

A resource guide on neurodiversity and science

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This resource guide was made by neurodivergent scientists for the broader scientific community. Its purpose is to present and define basic concepts while answering frequently asked questions about neurodiversity and the active (*and often harmful*) role scientific researchers play in the trajectory of disability rights. This guide aims specifically at clarifying current perspectives on autism that anyone interested in the sciences of neurological, cognitive and psychological development should be familiar with. The overarching goal is to shift our collective thinking about developmental disability research by building new frameworks that amplify and integrate the experiences of the neurodivergent community.

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What is neurodiversity?

Neurodiversity means that there is no such thing as a *normal* or *typical* brain. The neurodiversity movement [1] posits that a range of neurotypes exist as a result of natural genetic variation and early plasticity of the nervous system. What this suggests is that there is not one standard or correct developmental trajectory. All individuals have different sensory, perceptual and motor experiences that require different levels of support. Thus, the goal of future scientific research, particularly that of neuroscience and psychology, should focus on finding optimal ways to support people with brain-based disabilities (i.e. autism, intellectual disabilities, learning disabilities and/or mental health disabilities). This can only be done if scientists work *with* the disability community and not *on* them as scientific subjects. This way, rather than generating research that seeks to cure-and therefore eradicate-certain neurotypes, we can move towards embracing, understanding and accommodating for neurological uniqueness.

What do we mean by disability?

Disabilities may affect how we engage, learn about and navigate the world. How we communicate is a big part of the human experiential process. One of the central tenets of the neurodiversity movement is that disability does not arise from physiological differences in themselves, but from the struggle of existing in a deeply *ableist* world. *Ableism* is a form of discrimination against disabled people and communities, operating at both the interpersonal and structural levels of society. Many of the limitations neurodivergent and disabled people face could be removed by addressing ableist societal practices (for instance, following the federal Americans With Disabilities Act Standards for Accessible Design [7]), rather than solely through medical research.

Disability Rights are Civil Rights

The disability rights movement [2] is a part of the broader civil rights movement. It encompasses all intersections of society. This means that the struggles against the oppression of communities of color, the LGBTQIA+ community, women and the disability community are inextricably linked. The history of disability rights is full of scientific inaccuracies that have aided in the discrimination of disabled individuals from all aspects of society. The disability rights movement seeks to challenge common conceptions of what it signifies to be disabled while shedding light on the structural inequality that has been forged into social systems and services. One must evaluate the role of the Mental Health Industrial Complex in the ever-growing carceral

pipeline. For example, ~90% of state psychiatric-care beds are located in prisons/jails [8] and mentally ill, neurodivergent and/or disabled people make up ~20-50% of those killed by law enforcement [10-12]. The disability rights movement seeks to center the voices of disabled people, as it is the only way to approach the issues surrounding humanization and accessibility in any environment.

How does this concern me as a scientist?

Historically, the scientific field has been the stage for ableist exclusion of disabled scientists [3-6] through the unsupportive expectations of able-bodiedness and high productivity demand in academia that typically lead to lower hiring and funding rates. Beyond that, scientists are the primary drive behind the medical definition of disability. The National Institute of Health defines disability as the inability to perform routine activities of everyday life. This medical model is perpetuated through research that frames differences in physical, mental and emotional capacities as deficits that individuals must work to overcome in order to be considered part of the human community. Through this curative framework based on specific diagnostic categories, scientists and healthcare professionals --consciously or unconsciously-- reinforce the assumption of biological inferiority while erasing pervasive structural and social causes of disability. The medical model may have its place in advocacy, by ensuring access to all individuals who seek and advocate for medical treatments to alleviate conditions that cause them suffering. However, scientific endeavours that truly seek to better the lives of disabled folks must be wary of "deficit" framing and can benefit from the social model of disability, that offers guidelines for centering disabled people as humans with legitimate needs, and not problems as burdens.

But I thought searching for cures was the best way to help the world, is it not?

Although this realization may be surprising or even upsetting to some, it is important to discuss further. Research and academia as we know it greatly favors publishing as a marker of success, pressuring researchers to present "groundbreaking" and "profound" findings. This often manifests as sweeping statements about the fundamental nature of human functionality. In reality, the scientific models of disability most of us have contributed to with our work are rooted in eugenics, the white supremacist notion that the human race should fine-tune its own evolution [8-9]. Historically, this has been carried out more blatantly through the forced sterilization and eradication of individuals often belonging to several marginalized communities. However, it is important to keep in mind that this ideology predates World War II and is, in fact, the foundation of the American public health systems and policies.

Disabled people form the basis of most scientific research endeavors. However, most funding goes towards studies aiming to cure (i.e. eradicate) disabilities by deeming certain traits as *disordered* or *abnormal*. If one explores further and truly listens to the experiences of disabled folks --*not their able-bodied/neurotypical parents or caregivers; not the neurotypical people around them*-- one realizes that our scientific endeavors rarely overlap with the issues that are most pressing for the disability community and their quality of life. Listening to the insights and lived experiences of disabled folks can actually move us towards understanding and addressing their support needs [17]. It is up to scientists to introspect and evaluate what are the true bases of our lines of inquiry, intuitions and hypotheses about development and health. It is up to us to understand the true impacts of our science on the rights of the persons our research focuses on.

Community-Based Participatory Research

Moving forward, the scientific community must strive to adopt community-based participatory research (CBPR) models [13-14] where scientific experts work in tandem with members of the specific community they wish to serve through their work. CBPR is known as a form of action research. It aims to focus research efforts on the specific changes desired by the community because it is the people who uphold the collective wisdom and the cultural knowledge necessary to enact meaningful progress for themselves. This can only be achieved through projects that research *for* and *with* the people rather than *on* them. This is exemplified in the motto "Nothing about us without us" [15]. The general outline of CBPR projects involves developing scientifically rigorous

proposals that prioritize community needs. Implementation must ensure accessibility of research instruments and resources while practicing safe recruitment that represents the community as a unit of identity. Ultimately, the interpretation and dissemination of findings must be accessible to the community in order to holistically build on scientific theory.

On Autism

The autistic community -- yes, autistic -- is often deeply misunderstood and misrepresented in general social forums. Autism is frequently framed by allistic (non-autistic) people as a scary, crippling disease that keeps an otherwise neurotypical person trapped in a shell. This is incorrect. Although autism is considered a developmental disability, it is better defined as a *neurotype* that often presents as a spectrum of traits [16] -- not symptoms. Autistic traits include (but are not limited to) differences in interoception, social behaviors, communication, and sensory processing, accompanied by literal/straightforward ways of thinking, deep interests in specific topics, stimming/repetitive behaviors for emotional and sensory regulation, and, in some cases, dyspraxia, executive dysfunction and/or intellectual disabilities. Also, please note that we are using autism and not Aspergers. Aspergers is an outdated and offensive term coined by a eugenicist Nazi doctor to identify autistic individuals that -in his opinion- were *normal* enough to be spared and converted into productive members of the labor force.

Functioning labels might sound nice, but they aren't. Here's why:

When we speak of autism being a spectrum, we refer to a circular spectrum, like a color wheel. Each autistic individual experiences different traits to different degrees. Functioning labels (i.e. high/low functioning, mild/severe autism) enforce a linear conception of the autism spectrum, focusing on traits such as the level of speech a person has. These labels only serve to categorize autistic people based on assumptions that often perpetuate stereotypes rooted in eugenicist models of disability. Moreover, most autistic people go through a --conscious or unconscious-- act of inhibiting their autistic traits to appear more allistic or neurotypical in order to avoid discrimination and abuse. This is a phenomenon known as *masking* or *camouflaging* [18], which may have drastically negative effects on a person's mental health. The externally-enforced need to mask can lead to higher rates of under/misdiagnosis -- particularly for adult people that are assigned-female-at-birth (AFAB), queer, trans and/or nonbinary. As a result, we see increases in the risk of extreme burnout/fatigue, anxiety, depression and suicidality amongst the autistic community. When taken together with the intersectional profile of disability, it becomes clear how BIPOC, AFAB & LGBTQIA+ individuals are often overlooked and disproportionately affected by the lack of disability justice in our current societal structure.

Practice identity-first language!

Identity or person-first language [19] is preferred by the disability community because it reinforces the idea that disabilities like autism are a part of one's core existence. Referring to an autistic person as "a person with autism" only perpetuates the belief that autism (or any other disability) is separate from who you are. It further encourages the idea that the disability is a burden one carries, that it is something to be fixed or eliminated rather than recognized and accommodated for in the proper ways for each person.

Issues with autism "awareness" (applicable to neurodivergence in general)

Many organizations are led by allistic & neurotypical people seeking to raise *awareness* of autism. These groups operate based on many myths and misconceptions around the experience of being autistic. Their goal is typically to make people afraid of autism, treating autistics like burdens to families and overall society in order to persuade donors to contribute to their *seemingly* noble cause of preventing autism. Organizations searching for cures threaten that autism ruins families and compare an autism diagnosis with that of a terminal illness. Furthermore, these types of organizations often fuel an array of misinformation including vaccination- and nutrition-related pseudoscience. These groups also make use of symbols such as the puzzle pieces to

represent autism as a childhood-specific puzzle to be solved through eugenicist methods such as prenatal genetic engineering. The misguided influence of these organizations has shaped the perception of autistic and other neurodivergent individuals as less-than-human deserving of all sorts of abuse. Sometimes the abuse comes under the guise of “expert” treatments or therapies to cure the person from what is nothing more than their unique neurotype and identity.

Re-evaluating therapeutic interventions

Therapy modalities such as Applied Behavioral Analysis (ABA) or Intensive Behavioral Intervention (IBI) use behavior reinforcement paradigms to train autistic people to act *normal*. Despite being hailed as the most effective way to help autistic children by therapists and parents of autistic children, there is little-to-no scientific evidence supporting this notion. In fact, attention to adverse outcomes is often absent in a plethora of studies on autism interventions[20]. ABA is considered abusive [21-23] by most autistic adults who underwent this therapy as children themselves. To understand this, one must consider the origins of ABA. Its founder, Ole Ivar Lovaas, used all types of positive and negative reinforcements (including electric shocks, which are still used at the Judge Rotenberg Center in Massachusetts), to inhibit *undesired behaviors*. Notably, Lovaas used these same techniques to pioneer gay/transgender conversion therapy. These modalities have been shown to be deeply harmful [21] for obvious reasons. And although it is true that most ABA therapists no longer use overtly aversive reinforcers, there are some less-obvious reasons why this modality is still considered abusive. The therapeutic goal of any intervention related to developmental disabilities should never be for a person to appear *normal* or *less* neurodivergent. ABA therapy focuses on modifying a child’s behaviors, not on meeting their needs. It is about training children to tolerate sensory-induced distress, discomfort and sometimes pain in order to comply with external expectations. This can result in the loss of autistic interests and important, adaptive behaviors that are beneficial for the child’s specific neurodevelopmental trajectory. In the long-term, it can hamper the autistic person’s process of individualization and inhibit the growth of their sense of independence. Instead, modalities like physical, occupational and speech therapy can be very beneficial and helpful for autistics. The development of and access to technologies like Augmentative and Alternative Communication (AAC) should also be prioritized in research, if the true goal is to help make the world better suited for neurodivergent individuals.

Links to key resources

Science & Disability history

- [1] [Neurodiversity: some basic terms and definitions](#) (Nick Walker ‘14)
- [2] [Disability rights history](#) (Equal access and disability rights commission)
- [3] [Science and Disability](#) (Jessica Martucci, Science History Institute '17)
- [4] [Disabled in academia: to be or not to be, that is the question](#) (Yerbury & Yerbury, Trends in Neurosciences '21)
- [5] [Report on the impact of ableism in medical and scientific practice](#) (Special Rapporteur on the rights of persons with disabilities, UN Human Rights Council '20)
- [6] [How STEM Can Be More Inclusive of Scientists with Disabilities](#) (Amanda Heidt, The Scientist '21)
- [7] [2010 Americans for Disabilities Act \(ADA\) Standards for accessible design](#) (Department of Justice, '10)

Disability & law enforcement

[8] [Administrations of Lunacy: Racism and the Haunting of American Psychiatry at the Milledgeville Asylum](#) (Mab Segrest , The New Press '20)

[9] [How asylums became the crucible of genetics](#) (David Dobbs, Nature '18)

[10] [Overlooked in the undercounted](#) (Treatment Advocacy Center '15)

[11] [Media coverage of law enforcement use of force and disability](#) (Ruderman Family Foundation '15)
-disabled folks make up 33-50% of those killed by law enforcement

[12] [Police shootings database](#) (The Washington Post '15-'21)-mentally ill folks make up 26% of those killed by law enforcement

Community-Based Participatory Research

[13] [What is Community-based Participatory Research \(CBPR?\)](#) (AASPIRE collaboration toolkit)

[14] [Collaboration Strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons From an Academic–Community Partnership With Autistic Self-Advocates](#) (Nicolaidis et al., Prog. Community Health Partnersh. '11)

The Importance of Autistic Self-Advocacy

[15] [Position statements](#) of the Autistic Self-Advocacy Network

[16] [About autism](#) (Autistic Self-Advocacy Network)

[17] [How listening to autistic adults helped me understand and support my son](#) (Shannon Des Roches Rosa, Washington Post '19)

[18] [A conceptual analysis of autistic masking](#) (Pearson & Rose, Autism in Adulthood '21)

[19] [The significance of semantics: Person-first language: why it matters](#) (Lydia Brown '11)

Applied Behavioral Analysis & what's wrong with it

[20] [When autism researchers disregard harms: A commentary](#) (Dawson & Fletcher-Watson, *Autism* '21)

[21] [Long-term ABA Therapy Is Abusive](#) (Sandoval-Norton et al., Advances in neurodevelopmental disorders '21)

[22] [Invisible Abuse: ABA and the things only autistic people can see](#) (C.L. Lynch, '19)

[23] [Why ABA therapy is harmful to autistic people](#) (Compilation of research articles and first-person reports by AutisticSciencePerson)