

Actually Autistic Educator

Episode 2.5: The Problems with Functioning Labels, July 2021

Overview

In this mini-episode, Jeanne (she/her) talks about how splitting autistics between “low” and “high” functioning does immense harm, and how these and other labels are used to justify abuse, as seen in both the Free Britney and Stop the Shock movements in response to current cases in disability rights in the US. Additionally, these functioning labels over-simplify an autistic person’s capabilities and limitations, leading to assumptions about support needs that lead to some autistics losing all personal rights due to only minor communication struggles or lack of body control, while leaving other autistics struggling with limited or no accommodations because of assumptions around their “functioning” level.

Key Points:

- The division of autistics by function has a concerning history, including Hans Asperger being a Nazi collaborator who sent “low functioning” autistics to be euthanized. The concept is centered around how “productive/functional” a person seems, where those seen as “low functioning” face loss of all rights and control over their life. This is an inherently flawed understanding of autism and is frequently used to justify abuse.
- The autism spectrum is not a single dial that moves from more or less autistic - rather it encompasses an array of traits and any individual will have a mix of different levels, including verbal communication, body control, sensory issues, processing speed, and more. These all have different limitations and may require different supports, and using “high” or “low” often means missing that a person who can’t speak verbally may still be able to hear and think, and also that someone who can “look normal” may still face serious mental health struggles that could be mitigated by a more sensory-friendly environment.
- Time: 20:43

Quotes:

“This was the split, 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.”

“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.”

“Everyone has their own goals and sources of joy, and no matter what our 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.”

“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.”

“When using a wheelchair, the baseline assumption of the majority of people I interact with is that I am

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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."

"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."

"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."

"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."

"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."

"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."

Studies referenced:

Baron-Cohen, S., Klin, A., Silberman, S. et al. Did Hans Asperger actively assist the Nazi euthanasia program?. *Molecular Autism* 9, 28 (2018). <https://doi.org/10.1186/s13229-018-0209-5>

Neumeier S.M., Brown L.X.Z. (2020) Torture in the Name of Treatment: The Mission to Stop the Shocks in the Age of Deinstitutionalization. In: Kapp S. (eds) *Autistic Community and the Neurodiversity Movement*. Palgrave Macmillan, Singapore. https://doi.org/10.1007/978-981-13-8437-0_14

"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_KTFqJEwSkvf7ccdY1vxx0ei3lak/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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