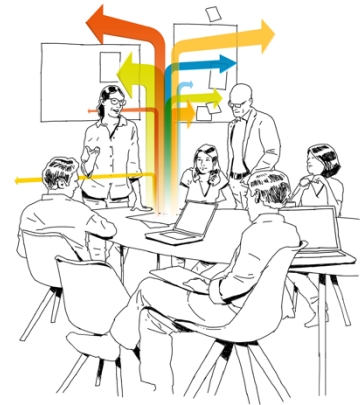


Terminology Guideline for Autism Researchers

Language is action

For many non-autistic autism researchers, language choices may be dictated by historical conventions and a desire to be consistent with language in the academic journals in which they publish. However, language used to communicate about autism within autism research is also reflective of power structures. It mirrors dominant narratives and ideologies about social phenomena, and can reflect and perpetuate ableist ideologies (i.e., beliefs and practices that discriminate against people with disabilities). Therefore, it contributes to stigmatization, whether or not researchers intend to have such effects or not. The effects of ableism on autistic people include, but are not limited to, underemployment, mental health conditions, and victimization.¹⁻⁵



These conventions persist, despite autistic preferences. Autistic adults have been writing and speaking about ableist language for several decades. There is also an already large body of autistic scholarship on this subject, along with research and theory from disability studies and discourse analysis.

In a nutshell:

- How we frame autism: it matters to autistic people and to autism science
- Autistic scholarship on this subject abounds: incorporate it into your work

Recommendations for avoiding ableist language in research

This compilation draws on suggestions from Bottema-Beutel et al. 2021. It also leans on the publication guidelines on terminology of the scientific journals *Autism*⁶ and *Autism in Adulthood*.⁷ All recommendations have been discussed by the [Autismus-Forschungs-Kooperation \(AFK\)](#).⁸



For more examples, a discussion in detail, and literature to back up your choices also see Bottema-Beutel et al. (2021)⁹ and/or the above-mentioned publication guidelines.

Terms related to autism diagnoses

The term “Autism Spectrum Disorder” (ASD) may be used when specifically discussing autism diagnoses and the term is clearly cited according to for example DSM or ICD. When referring to historic data, historic diagnoses such as Asperger’s syndrome may be used; however, these terms should be considered out of date. Otherwise, we recommend using terms such as “autism”, “autism spectrum”, or “Autism Spectrum Condition(s) (ASC)”.

There is a growing body of scientific and community literature documenting the dislike, amongst autistic individuals, of person-first language (e.g., person with autism) and its potential for increasing stigma. Based on this literature and the strong preference of the autistic members of the *AFK-board*, we recommend either using identity-first language (“autistic adults” or “autistic participants”), or more neutral terms such as “person on the autism spectrum”.

Subpopulations within the autism spectrum

Terms such as “high functioning” or “low functioning” autism, or “mild”, “severe”, or “profound” autism, are ambiguous and potentially offensive. The *AFK-board* recommends avoiding these terms as they fail to acknowledge the complexity of autistic abilities. Instead, we recommend describing subpopulations using precise characteristic(s) that make them a subpopulation. For example, “autistic people who qualify for developmental disability services,” or “autistic people who primarily communicate using speech.”

Comparison groups

- To compare autistic groups with other (e.g., non-autistic) groups, writers should refer to these groups as “comparison” groups.
- Exemption: in the context of an intervention study, where the “control” group refers to a comparison group that has not been assigned to receive an intervention.
- Avoid referring to comparison groups as “normal/healthy/typically-developing” or “neurotypical.” Participants may be otherwise neurodivergent (e.g., because of a health condition like epilepsy or depression); therefore “non-autistic” or “without autism” may be more accurate.¹⁰

Avoid medicalized and value-laden terms

- ... referring to autism as a condition or disability instead of as a disease or illness;
- ... referring to „co-occurring” or “secondary” conditions instead of “comorbid” conditions.
- Avoid emotional phrases such as “suffering from autism”.
- “At risk” for autism has negative connotations, and an international online survey has suggested that this term is disliked by many people with personal/professional connections to autism.¹¹ The term “at increased likelihood” of autism has been proposed as a neutral alternative.
- Refrain from using derogatory terms such as “retarded”, “mentally handicapped”, or “backward”.

Strengths-based vs. deficits-based language

- limited/ restricted/ circumscribed interests → special/ thorough/ intense interests;
- referring to autistic characteristics in a neutral manner, as opposed to deficits or dysfunction (e.g., “autistic traits”, “characteristics of autism”, or “features of autism” instead of “symptoms of autism”; “communication differences” instead of “communication deficits”; “emotion regulation difficulties” instead of “emotion regulation dysfunction”).

If you are unsure of a choice you have to make, consider answering those questions as a guideline for language choice discussions

- Would I use this language if I were in a conversation with an autistic person?
- Does my language suggest that autistic people are inherently inferior to non-autistic people, or assert that they lack something fundamental to being human?
- Does my language suggest that autism is something to be fixed, cured, controlled, or avoided?
- Does my language unnecessarily medicalize autism when describing supports?
- Does my language suggest to lay people that the goal of my research is behavioral control and normalization, rather than granting as much autonomy and agency to autistic people as reasonably possible?
- Am I using particular words or phrases solely because it is a tradition in my field, even though autistic people have expressed that such language can be stigmatizing?
- Does my language unnecessarily “other” autistic people, by suggesting that characteristics of autism bear no relationships to characteristics of non-autistic people?

(Bottema-Beutel et al., 2021)

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How people talk and write *influences how people understand disability*

Medical Model

001010010010011110010000
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Uses language that construes disability along a **normal/abnormal** binary, which dichotomizes people as


'healthy'
or

'sick'


...without reference to the social systems that render these categories meaningful.

This type of language can be **damaging** for autistic people and serve to perpetuate negative stereotypes.


For example...



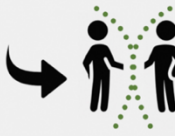
Theory of mind has been used to argue that autistic people lack key features that 'make us human.' This type of rhetoric...



positions autistic individuals as 'other,'




questions autistic individuals' autonomy,




and can result in stigma, hindering their ability to form relationships.

Social Model



Emphasizes the distinction between:




impairments
(socially-valued differences)

&


disabilities
(environmentally-mediated loss of opportunity)

Neurodiversity scholars recognize society's responsibility to remove barriers for autistic people and acknowledge the interaction between the social environment and inherent challenges related to being autistic. This type of language asserts that autism is both a **difference** and a **disability**.

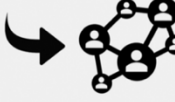
For example...




The "double empathy problem" suggests that autistics and non-autistics have difficulty understanding each other, but a social context that prioritizes the non-autistic perspective makes this disabling only for autistic people.



Breakdowns in understanding are due to differing ways of experiencing the world...



differing cognition and interests, as well as the social context.



However, shared experiences can lead to better mutual understanding.

(Infographic from Bottema-Beutel et al., 2021)