

Episode 7: Neurodiversity (and Other Models), Part 1

Jeanne: Welcome back to Actually Autistic Educator! As always, a link to the transcript for this episode is posted in the show notes and on our social media pages.

Today we're going to be talking about a term I've used before but haven't gotten into detail about - neurodiversity. The word was coined in 1998 by an autistic Australian sociologist Judy Singer and is a way of viewing the neurological differences seen in our society - rather than assuming differences are bad, it says that diversity can be a strength and is a natural part of existence.

When I started writing my notes I was planning on this episode being half about neurodiversity and the other half being how to incorporate the neurodiversity perspective into practice with students, clients, and patients, but then I realized I should include a bit about other lenses like the medical and social models, how this all interacts with the deficit model, and more, and it got a bit long, so this episode will be talking about these models and the pros and cons of each, and in part two we will be looking at concrete ways to incorporate the ideas behind neurodiversity into our work as professionals, family members, or coworkers to improve quality of life and ease of work.

First up is the medical model for viewing disability/difference. This is a very common one, especially in healthcare. The medical model says that disabilities are caused by the individual's body and therefore the solution is to change the body to stop the disability. The focus is usually on some form of treatment, either curative or to improve functioning through physical or other therapies, medication, and such. This is often the first perspective seen, as many differences may be noticed by a doctor, who understandably is likely to be working from this medical model. Sometimes the medical perspective can be very helpful if the issue causing problems for someone can be improved

through medications, surgery, or physical therapy.

However, it can't stand on its own in many situations, and in others can be directly harmful, such as when money is funneled primarily towards "treatments" or testing that are unsuccessful or even harmful rather than towards alternative needed supports, and through the viewing of differences through this pathologized and defective lens which directly encourages ableism. It is especially concerning when we look at things like autism, where we have seen numerous studies saying that trying to force autistics to behave like non-autistics causes immense psychological harm. There is also a long history of it being applied to other protected classes, such as gay conversion therapies prescribed due to seeing homosexuality as a medical issue - as a reminder, until 1973 the Diagnostic and Statistical Manual (DSM) listed homosexuality as a mental disorder, with the first edition calling it a sociopathic personality disturbance - and in the early 2000s I remember seeing certain groups arguing that with research tying fetal hormone levels to homosexuality that we should look into "preventing gayness" through in-utero testosterone. As a bisexual autistic woman with multiple disabilities, this is a real concern for me. And yes, these are not all exactly the same thing, but, throwback to our episode about the Spectrum 10k controversy and eugenics, it's important to acknowledge the very real harms that the medical model and medical establishments have done to a variety of marginalized populations through medical "treatments" that included lobotomies, horrible things involving genitals that I will not describe here but do a web search for 19th century gay conversion treatments if you want some traumatizing visuals, forced sterilizations, and more. The medical model can be a useful tool in some situations, but a hammer can bash a head instead of a nail, it's important to make sure we use these ideas appropriately to avoid causing immense harm and to not make this the

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base of how we view differences.

The social model of disability is often a counterpoint to the medical model, saying that the issue is not in the differences a person has, but in the way society responds to them - the primary issue limiting quality of life is not that a person is in a wheelchair and can't get into their workplace up a flight of stairs and needs to find treatment to not need the wheelchair, the issue is that the workplace is not wheelchair accessible. Impairments regarding differences exist, but what makes something a disability in this model is how society responds to it through barriers placed.

This model often is favored as the starting point by many disabled people because it avoids viewing them through a deficit or assuming that they should be the ones responsible for figuring out ways to change themselves to access the world, rather than society making accommodations, and the principles are central to many advocacy policies, including the United Nations Convention on the Rights of Persons with Disabilities from 2008. There are some detractors, mainly regarding critiques that some people with disabilities may still require more than just the removal of barriers to be happy and supported, with less common models such as the human rights model focusing more on the importance of various supports, which is why it is important to recognize that no one model can encompass all needs and situations, but the general principles should definitely be considered. For more information on these models of disability check out Sara Goering's "Rethinking disability: the social model of disability and chronic disease" published in *Current reviews in musculoskeletal medicine* in 2018 or check out some of the links at the end of the transcript for this episode.

These two are probably the most common models you see referenced regarding general disability advocacy and have been in somewhat common use for decades, but especially in the last ten years the neurodiversity model or perspective has been

a major way to view autism and other neurological differences and varieties.

Judy Singer first presented the idea in her thesis in 1998, and in '99 her chapter "Why Can't You be Normal for Once in Your Life?" was published in the book *Disability Discourse*, edited by Mairian Corker. In it she detailed her "anticipation of a politics of neurological diversity, or 'neurodiversity.'" The neurologically different represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability." The purpose was more regarding a social justice push initially - Singer states on her blog she intended it "as a political term to argue for the importance of including all neurotypes for a thriving human society" and "an addition to the categories of intersectionality thus an analytical lens for examining social issues such as inequity and discrimination." Check out her blog at neurodiversity2.blogspot.com, and follow her on Twitter at [@singer_judy](https://twitter.com/singer_judy) for more of her work.

The central premise is that different people have brains that function in different ways, is a normal and expected subset of biodiversity - that different species do different things, and differences should not be assumed to be lesser. While originally coined as a political term by Singer, autistics and others with neurological differences, especially ADHD, have embraced it as a larger philosophy or lens for viewing differences and disabilities, and regarding what treatments versus supports should be considered for people with neurological differences, as well as a label.

Several other terms grew from this idea. In its original definition, neurodiversity does not describe a given individual - I would not be neurodiverse because I am autistic, but my house could be described that way because we have three people all with different ways of thinking. Neurodiverse means a variety. Within this neurodiversity philosophy that difference is not bad, it's important to find labels that move away

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from the concept of “normal” as default, without a specific label, and others as illness or disorders. From here we get the term “neurodivergent” - this is someone whose brain operates in ways outside of what is considered typical, but without the negative connotations of words like “disorder” and the medical or deficit model often associated with them. Meanwhile “neurotypical” describes someone whose brain is closer to what is socially considered as typical or normal.

But, when used as a label rather than a lens or philosophy, many people have adopted “neurodiverse” specifically as a group name for people who for neurological reasons are outside of what society deems “normal,” so you’re likely to see it used in both ways, and in general I try to avoid telling people what labels they need to use for themselves. If someone says “society is neurodiverse” they are probably using the original meaning, but writings about neurodiverse students likely mean students who are neurodivergent and not neurotypical. I will admit, it’s so common, I sometimes say neurodiverse when I mean neurodivergent because I’ve seen it used that way so much.

While autism was the first difference associated due to Springer’s connection with it, numerous other folks ranging from ADHD to bi-polar to BPD who also really resonate with this term, and many advocates online have found it a far more welcoming mindset. Framing these as differences without automatic judgement can be huge, and thinking of neurodivergent vs neurotypical allows us to acknowledge ways that neurological differences may impact someone without framing it all as a deficit or something bad.

There is a lot of shame that gets internalized with these conditions, with people never knowing if disclosing will mean a teacher or friend will suddenly judge or punish you for it, and while having to struggle if not given accommodations, or even struggling with accommodations. I am frequently up-front with my own diagnoses in my work because it makes my

neurodivergent students more comfortable sharing their own, and reminds everyone to rethink their prejudices about what autism must look like, but it honestly breaks my heart everytime a student nervously shares that they have ADHD but promise they are trying, or that they have bi-polar or BPD and worried I won’t want to work with them anymore. They have faced very real discrimination and harm from people who have taught them that their differences are bad and they should feel shame, but by talking about neurodiversity and being neurodivergent versus neurotypical, it’s is a way to address differences without shaming their needs, preferences, or best coping mechanisms, which are often very different from neurotypicals.

I had a student this week whom I adore talk about how she was frustrated that she couldn’t manage more what she considered “neurotypical” days in a week without burning out, but I made the connection to lefthandedness. She’s left handed, and we talked about how in English the writing of left to right makes it easier for right handed people and harder for lefties, and how there’s only a few lefty desks in a given classroom, and other issues that directly benefit right-handed people, and pointed out that it’s not fair to punish herself for not being able to pretend to be neurotypical any more than it would be to punish herself for her left handedness, and that we need to acknowledge the changes to techniques or challenges, but without saying that she’s failing at being right-handed. Once we break away from the idea that being “normal” is a moral good and the goal and different is a failing, which on top of being cruel is also straight up not effective, we can embrace neurodiversity and a student’s neurodivergence and find the best ways for that individual to work with their brain to achieve their goals, instead of trying to force everyone to try to think and act the same. It’s so much more effective, and so many students suddenly thrive when given space to find their own best practices.

Neurodiversity is not saying that our differences

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are all positive inherently and aren't disabilities - things like food issues, dyspraxia, sensory overload definitely are serious problems for many people - what it's saying is that we need to look at the specific differences an individual has without assuming that all differences are bad, and center the person's wants rather than making assumptions about their goals. I've seen non-autistics argue that this lens denies the reality of autism, which is frustrating because it shows they really aren't listening to what we are saying. I spoke about this at length in the mini episode about the deficit mode and don't want to repeat myself, but the goal isn't to deny that we need supports or have struggles, the goal is to give people agency and to let them view themselves outside of this negative perspective. **Their autism isn't going to change depending on how you talk about it, but their sense of self-worth can, and finding ways to work with their neurology instead of against it is so much better!**

Just because stimming is associated with autism doesn't mean that it should be stopped! It's essential for regulation and can be so wonderful! But maybe an individual autistic would want physical or occupational therapy to help them improve motor control for certain tasks if their coordination was a source of frustration for them. Some autistics find their sleep issues go away when they are able to work later shifts and reduce social stimulation before bed, others need sleep aids or other help or else have severe issues. Likewise, I know many ADHDers who are very happy to take medication even though they subscribe to the neurodiversity paradigm - for some regulating dopamine seriously improves their quality of life, while others have tried meds and found modifying the environment without meds worked much better instead. **The diversity element is key - what works for one person might not work for another, so it's on us to support a wide array of goals and supports, and to figure out what their priorities are, rather than pushing ours on them.**

Growing out of this neurodiversity movement, I

recently read a great piece on a new perspective of the ecological model, which ties back to Singer's connection to biodiversity, by autistic researcher Robert Chapman, "Neurodiversity and the Social Ecology of Mental Functions" published in Perspectives on Psychological Science in 2021. I'll be going more into his work in part two as it has a lot of ways of thinking of neurodiversity that can help us visualize how to put it into practice, but it's really great seeing how many researchers are really examining the ways we think about differences.

As I said at the beginning, it's important to note that different ways of thinking about difference and disability will apply to various situations, it's not that only one is good or bad when looking at the medical model and social model especially. I have rather severe joint issues that often mean I require both societal accommodations and medical support. Medication, surgeries, and physical therapy have all been essential to my quality of life to reduce my chronic pain issues and allow me to engage in things that I enjoy doing. But I also rely on things like alternative work set-ups, a parking pass for closer to my office, friends who adjust their plans so I can participate, and in the US, protections from the Americans with Disabilities Act, though they are not so strong as many people believe. When I was 20 and had my first surgery I was horrified at the idea of having my walking and weightlifting limited, but after 14 years I really don't even think of my spine issues as something bad - I have great accommodations so I can still do all the things that are important to me, but I also appreciate the meds that let me get through bad pain flares, and I really don't think of it as a big deal at all, so it's important to remember that just because something might seem like it would be a problem for us, doesn't mean everyone else would feel the same way. Especially when many treatments can cause pain, both physical and psychological. I'm still regretting trying a treatment this summer that set off an issue and left me unable to walk normally for 3 months, I'm still getting my mobility back to my normal reduced levels. My students even who have

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a single diagnosis often have wildly different goals - the working in long bursts of creativity then needing to rest can be a boon to one student while a source of frustration to another and something they want to work on; neurodiversity to me means both are valid.

So, with the change to this topic being two episodes instead of one, I'm saving the full interview I had scheduled for next time but I'm going to share a short clip from frequent guest Morgan, something that was just a bit off topic for that episode and I ended up cutting for time but that really highlights the issue of perspective. We had been speaking about the assumptions often made that as a teacher or other professional we think of our perspective as clearly the correct one - the dialect or accent that we are used to is correct and others are wrong, what we think of as professional or social standards are absolute and not cultural, but this often breaks down when you actually listen to people who are different from you.

Morgan: One of the things that occurred to me while you were talking about we've the ways in which society has misshapen the enculturation and teaching for children in these ways, but the way that we've sort of adapted things wrong for them and, and made it about fitting the square peg into the round hole, instead of just getting the proper sized compartments with them in, and I think the thing that most occurs to me is just how, how much further it can veer from my own experience to, um, a story just occurred to me, which you may end up cutting this, but maybe not. There was a young man that I worked with at one of the facilities that I worked at and he had. Um, he had a lot of communication difficulties. He's struggled with being able to get out of repetitive behaviors to achieve goals. And, and so we work with him a lot on that sort of thing. One of the most difficult lessons that he had on a regular basis with speech therapy. And at one point he came back from a speech therapy appointment early, and it was after behavioral outburst. There's had been like the seventh behavioral outbursts at speech pathology.

And. After the third or fourth or fifth time, I don't remember which one. The mom finally asked her that the session will be recorded to try to figure out what's going wrong. Like maybe, maybe there's something that is in the environment. There's like a light or flat fluorescence. And they ended up realizing that the problem was is this young man who was from Cuba was getting upset because the speech pathologist was pronouncing it Cuba, which is the Americanized bastardized version. And he was forced. Him to say it that way. Despite the fact that he knew full well that his home was called Cuba.

Jeanne: So, technically this is really more about colonialism in some ways, but I think it's a good example of this principle - just because something in your perspective is wrong, like saying Cuba (coo-ba) instead of Cuba (que-ba), well, your perspective might not be as universal as you think. A student or client's goals, needs, and sources of comfort might be wildly different from our own, and assuming that we know best and they need to conform to our assumptions and to a specific idea of "normal" is so very harmful.

Before we wrap up I know I've touched on another model in a previous episode, the deficit model, but I want to loop back to it here. This is the practice of automatically assuming differences are bad and the focus is on the individual to change to improve. While there are similarities to the medical model, the deficit model is not something that most people will admit to using. Indeed, in my education degree we had frequent reminders to avoid the deficit model and looking at students from a perspective of what are they lacking versus focusing on their strengths, and the huge improvements it could make to student wellbeing and achievement if we used strengths based instead, but in practice, especially about autism, the deficit model is rampant in both research and education.

Do a study and find that autistics are more likely to make the moral choice even at their own expense compared to non autistics? Can't say that this is good,

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clearly, so instead the study “Right Temporoparietal Junction Underlies Avoidance of Moral Transgression in Autism Spectrum Disorder” from 2021 finds “a reduced rTPJ representation similarity in ASD, unique to the moral context, explains that ASD individuals prioritize the negative consequences of an immoral action. This may block further recruitment of the intent-based system and thus lead to a lack of consideration for social reputation when making choices... This difference in moral cognition and behaviors in ASD individuals is specifically associated with rTPJ and consists of a reduced capability to represent information concerning moral contexts.” Literally the study found that autistics would not accept money for themselves if it meant hurting other people regardless of if they were being observed or not, while the non-autistics were more likely to only make the moral choice if others were watching. And yet the autistics are considered the disordered ones for this. God forbid we do things for the good of others even when no one is watching and how dreadful that we are less likely to fall to peer pressure. I’m a little bitter. I saw another study that said it was a failure in reasoning abilities that autistics on average prefer the philosophies of Kant to moral relativism, which...one of my majors was philosophy and this made me so mad I almost screamed, seriously, like half a season of watching *The Good Place* should have taught this person why that was wrong. For non-philosophy folks Kant says dreadful things like manipulating other people for your own ends is bad, and in general is a respected moral philosopher, so this argument is incredibly wrong. But this is so common in research - anything that is found to be a difference, even when it frankly is clearly a good thing, is immediately framed as a deficit. For more details see “The Deficit View and Its Critics” in *The Disability Studies Quarterly* from 2016.

The problem is, when anything different is automatically treated as wrong we can justify anything in the pursuit of “fixing” them, with often no regard for how it will actually impact the person, who usually is not given the option to consent. If autism

is bad, then anything associated with autism is also bad, be it stimming, having focused interest, thinking in paragraphs, liking Kant, and all manners of harm can be justified to make us seem more “normal.”

Most people assume that their experiences are the norm and subconsciously or consciously think anyone else is weird or wrong, I get it and fall into this myself sometimes, but we need to be breaking down our various perspectives and biases and looking critically at them, especially around areas of marginalization and privilege. Being willing to truly focus on someone else’s perspectives, goals, workstyle, and needs can lead to such a better understanding. Now that you’re on-board hopefully with this idea of acceptance and neurodiversity, I’m looking forward to part two, where we look at specific ways to bring this into your practice as a teacher, therapist, medical professional, family member, or even in the workplace.

Speaking of future episodes, I’m mostly coming up with ideas based on what questions folks have asked me in the past, things that seem to be sources of confusion, or something topical. I have some ideas for future episodes, autism and common medical co-conditions like EDS, how autism overlaps with gender and sexuality, but I’d love to answer your questions and know what you’d like to hear more about! If there is anything about autism, or me, that you are curious about please comment on a post or message me on Twitter or Facebook, or through my podcast platform Anchor. Also, if you are autistic and would like to share your perspective on an upcoming topic please reach out, I’m always looking for more perspectives! Especially if you have ideas about incorporating neurodiversity into practice! Honestly, I see my play count going up steadily but sometimes I feel a bit like I’m just screaming into the void, so really, any engagement is seriously appreciated.

Thank you as always for listening, have a great December, and I’ll see you January 1st of 2022!

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