History, Terminology, and Sensitive Topics for Neurodivergent Inclusion and Accessibility

# History of the Neurodivergent Self-Advocacy Movement

* The Neurodiversity Movement is a branch within the disability rights movement, that focuses on understanding and accepting brain-based disabilities. Instead of focus on ‘curing’ or ‘fixing’ the person’s brain function, the movement promotes support systems, such as inclusion and accommodation, communication and other assistive technologies, and independent living support.
* The self-advocacy movement was initially led by institutionalized people and people with intellectual disabilities and multiple disabilities.
* 1960s: The movement grew out of the Swedish system of encouraging clubs and gatherings of people with intellectual disabilities. National conferences of these clubs were held in 1968 and 1970, where participants produced statements on how they wished to be treated.
* 1972: The national conference idea spread to the UK and Canada.
* 1973: Attendees at the Canada conference (from Oregon) felt that the conference was dominated by professionals and not people with disabilities. They formed their own self-advocacy group, People First. Self-advocacy groups began to form nationwide.
* 1991: Self-Advocates Becoming Empowered forms and holds a national conference in 1993. At this time, there are 27 state-wide self-advocacy organizations.
* 2006: Autistic Self-Advocacy Network is founded in response to the national conversation about autism being oriented to professionals and parents of autistic children.
* 2010-current: Proliferation of books, websites, groups, and other resources for neurodivergent people and their allies. (Such as the book, *NeuroTribes*.)
* 2000s overall: Increasing engagement in intersectional social justice, and the increased visibility of Nonspeaking, LGBTQ Neurodivergent, and Black, Indigenous, and People of Color (BIPOC) Neurodivergent self-advocates. Self-advocacy groups have increasingly challenged the primacy and merit of organizations that support medical model cure/fix paradigms.
* Current: Language and terminology continue to evolve; visibility of more marginalized neurodivergent people continues to expand, especially with the increased access to assistive communication technologies.

# Definitions

* **Neurodivergent person**: a person with a brain-based disability (OCD, anxiety, depression, PTSD/cPTSD, autism, learning disabilities, intellectual disability, schizophrenia, migraine disease, traumatic brain injury, etc.).
* **Neurodiverse people**: a group of people that includes multiple neurotypes, such as both those with and those without brain-based disabilities, or with multiple different neurotypes represented.
* **Neurodiversity Movement**: The Neurodiversity Movement focuses on improving life experiences, access, and meeting needs for neurodivergent people with all levels of support needs, regardless of whether their needs are visible to the external world.
* **Co-occurring (‘comorbid’) conditions**: Physical and brain-based disabilities that occur alongside a specified brain-based disability. For example, developmental speech disabilities and developmental movement disabilities often occur in autistic people. Autism is not defined by being non-speaking or having a movement disorder, those conditions can also occur in people who are not autistic.
* **Functioning labels**: Labels that classify autistic people into categories based on how closely they match neurotypical norms (‘high-functioning’ autism, for example). These labels are commonly confused with support need levels, having or not having speaking or movement disorders, or with intellectual disability. Many autistic communities consider functioning labels ableist.
* **Nonspeaking person**: a person who communicates through methods other than spoken language. Some people are nonspeaking conditionally or partially. Communication differences can occur in people of any intellectual ability, and is not an indication of degree of desire to communicate. The term “nonverbal” is considered pejorative.
* **Self-advocate**: a person who is advocating for needs, access, and inclusion that are relevant to their own and others’ neurodivergence and/or disability. Self-advocates are activists on issues that affect people with disabilities. The term applies to anyone who defends or advocates for themselves or others.
* **Identity-first language**: Placing the identity or disability first in the grammatical construction describing a person. For example, “I am autistic” (versus ‘I have autism’), or “Sharon has an autistic teacher” (vs. ‘Sharon has a teacher who has autism’). Identity-first language preference varies by disability, community, and individual. Typically, autistic communities prefer identity-first language, but individuals may differ in preference. It is always fine to ask.
* **Person-first language**: Placing the person before the identity or disability grammatically, such as person with autism, person with OCD, person with depression. Whether person-first language is preferred for any specific neurotype or disability is individual.

# Sensitive Topics

Note that there are topics and common interactions that may cause unexpected reactions due to the experience history of people in neurodivergent communities.

* **Forced Intimacy**: Disclosure of diagnoses in order to be granted accessibility and inclusion is a form of forced intimacy. This is the ‘prove you need the accommodation’ response to a request, or prove that the need is enough to take on the effort required. Invisible disabilities like neurodivergence are often met with demands of disclosure in order for needs to be considered valid.
* **Asperger’s Syndrome**: While people still use this term for autism with no intellectual disability and lower support needs, it is falling out of favor in the United States. Autistic social justice organizations are discarding it actively, in part due to Hans Asperger’s association with Nazi eugenics. There is ongoing disagreement over the use, but it may be a sensitive topic for some people. The DSM-V no longer has Asperger’s Syndrome as a separate diagnosis, but in other countries it is still being used.
* **Aspie Supremacy**: Within some autistic organizations and groups, the Asperger’s diagnosis is elevated above those who have higher support needs or have intellectual disabilities. This is an unjust hierarchy of worth, and is being fought within these organizations much the same as white supremacy. Some groups or individuals may see Asperger’s as an evolution of humanity, and therefore better than other neurologies.
* **Autism Parents/Warrior Moms vs. Self-advocates**: There can be a strong divide between these two groups, especially in terms of the impact of behavioral control therapies, consent for disclosure of diagnoses, and exposure of autistic children’s personal experiences on social media with or without consent. The strongest divide is between the desire for the child to behave according to neurotypical society, versus the desire for society to accept neurodivergent children for themselves as they are.
* **Diminishing**: “Everyone’s a little… (insert neurodivergent identity here)!” is a way that neurotypical people often try to make neurodivergent people feel at ease, or indicate they are in understanding company. This diminishes the real experience of the disability or difference, and erases the distinguishing characteristics. It also can indicate a lack of understanding of the impact of symptoms and characteristics.
* **Dismissing**: “You don’t seem (neurodivergent identity) to me!” is a way neurotypical people may deflect the disconnect between their own expectations of what that disability ‘looks like’ and how the other person is presenting at that moment. It reads as lack of curiosity, lack of awareness, disregard of medical diagnosis, believing in stereotypes, or dismissal of the lived experience of the neurodivergent person.