

Episode 4.5: Labels and Language of Autism: Person-First vs Identity-First

Hello all, Welcome to another mini episode of Actually Autistic Educator. Today we're going to talk about something that comes up a lot in discussion about autism and language, mostly by non-autistics ironically, what are the commonly used terms for the autistic community and how does it intersect with the larger disability/neurodiversity/mental health communities and their preferences. Also, since our last episode was about eugenics and horribly depressing things and autistics listening deserve some extra positive representation, I'm including a bonus to last month's mini episode of cool famous autistics and we will be wrapping up by learning a bit about the incredibly awesome autistic woman writing the new Harley Quinn and Poison Ivy comic series!

First, regarding labels the most important thing to note is that I am talking about general themes seen within communities, but nothing I say should ever be used to tell someone else how they get to self-identify, especially if you are not a member of a given community. Constantly on social media there are non-autistics who jump in to "correct" autistics and disabled folks about why they shouldn't define themselves a certain way, do not do this. Language changes over time, people have a wide array of preferences and backgrounds, and so if a given person has stated they prefer to use a certain label for themselves it is not your place to correct them.

I'm going to be sharing a study about how certain euphemisms impact perception, and talking about some of the more common preferences seen by the autistic community online. This was recorded in September 2021, I have no doubt things will change in the future, so when in doubt look to current communities and see what they are saying now.

The biggest language or label question with autism

is regarding a concept called person-first language versus identity-first language. The idea is that some labels may seem negative, and people may not want to define themselves by a specific medical or neurological condition. For many people with certain diagnoses this feels better for them - for example rather than a depressed person, most folks prefer person with depression, as it centers the person, with depression as a modifier separate from the self. However, many people see specific diagnoses as inherent to who they are as a person and not inherently negative - for myself there is no version of me that is not autistic, it is not something that can be separated from my self identity. It encapsulates who I am and how I interact with the world and is an essential part of me, and there is nothing wrong or bad about being autistic. In my experience it makes you more likely to know cool stuff and be chill to hang out with. This is not how everyone autistic identifies, but in my experience the vast majority of autistics prefer identity first, I am autistic or an autistic person, I am not a person with autism. That is why this is the language that I predominantly use for this podcast.

But, I am a teacher first and foremost, and believe in teaching skepticism and critical thinking to everyone, so always check the citations! Two of the best known autistic-led organizations centered on autism, the Autistic Self Advocacy Network and the Autistic Women and Nonbinary Network both have articles on their websites explaining the preference for identity first language that I link in the transcript, also the 2021 article in the journal Autism in Adulthood, Avoiding Ableist Language: Suggestions for Autism Researchers uses identity first language of "autistics," and hashtags like #ActuallyAutistic in social media likewise show the preference by many of us to center our autistic identity as an inherent part of ourselves that we do not want to

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be distanced from linguistically. If you are autistic you are probably rather confused at why this is even something I am bringing up, I mean it's literally in the title of my podcast that I identify as autistic, and is the predominant language used by autistics online, but sadly if you're not autistic and work in education or counseling this probably sounds very different to what you have been explicitly told in trainings.

Now, we are all individuals, not a monolith, so there are some folks who may identify as a person with autism, and that's ok too. Labels are deeply personal, you get to define yourself in whatever way feels right for you. However, many well-meaning non-autistics have decided that because some communities prefer person-first that therefore it should be used for all communities, and therefore explicitly teach that the default should be "person with autism" and will even step in to tell autistics we are limiting ourselves and other frankly ableist trash statements that all rely on the premise that autistic is something that is bad to be. Autistic writers have reported their articles have been edited to change their language for themselves to meet "industry best practices" to change them from being an autistic person to a person with autism, without recognizing that their preference should take precedence.

I have also seen this extensively reported in professional development trainings for teachers where person-first is explicitly taught as the preference for autistics, despite the fact that none of the people running the training are autistic themselves. The idea still focuses on the concept that autism is bad, that being defined that way is somehow bad too. Autism is not a bad word, and treating it as such will not improve the daily systemic ableism we face in the world. Actually listening to us, rather than speaking over us on the other hand, really could.

I will make a note here that because different subgroups within the larger disability community have expressed different preferences here I do personally vary my language regarding larger disability issues

between the identity-first disabled people and person-first people with disabilities to recognize that depending on the disabilities in question there are different preferences, and it is not my place to speak for people with disabilities other than my own. I call myself disabled because again, it's not a bad word, and if people are going to be ableist then dressing it up with other words is not going to stop them from judging me for my differences, but that's on them, not me, but that's my choice, I don't get to make it for others.

Related to this, there have also been debates regarding euphemisms such as "special needs" or "differently abled" rather than saying "disabled." This again is a personal thing, so if a given individual states a preference for themselves then use that, but when looking at broader communities we do need to look at general preferences rather than your own assumptions, and to also consider what the effects of language choice are. A study from 2016 titled "'Special needs' is an ineffective euphemism" unsurprisingly given the title, found that when people were given a brief description of a person that including labels of special needs, disabled, person with x disability, and such were then asked to share their perception of the person, the label special needs was associated with more negative views of individuals that the word disability was, and in word associate exercises it likewise was connected more to negative perceptions. When we use euphemisms it implies there is something bad or shameful about the subject. Disabled is not a bad word, and in the long run it would be better to address the severe ableism in society that makes people think it is, rather than to come up with euphemisms about it. Again though, this is deeply personal, and we have all faced serious trauma from a society that clearly doesn't care about actually supporting us. If the word doesn't feel right as a label for you, you get to pick what does.

Ableism is deeply ingrained into our culture, and there are many changes that happen in language as we examine different labels used and consider the

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impacts they have. Many phrases that were common clinical descriptors in the past have been phased out entirely with good reason, but it's always important to check in and see what people within a given community feel about language, and to update it as preferences change. As always, look to people with lived experience, and don't assume that what you saw in a training by a person outside that community should take precedence. Because seriously, I've had like 3 people tell me not to call myself disabled or to center myself apart from my autism on social media since I started this podcast and buddy, literally all the coolest people I know are disabled and/or neurodivergent. We are amazing and badass, and it's not in spite of our disabilities or autism, it's all just a part of who we are.

And to finish, we're highlighting one of these amazing people, the writer of the new DC Comics run Harley Quinn, the Eat, Bang, Kill tour, Miss Tee Franklin, who self identifies as Black queer disabled autistic wheelchair user. Tee Franklin is the founder of the #BlackComicsMonth initiative, which celebrates black creators as well as comics featuring black protagonists, and works with publishers to give away books that showcase black excellence in comics. She is perhaps best known for her comic *Bingo Love*, the story of a same-sex romance that spans over 60 years, which was listed on Amazon Book Review's Best Comics & Graphic Novels of 2018

NPR's Best Books of 2018 Newsweek's Best Comic Books of 2018, and is highly recommended. She is delightful to follow on Twitter, posting about comics, ableism, and more. You can follow her @ MizTeeFranklin, check out her personal site at <http://teefranklin.com/> and you can find her work at your local comic book shop or through internet searches. Disclaimer here, I'm not getting paid or anything, I am just incredibly excited about this. I personally am a huge geek and was interested in this run already just for the happy bisexual representation, but when I saw her on Twitter I was just ecstatic to find out she was autistic. I found out like 2 days after posting our

last mini-episode of famous autistics and so definitely wanted to add her to the list now.

We can be and do so many amazing things. Autism and disability aren't labels that limit me, they let me be open about parts of myself that others often aren't comfortable with, but are essential to who I am. I'm a red-head, bisexual, huge nerd, a woman, and I'm disabled and autistic. We all get to pick the labels that work for us, because as my cats will attest, there is a huge difference between someone putting you in a box versus a box you pick yourself. Whatever your box, may it be a comfy one.

Thank you for listening as always, our next episode drops October 1st finally actually wrapping up our three part series on autistic communication looking at autistic empathy from our perspective. As always, I'd love to connect on social media, find me on Facebook and Twitter at Actually Autistic Educator.

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.

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