

Actually Autistic Educator

Episode 2.5: The Problems with Functioning Labels TRANSCRIPT

Hello again, welcome back to Actually Autistic Educator. Quick reminder that transcripts are available for this and other episodes on our social media pages or as a link in the show notes.

So, a lot is going on in the disability world right now between the hashtags Free Britney, regarding the horrific abuses of the US conservatorship system, where once you get a certain label it can become almost impossible to regain your personal rights, and Stop the Shock, as the Judge Rotenberg Center in my home state of Massachusetts has been allowed to continue the now almost entirely banned practice of using electric shocks as a punishment for dreadful activities such as not taking off your jacket, moaning in pain, and other normal human behaviors that we all engage in, though most of us without being tortured. I've spent several days trying to write up notes on all of this as a cohesive mini-episode but with several negative court rulings it's been incredibly disheartening, though at least more recently we did get a positive ruling. Brittany Spears will be allowed to choose her own attorney - again, not something that really should need to be a victory but this is where we are, but with all of this nothing I was writing was different than what so many other disabled people have said on the topic, but it just really hammered home how certain labels are used to dehumanize us and the very real consequences these labels can have on our lives, so today we are going to talk about functioning labels, the practice of splitting autistics into "low" or "high" functioning, and some of the serious harms that this causes and why autistics are increasingly asking that these terms not be used.

First though, homework assignment for abled people listening - if you are not already solidly educated on the horrors of both conservatorship abuse and punitive electric shocks on the disabled, please check out some of the links posted to Actually Autistic Educator on Twitter or Facebook, or look at some of the many writings which listen to the perspectives of the disability community on these topics, and I'd like you to think about how the systemic ableism that makes

these horrors the law of the land might be influencing your field and community, and your own ways of thinking. Functioning labels are firmly established in the mental health and education fields, but just because something is the norm doesn't mean it's good.

A brief history - (content warning here for Nazis and eugenics, skip forward 90 seconds to avoid) - one of the earliest clinical divisions by function in autism was by Hans Asperger, where we get the term Asperger's. You'll note that I don't use this term on this podcast, because he was a Nazi. He looked at autistic children and split them between autistic, who were seen as too low functioning to be useful in society and were therefore sent to the Am Spiegelgrund clinic for child euthanasia as part of the Nazi eugenics program. As a reminder, this is the history of autism, and a big part of why so many of us speak out against a "cure" for autism, because most of the time the cure being worked on is genetic testing to identify us in-utero and remove us from the gene pool. Eugenics of the disabled is never a cure, it's genocide. Hans Asperger identified other children as being higher functioning, able to contribute more to society, and therefore not needing to be murdered. This was the split, those seen as low functioning lacked value and could be killed, higher functioning were productive enough to be allowed to live. And the sad thing is this is not too far from the current way we use these terms - your worth as a person is primarily decided based on how much it is assumed you can contribute to society versus how much support you may need, and your rights will vary accordingly. For more information on Hans Asperger and his ties to Nazi eugenics check out Molecular Autism from 2018, both the article by Herwig Czech and the editorial by Simon Baron-Cohen et al.

And a note, while I don't use the term Asperger's because of these issues, I'm also not going to police someone using it for themselves. These labels are often very personal, but it's definitely not a term you should use for someone else, regardless of your

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own diagnosis, and especially if you are not autistic yourself.

The DSM V, the main manual in the US used to classify mental health differences, a few years ago removed Asperger's as a separate diagnosis and moved everything under Autism Spectrum Disorder, or ASD for short, recognizing that autism is a spectrum and the hard split of autistic vs Asperger's did a disservice to many autistics. But many people still misunderstand what this concept of autism spectrum means and still treat it as a single dial, someone is either severely or mildly autistic.

But that's not at all what it means and thinking of it in that way is incredibly harmful. Autism encompasses a wide array of traits, and any autistic will have a mix of them all at different individual levels. Some examples might be differences or struggles with language use where we may either use language in unexpected ways or not be able to speak verbally at all. Sensory issues where our bodies process light, sound, smell, touch, and taste differently, so high or low sensory places may cause pain or we may require sensory regulation in some way. Motor skills, where someone may struggle to get their body to move and do the things they want it to. Plus there is executive dysfunction, comprehension speed and response time, and others. The trouble is when we try to break people into a single dial of more or less autistic, it can't encompass such a wide array of options, and we end up making a lot of assumptions that cause serious harm.

There are many autistics who are non-speakers, they cannot communicate verbally with most people. Now in the classic model of high and low functioning these people would automatically be written off as low functioning, which in practice means they would likely be forced into a conservatorship where they are not allowed to make choices for themselves, people would assume they can't comprehend what is being said to them so treat them as if they're not there, and in general they get infantilized and

not allowed to make decisions for themselves that we all take for granted. But verbal speech does not equal comprehension or capability. I follow a lot of autistics on Twitter, including quite a few non-speakers, one of who is currently working on his Ph.D but communicates using AAC – augmentative and alternative communication device, where you use different methods to type and the device reads it out. But many parents of adult children who are non-speakers report being told that if a child can't speak verbally then the parent must file for conservatorship, which can leave them with fewer rights than prisoners. For more information on this check out Communication First on FB and Twitter, an advocacy group run by and supporting non-speakers. Meanwhile disabled parents have been threatened with or straight up lost custody of their children for things such as being deaf or blind, or being a wheelchair user, because we as a society have said that once someone has the label disabled it must mean that they are incapable of making decisions for themselves. Some people may require specific support needs or accommodations, but that does not mean they are incapable of self-determination. Just because an autistic is non-verbal doesn't mean you can make any assumptions about their ability to comprehend a concept or have opinions or preferences.

Likewise body control can be a struggle for many of us. I have a hard time telling when I need to eat or drink, my brain thinks I'm about 3 inches left or right of where I actually am in space so I walk into things all the time, and I can't play most video games that require fast response because I struggle to move and orient myself in space. For me, fortunately, it just means I get a lot of bruises and stick to playing logic games instead of fighting ones, but some autistics require substantial help for daily activities because our bodies just don't always do what we want them to do, and this can mean needing help with feeding and other bodily functions. This is another time when the phrase "low functioning" traditionally would be applied, but just because a person's body doesn't

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respond the way they want it to doesn't say anything about their abilities to think, or their need to be allowed to make their own decisions.

And even if someone has limitations on comprehension that doesn't mean that they therefore shouldn't be able to decide anything for themselves and that we should keep them in a forced childhood of dependency and lack of control. Everyone has their own goals and sources of joy, and no matter what their limitations or capabilities none of us should be forced to lose all autonomy just because of a label applied to us by others, especially when so often it relies on ableist assumptions of incompetence caused by prejudice.

On the other side, the term high functioning also can cause its own damage. The assumption often becomes that those who can pass for non-autistics in some situations, or who can get a job or do well in school or otherwise seem to be "of value," therefore don't require additional supports or accommodations, even when we may still be seriously struggling. Remember Gigi from my first episode, who was and is massively successful in education but her masking caused frequent burn-outs and crashes that ended in hospitalization intermittently. I have had a ton fewer migraines and melt-downs since I learned that I needed to cater to my brain and let myself set firm boundaries, like wearing sunglasses or ear plugs indoors if needed or saying no to socializing with someone, but my quality of life would have been dramatically improved if I had been encouraged in this from a younger age. For many of us the result of a label of high functioning means people just write us off as quirky or weird, without understanding our sensory needs and communication struggles we have that may still require other support and understanding. Most therapists, teachers, and other professionals just do not have a comprehensive understanding of autism and the wide variety of needs autistics may have, this is not a critique of them as individuals, but rather of the systems that are in place regarding how we train professionals, and the systemic issues we

have spoken about in past episodes about historical issues in research of autism. For those professionals listening to this podcast, thank you for being open to improving your understanding.

These labels also divide the community in really harmful ways. I think I may have spoken about this before, but I had a lot of my own internalized ableism I had to unpack when the DSM V came out because at first I really didn't want to be classified as autistic. The Asperger's label made people think I was someone who might be weird but still should be treated as an adult and competent, whereas I had seen how everyone treated my autistic brother, acting as if he couldn't understand anything, not giving him any rights to make his own decisions. I was working in education at the time, I knew how people thought of disabled people and the assumptions that were made about their abilities. The idea that I could end up being treated like that was terrifying, so I pushed back against the label. It took a lot of breaking this down and recognizing where this fear and anger was coming from before I finally understood it all, that I was scared of what it would mean if I got labeled as autistic and suddenly found myself losing my rights. And this isn't an exaggeration, in grad school a fellow student felt totally fine telling the whole class that all autistics should all be locked up in institutions because we were "crazy" and normal people shouldn't have to be exposed to us, even after two of us in the class had self-identified as autistic.

I often see parents of autistics making statements about how those of us who are advocates online shouldn't be grouped in with their "low functioning" child because we don't understand what it's like, but as I said in the last mini-episode - I as an autistic can definitely understand another autistic and their struggles around sensory issues, body control, or ability to verbalize because I have them too, even if not to the same degree, better than someone who has only ever seen these traits from the outside. We are all autistic, and we are stronger together, and no one outside should be trying to arbitrarily split

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us up and place us in a hierarchy based on a single element like verbal communication or body control. It's just not accurate.

I'm also disabled in other ways, I have an autoimmune condition that causes joint problems, so I have a lot of physical limitations and use wheelchairs or canes intermittently, and the assumptions that get made about me are really horrific. When using a chair, the baseline assumption of the majority of people I interact with is that I am incompetent. I've had people stop and grab my chair and start pushing me randomly and asking where my aid is, speaking extra slowly and loud. I had a guard at one museum grab my purse and tie my scarf as I tried to push her away because she decided I looked cold. Britney Spears has something like a 60-million-dollar estate and a major career, but can't even pick her own therapist. (Content warning for descriptions of torture of autistic minors, skip 45 seconds to avoid.) A video was released in 2012 from the Judge Rotenberg Center of an autistic minor who was tied face-down to a four-point board and shocked 31 times at the highest amperage setting, first for failing to take off his coat when asked, then the remaining shocks for screaming and tensing up while being shocked. He was hospitalized with third degree burns and acute stress disorder, but nothing was done against any of the staff as this is perfectly legal and broke no policy, and the center has managed to evade all attempts so far to have the practice made illegal on the ground that they work with "low functioning" or "severe autism" cases. All it takes is for a certain label to be applied and suddenly torture is permitted, all rights can be removed, and regaining them can be nearly impossible, especially if family members are against it.

I understand the usefulness of quick descriptors in clinical settings - my fiancée is a licensed mental health counselor and like with education, the field is seriously underfunded and clinicians are often asked to make rapid decisions about care with very little time. But these labels of high and low functioning cause

very real problems due to their inherent inaccuracy. This is not just about asking for a less offensive sounding, more politically correct label, these labels straight up do not work as intended because they are too broad to be accurate. "Capabilities and limitations" as a descriptor can briefly explain support needs without encouraging the assumption that because someone is non-verbal or needs assistance with bodily functions that they are incapable of self-determination or comprehension. A student may be able to be in a mainstream classroom with different accommodations even if they have traits that would traditionally get them labeled low-functioning, and a student who was labeled high functioning might really benefit from accommodations around sensory seeking or overloading to avoid burn-out, even if much of the time they seem like they are able to do classwork. And as a reminder, students of color are disproportionately less likely to receive correct supports in education, as well as to be subject to more punitive systems, and parents of color face higher rates of loss of parental rights than white parents, meaning disabled people of color are disproportionately more impacted by these issues. According to the National Center for Education Statistics, in the 2015–2016 school year, people of color or racial minorities made up 87.4% of the minors in the Judge Rotenberg Center.

The best thing professionals can do is to continue to educate themselves on the wide variety of autistic experiences out there and learn from the autistic community about how we like to describe ourselves and what supports we have found most useful, and what we have found harmful. And for those of us who are autistic, it's scary, but we can try to let ourselves be autistic, without feeling that we have to hold ourselves to neurotypical standards. My body doesn't like bright lights or loud noises, so now I carry sunglasses and earplugs, and if anyone doesn't like it that's their problem. I can have accommodations and still be capable of deciding things for myself and doing amazing things, regardless of how the world tries to scare me into thinking it's one or the other.

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If you are interested in ways to support the autistic and disabled community, please look at what your state and national bills are being proposed to improve our rights regarding conservatorship and write your representatives in support. In the post for this episode on Facebook and Twitter, I am including a link to a google doc with a list of action items to support the movement #StopTheShock to stop the shocking of disabled people as punishment.

Our next full interview-based episode, focusing on masking and looking at how new studies are showing the serious damage it and socialization training can cause to autistic mental health, will drop August 1st. If you have thoughts about this episode or other questions about autism, please connect with me on Twitter or Facebook at Actually Autistic Educator, and as always please share, like, and subscribe to help us grow.

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 enforcement, CARE and threat teams, and diversity/equity and inclusion. Check us out at InterACTT.org

Studies referenced:

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“For the Disability Community, Britney Spears’ Situation Is All Too Familiar” Mary Harris, June 29, 2021 <https://slate.com/human-interest/2021/06/britney-spears-conservatorship-guardianship-disability.html>

Stop the Shock Action Items https://docs.google.com/document/d/13wOLYBZq7iq13M_KTFqJEwSkvf7ccdY1vvx0ei3lak/edit

Understanding The Spectrum – A Comic Strip Explanation <https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/>

Communication First <https://communicationfirst.org/>

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