrates their feelings in a fashion recognizable to a Neurotypical.
- Again, **people are confusing**, and the very idea that other people can be interesting or useful or beneficial to oneself, rather than a hindrance or an obstacle, can be very odd to an autistic person.
- Also, Neurotypicals relate in a very different manner than autistics do, so there is a **cross-cultural difference** that needs to be considered.
- Emotional **expression** can be difficult for autistic people. Either at all, or just in a way that Neurotypicals expect, and/or can interpret.
- **Emotions can be confusing**. They are abstract in a lot of ways, and often not logical, which doesn't work well with the concrete, logical nature of autistic minds.
- **Words are hard**. Words relating to emotions are even harder. Find out how each person communicates best. Use that. Many autistics communicate better in writing than they do in person. It allows them to put their thoughts together with less pressure, take their time to compose a response, and doesn't involve the pragmatics involved in speech. (**Pragmatics are very hard**. Sometimes incomprehensible.)
- **When there are auditory processing issues, words are even harder**.
- The concept of expressing emotion in words, or talking about personal experiences seems to develop fairly late in many autistics. (Sometime in the teens – which may or may not have changed in this generation as a result of the increased level of understanding and supports available) Even if speech on factual subjects seems to be sufficient, the ability to do so on emotion-related subjects, or even the comprehension of the concept of emotional expression may be missing, elusive, or just developing.
- It is extremely common for higher functioning autistics to hear “everybody experiences that”, or “Oh, I’ve experienced that too”, or other similar phrases when trying to describe their difficulties. **Phrases like this only make things worse**. They usually make the autistic feel like they’re not being listened to, and their experiences are being minimized, because **odds are, unless you’re on the spectrum yourself, or have similar neurological differences, you haven’t experienced whatever they’re talking about**, certainly not to the extent they do.
- **Being able to describe one's difficulties does not mean that one does not experience said difficulties**, no matter what people on the outside think. It only means one has been able to figure out how to conceptualize and articulate them at some previous moment, and may have devoted an extreme amount of effort towards being able to communicate said difficulties in the current interaction, in order to get assistance with them. **Being able to communicate said difficulties may mean crashing and not functioning for a significant amount of time after one gets some alone time, or down time**.

- **Being told that being able to communicate one's difficulties means they can't really exist, is extremely frustrating and only likely to result in the person being less likely to look for help in the future with other difficulties.**
- Acknowledging, and understanding the difficulties autistics can have with communication, particularly initiating conversation, especially about important things, can go a long way in overcoming the autistic person's inertia surrounding communication. It can also go a long way to counteract the autistic person's self-belief that no-one's going to care, or believe, or comprehend their problems. This belief further prevents the autistic person from bringing up problems in the first place. **When you know someone understands how hard communication can be in the first place**, and (at least some of) the obstacles to initiating, or maintaining conversation, **it makes it much easier to be willing to try to communicate with that person.**
- It bears repeating that an autistic person's functional capabilities, and coping skills will fluctuate greatly, depending upon how much stress they are under, whether that be sensory, emotional, medical, or otherwise. Therefore, certain skills they may have at calm times are likely to disappear under stressful circumstances, and **it is unreasonable to expect them to be able to maintain them.** If an autistic person is **suddenly unable to do or manage a situation or ability they usually have**, or have had in the past, **it is a likely bet that they are experiencing stress, and are not able to access those skills at this time.**
- Shah (2019) provides a useful partial list of potential causes of autistic stress that are often overlooked or ignored by non-autistics. This list considers ecological, psychological and relationship domains.

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Author Note:

The author is an adult-diagnosed, autistic self-advocate with a B.A. in Linguistics, and a B.A. Honours in Psychology, who has a lifetime's experience in dealing with depression and trauma, and has been involved in autistic self-advocacy for 25 years, since the concept was in its infancy. This document was created at the request of a family friend who works with autistic students, who asked for advice on mental health issues in autism, from an insider's perspective, in order to better be able to help. After the initial composition, this document was formalized for distribution, in the hopes it will help other non-autistic service providers with understanding the issues we deal with, and the things that have been helpful in my journey to self-acceptance, self-confidence, and peace of mind.