

Episode 12: Autism and Rejection Sensitive Dysphoria

Hello all and welcome back to another Actually Autistic Educator, as always transcripts are linked in the show notes and on my Twitter and Facebook posts for the episode. This month's episode is a mini-one, because while working on a longer one on autistic burnout I reinjured myself a week ago and have had some bad sensory overload from the pain, and after writing up a bunch of notes on the research showing how you shouldn't try to push yourself through burnout and that we all need to be more caring and considerate to ourselves, my partner pointed out I should practice what I preach and take things a bit easier and not try to put together the other interviews and all the editing they take, so instead I'm going to talk a bit about why many autistics and other neurodivergent folks struggle socially with feeling like a disappointment (like for a podcast episode), annoying, or burden to others and how it connects to a newish term describing how this impacts many of our emotions around social interactions - rejection sensitive dysphoria.

I was helping one of my students this week with her final paper for psychology and we were looking at how your childhood environment impacts your sense of self as an adult - the lessons you learn about what love, friendship, and such look like, how you see yourself and your own value - these heavily influence how we interact with the world even decades later.

Like many neurodivergent people, I struggle with assuming that others don't like me or find me annoying, even against substantial evidence to the contrary - my brain is constantly worried that people who seem to be friends with me actually find me a burden or annoyance even when it clearly clashes with reality, and that everyone will abandon me if I'm not perfect. With RSD this often goes beyond standard social anxiety to cause severe emotional responses. This is a very common trait in neurodivergent people, especially autistics and ADHD folks (though

identified first in connection with ADHD), with some suggestions that it may be more common in people socialized as female as children. This is still a pretty new concept with limited firm research regarding exact causes, and many psychologists are not using the term widely as of yet, but it is quickly catching on as it describes something that resonates deeply with so many neurodivergent people. RSD can manifest as extreme panic, rage, embarrassment, shame, and/or hopelessness at only minor social rejections like turning down an invitation or not responding to a text, reading too much into statements and thinking others are upset at you, or constant concerns that others secretly dislike you even if they seem to be completely nice in their interactions with you.

RSD has been mostly associated with ADHD in the past and considered a part of "emotional dysregulation," which had previously mostly been looked at from a brain-chemical perspective - that the person's brain isn't making or using certain neurotransmitters effectively which causes a disproportionate emotional response to a situation. But in recent years with the creation of the term, the environmental experiences, especially in childhood, are beginning to be more understood to have a major impact too. Dr. William Dodson's article "Emotional Regulation and Rejection Sensitivity" from 2016 states "Children with ADHD hear 20,000 additional critical or corrective messages before their twelfth birthday when compared with neurotypical children. This cannot help but have a tremendous impact on the emotions and sense of self of a developing child. People with ADHD are "the last picked and first picked on." Most grow up with the feeling that they are less than, uncool, unwanted, defective, incompetent, and "damaged goods." The resulting shame and guilt often negate positive feedback and the formation of a positive self-image." While this was written in regards to ADHD, it's clear why this experience is common in autistics too. Your

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brain learns from all of its past experiences, and unfortunately most neurodivergent children have a long history of having people treat their mannerisms of excitement as rudeness, of being blamed for being bullied because “what did you expect when you look/act like that,” of people insulting them for the way their brain works to process information, and of parents, teachers, and therapists saying that if the child doesn’t change then no one will like them or they will not be successful - what else can a child take from this other than “I must be wrong”? For more recent evidence check out “Experiences of criticism in adults with ADHD: A qualitative study” by Beaton et al from just two months ago, beginning to look at the impact of increased criticism of ADHD youths, with concerning results.

Now, really, this is pretty obvious when you think about it - we are a product of our history and our brains make decisions accordingly. We expect something from the oven to be hot, rain to be wet, cats to be fluffy, because that is what we have found in the past when we interacted with those things. So then, isn’t it obvious that if a variety of trusted adults repeatedly tell a child, often with the intent to help them, that people find them annoying, that the child is playing wrong, that no one will like them if they don’t make eye contact, that their brain will internalize deeply that they as a person are wrong and annoying, and they must constantly be on the look-out for signs that they are annoying others? If their hands get burned enough times by others, often with no warning, are we really surprised when neurodivergents have this response?

It’s unclear on if I have ADHD or if it’s just that my autism presents with a lot of similarities to ADHD, while the two are documented as having overlap it can be a challenge to suss out the specifics, so since I currently don’t use the label for myself I don’t speak for the ADHD community, but because I at least know what it’s like to be neurodivergent I find it a lot easier to work with other folks whose brains are considered outside the norm for various reasons. It’s why I love

my job working with students with disabilities, non-native speakers, and low income students, every student is unique and many have serious educational trauma for being different. I work with a lot of ADHD students and the amount of shame and self-loathing they express breaks my heart. My coworkers often call me a miracle worker for my results with them when all I do is help them learn to work with their brain rather than trying to force their brain to work like others, and I exist as a safe person who won’t invalidate their experiences or shame them for being different.

This is one of the reasons I and other autistics have so many concerns with existing social skills training - if you start from a position that the child’s natural ways to communicate, play, think, and move are “wrong” it teaches permanent negative thoughts and makes them work so much harder to function. There are less hurtful options that autistics may share with each other - hacks and tricks for understanding non-autistics abound in some spaces, and some things may be a genuine safety issue - especially for autistics of color who have to navigate being seen as a potential threat just from stimming or not making eye contact, such as with Matthew Rushin, a black autistic man who was finally released from prison after several years after a social media campaign resulted in a pardon. But the trouble is the perspective that so much of this non-autistic training comes from, that all children need to think, play, and work in the same way, and anything outside the norm is pathologized, so kids who are different should be told they are wrong.

An example that has been going around on social media this week was an image of a bunch of small toys lined up by an autistic child in a variety of intricate spirals and lines on a floor, with a text sidebar saying that this image was shown to four online communities of individuals with different backgrounds and each was asked for their thoughts. The first group was mothers of non autistics, who made statements comparing it to a zen garden, that

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it was like a piece of art, and showed patience. The second group was a support group led by non-autistics for parents with autistic children, whose comments were more “it’s sad they don’t know how to play” and commenting on how frustrating it is when their child does similar things. This is such a common issue I have seen by the way, behaviors that are accepted or even championed in those without a label of autistic suddenly become a tragedy in need of fixing when autism is applied - teenager spends several hours a day for 5 years drawing or learning to code or play piano, they are incredibly skilled with so much focus and drive. Add the label autistic and suddenly this becomes a concern, anti-social behavior and a refusal to interact with society, and something that requires a fix. A different perspective around the image is seen by parents of autistics in a autistic-led support group, where instead the creativity and focus is commented on - because the parents have been given a different lens to view the behavior, one where autistic behaviors and mannerisms aren’t automatically seen as bad, because this sort of play isn’t inherently better or worse than any other, it reduces stress for both the child and the parents. The last group was non-autistic professionals who work with autistics, who talked about ways to teach the child to play correctly and other ways to modify the behavior.

I can’t be certain of the veracity of this post, it was not part of a formal study and published somewhere for peer review, but it lines up exactly with my own experiences, and helps to explain how this framing of autism and other neurodivergent behaviors can cause trauma - when we look at differences through a deficit lens it dramatically influences our perspective, and children who see the adults reacting to their play with disapproval, pressure to change, and comments about their lack of creativity will internalize this, and it will color their perceptions of themselves as adults.

In a post about RSD on Facebook several of my autistic and ADHD friends and I were sharing experiences from childhood and found a concerning

pattern - all four of us were at least once blamed for being bullied by a teacher on the grounds that our weirdness was “asking for it,” another shared that a parent who told them in middle school “no one is going to like you for you, be someone they will actually like” then was confused when the child developed crippling social anxiety and depression, and so many had experiences of some sort where they had thought they were having a good time socializing just to find out later that no, the other person was just “being nice” and didn’t actually like them or want to spend time with them in the future. I had a teacher in high school, who genuinely thought she was helping, tell me that the reason none of the boys wanted to date me while my friends had all started dating was because I answered all the questions in class and it was clear I was smarter than the boys, which made them feel threatened, so I should try asking them for help instead. Yeah, I actually got that advice from a concerning number of people when I think back. But like the picture about styles of play, I get dramatically different responses to that statement depending on if I include the fact that I’m autistic. If I am only seen as a competent, intelligent, outspoken girl who refused to make myself seem smaller to appease the egos of high school boys then I’m lauded for my strength and self-confidence and the people who told me to hide my abilities are decried as sexist and backwards. If however I add the descriptor “autistic” then there is suddenly vastly more excusing done - after all, I said I wanted to be asked out, they were just trying to help me fit in better, my mannerisms could be very harsh and direct, it’s only sensible that I needed to learn how to make others feel more comfortable. These lenses we apply distort so much. Why do we rightly say it’s offensive to tell a non-autistic girl to smile more, but my non-speaking brother had his face squished without his consent as he was literally trained to smile on command through bribes and punishments?

A frequent complaint against autistic advocates is that we’re saying that autistics be allowed to be weird or different as children when they claim that

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autistics have to learn to fit in with others to be an adult. But what's incredibly amusing to me is that my experiences are exactly the opposite, and so many friends of mine have said the same. Many report huge improvements in their cognition and mental health when they are able to self determine food, sleep, sensory-input, socialization options, and more, when we can make our own friends based on shared interests and communication styles we click so much better. My friend circle is disproportionately other neurodivergent folks plus people who are cool with the fact that I hate phone calls, my nature is a hermit, and I like talking about ideas or topics more than social chatting. This is so much better and more authentic a connection than the poor attempts I was pushed into while pretending to be a non-autistic teen. But even though I know these people clearly want to continue spending time with me, and they like me for my autistic self and not just my masking, I still really struggle sometimes with these intrusive thoughts that my friends secretly are constantly annoyed by me, and so so many of my autistic and ADHD friends say the same.

So we can make things better for the next generation by understanding concepts like the double empathy problem, avoiding a deficit perspective, and supporting autistic kids to be themselves rather than telling them they're playing wrong, but how do we start to heal this trauma in neurodivergent adults? Again, this is relatively new and still being studied so it's unclear if this is completely based only on past experience. As we know there are some chemical differences seen in both ADHD and autistic brains, especially around dopamine, it's quite possible that it's the combination of trauma plus differences in neurotransmitters that make this happen or influence how it presents. Reminder, I am NOT a licensed mental health counselor, medical doctor, or psychiatrist, there are some options for medication that I have seen referenced in my research on this topic that are thought to assist in reducing some of the anxiety and negative thoughts associated with RSD, so if you personally struggle with this and especially

if it's strongly impacting your quality of life that is an option to discuss with your medical or mental health professional. However, many neurodivergent folks have also shared non-medical options that have been helpful to them, which might help you too, or in your work with others dealing with RSD.

Several forms of therapy can be used to work on awareness of why your brain is responding the way it does and how to recognize what of your thoughts are maladaptive coping skills - things that seemed to fix a problem when you were in a certain situation but aren't great in the long run. It can be a challenge to find a therapist who is a good fit for your background, neurology, and needs, plus navigating insurance and copays is an extra layer of problems, but this can be a helpful option. For therapists working with neurodivergent folks it's incredibly important to examine your own perspectives of bias around ableism and neurodiversity - this stuff is insidious, it's literally a special interest of mine and I have years of lived experience and I still catch myself having ableist thoughts sometimes because it is just so baked into our society.

For managing the emotions from RSD something I have found that has worked well for me, and for several others who have independently found similar fixes, is working with how my brain processes social information to reshape the narrative - how it usually manifests for me is I start detailing examples and create mental lists of my past social actions in examples of "bad" things that folks may be upset at me for and begin to panic and spiral, so I've been working on when I catch myself doing this I create a list instead of times folks said something nice to me, or asked me a question because they trusted my opinion, or thanked me for something, and then shift my focus to a different topic. It's a process of retraining my brain to say that my friends do like me, if they didn't then they wouldn't keep being around me. It's an ongoing process, retraining your brain away from a trauma response isn't easy, but it really can help given time.

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Quick aside, not all autistics have supportive spaces to heal in, I didn't until I found them in subsets of different geek communities in my early 20s, so if you're autistic (or anyone really) and don't have people who you can objectively feel like you for you, I highly recommend you check out online spaces for your interests and passions, and/or neurodiversity groups for your area or social groups - folks who are questioning and don't have formal or even self diagnoses yet are almost always very welcome in autistic and neurodiverse spaces. Oh, and on Twitter check out #NotAloneTalk, it runs every day and is a great and inclusive space to talk to others, meet people, and be supported by connecting with other folks using the hashtag.

I've also been working on feeling like I need everyone to like me, by reminding myself that everyone is different, there are many lovely people in the world who I wouldn't like to spend time with (I remember with horror the one super bowl party I was invited to by a roommate, I'm sure they were great people but we had zero overlap in interests and communication preferences, it was miserable) and it's not a statement that either of us is bad - the greatest goal cannot be to have everyone like me, because there are far too many options in the world! Some people want friends who will text or chat with every day while others would find that overpowering, some folks love reality tv or documentaries and others live for space adventures, some people love to talk loud and fast, stepping on each others sentences, and others would feel cut out or overwhelmed - there is no one right way to be or to communicate, and no miraculous way for everyone to always like you and still be you. Unfortunately, many autistics are taught to mimic and mirror, to change and hide themselves to try to fit in everywhere, instead of being taught how to find the spaces that will support and appreciate them as they are, or learning in a non-judgmental way that some folks are different and we might both need to change a little bit if we want to communicate effectively.

I would expound more, but this was supposed to be a very short like five-minute episode as a break for me, with just a general quick reminder to be gentle with yourself even if you usually are worried about disappointing people, but I've spent 7 hours on my notes and script now, have five journal articles and four blog posts open in my browser tabs, it's just past 3am and I already am starting to worry that this was not nearly as structured as it should be and I should really go back and heavily edit it all into more cohesiveness, but maybe I'll try to do more of that putting this grace for myself into practice and let myself have an episode that meandered a bit more than I intended.

For neurodivergent folks listening, or anyone struggling with this, let's make a deal: for a week just to start, if you find yourself being super self critical, positive that everyone hates you, pause and really think about what you would do if someone said those awful things in front of you to a child, or about your friend. Would you jump in and tell them to not say such awful things? Would you be horrified? Why do we feel it's ok to be far crueller to ourselves? Let's practice extending the same grace and concern to ourselves that we do to others. If you have tips for things that have helped you with this please send them in!

On that note, I hope your May goes well, and I'll see you back next month for our one year anniversary. Also, if you self-identify as autistic and are interested in sharing some of your thoughts and experiences, especially on autistic burnout, please send them my way for inclusion in our next or future episodes! Also, huge thank you to the folks who have shared this podcast on social media, every time I see your comments it brings so much joy and helps me keep going. Thank you.

This podcast is produced in conjunction with InterACTT, the International Alliance for Care and Threat Teams, supporting your day-to-day work in counseling, disability services, student conduct, law

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enforcement, CARE and threat teams, and diversity/equity and inclusion. Check us Living with Rejection Sensitive Dysphoria, by April <https://neuroclastic.com/living-with-rejection-sensitive-dysphoria/>

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