Community-Preferred Terminology around Autism: Glossary & Rationale

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First and foremost, it is important to note that preferences in terminology frequently differ between members of the autism community, and that the preferences of the autistic person with whom you are engaging should always be the first consideration. That said, a number of terms have emerged that are widely preferred within the autism community. This document, which has been developed with members of the autism community, explains the terms recommended by the AIMS-2-TRIALS communications and community engagement team. If you are unsure of individual preferences, or are referring to autistic people collectively rather than one individual whose preferences you know, we recommend using the terms listed below.

It can sometimes be challenging to remember the terminology used by autistic people to describe the autistic experience, especially when it differs from terminology that appears in textbooks, older research papers, and guides for clinicians. This is made more difficult due to the speed with which terms can become obsolete, given how quickly understandings about autism across many academic disciplines have improved over the past decade.

However, the terms used by autistic people have several advantages: **first, currently used terminology functions as descriptors of shared experiences.** Using these terms will assist the community in knowing exactly what you are asking of them and why. **Second, these terms also avoid deficit thinking and negative connotations about what it means to be autistic** that are rooted in long-standing historical pathologization of autism, all of which can be a barrier to cooperation between members of the autism community and researchers**.**

Use of community-preferred terminology will aid in getting your research relationship off on the right foot with autistic people whose help you are seeking. It is important to note, however, that language is the first small step to mutual understanding. Using these terms while neglecting the detailed and long-term work of community engagement, or while promoting research that does not engage authentically with community priorities, is likely to be judged as deceptive, inauthentic, and untrustworthy to the broader autism community.

We will note within this glossary the terms that are still either a matter of preference or the subject of disagreement within the community so that you can decide which terms you will use, with a full understanding of their context. This can be true of things even as basic as using the term “autistic person” or “person with autism” - for more on identity first language vs person first language, see resources in the appendix. The bottom line: we believe all autistic people should be free to use language and narratives which empower them and which help them make meaning of their own lived experience. This is the approach we find helpful, and we recommend that researchers do the same.

When in doubt, avoid any language that connotes a need for autism to be cured, or the implication that some autistic traits are better than others - especially if it is implied that neurotypical brains and their traits are superior or more desirable than neurodivergent ones.

Terms to Avoid or Limit Use	*Preferred Term*	*Definition of Preferred Term*	*Rationale*
• abnormal, etc. (any language which implies value); • Any language which implies autism is a medical problem (for example describing comparison group as 'healthy controls'); • neurodiverse (when describing one person - see appendix)	**neurodivergent**	describes a person with any neurocognitive condition(s) that cause them to interpret and respond to input in a way that differs from what might be considered 'typical', 'standard', or 'average'	This is a *blanket term* describing any person/people who are not neurotypical - generally it is preferable to use the specific term (autistic, ADHD, dyslexic, dyspraxic, etc.) being discussed unless multiple terms apply and are relevant. [Note: there are still disagreements within the autism community, often between autistic adults and parents/carers of autistic people with high support needs, about the meaning, usage, and relevance of this term. As mentioned above, when interacting with an individual, use terminology preferred by the individual.] For more resources on neurodiversity, see the appendix.
normal, healthy, neurotypical	**non-autistic**	Someone who is not autistic *<u>Note 1</u>: while a neurotypical person is indeed not autistic, many who are not autistic are also not neurotypical. Some will have ADHD or dyslexia, for example. When in doubt, be specific.* *<u>Note 2</u>: you may sometimes see the word 'allistic' used by some autistic people to describe someone who is not autistic. Usage of this word varies wildly from group to group and remains controversial among autistic adults.*	Non-autistic is simply someone who is not autistic. When describing anyone who is not autistic, do not imply that they are somehow more 'normal' than an autistic person - again, steer away from value judgements - and remember that autistic people can be healthy just as much as non-autistic people can be ill.

personalised / targeted medicine, personalised/ targeted interventions	**personalised / targeted support**	Support, whether pharmacological or otherwise, that is aligned with the specific needs of an individual	Support covers options that go beyond merely pharmacological treatments, which helps open up thinking around autistic needs; also, support is free of the medicalised context of other terminology (which implies that autism is a disease needing a cure). When discussing medicine or medical interventions specifically, the terms are fine to use; when discussing more generally options for meeting the needs of autistic people targeted to an individual's specific set of needs, use support.
subtyping stratification	**subgrouping**	Categorisation of a larger group into smaller groups that share a common trait	Many autistic people are actually in favour of subgrouping, as autism can look very different from person to person and can involve a variety of co-occurring conditions that often benefit from many kinds of interventions. Because of this, there is broad community support for research into subgroup-specific diagnostics and support. Subgrouping of autistic people is preferred to attempts to "subtype" autism. Many have argued that without first having a coherent concept of what autism is, it is not possible to identify subtypes within it. Prior attempts to do so, such as the "levels" of autism in the DSM and the proposal for a category of "profound autism", continue to be divisive. Some even note that subtyping can imply that one subtype is superior to another, or suggests a kind of hierarchy that connects back to the origins of autism research in eugenics. For more on this, see the appendix.

			If talking about subgrouping, be clear about the rationale and purposes, so that your audience is not left to make assumptions.
(being) high/low functioning	**(having) high/low support needs**	Describes the level and/or intensity of needs that a person may have at any given point in time relating to support in living their lives in the way they would prefer	The vast majority of autistic people need some form of support at some point, and this can vary between people and across a person's life. Stating this idea is not offensive. On the other hand, 'high/low functioning' implies a fixed and global state: once labelled as such, that label is perceived to apply across all aspects of life in perpetuity, regardless of circumstances. It also tends to be inaccurate: while 'high/low functioning' is often tied in the lay public's mind to pseudoscientific notions of IQ, autistic people do not fit neatly into this paradigm. Some autistic people have persistently high support needs in one or two areas of their life, e.g. communication, but are extremely independent when those structures are put in place effectively; other autistic people may encounter situations where their support needs are extremely high, but do not have those needs through most of their life. Still others may vary between high and low support needs over the course of years, months, or even over the course of their day. For more, see the appendix.
ASD	**Autism (preferred)** **'on the spectrum'** **ASC**	ASC = **A**utism **S**pectrum **C**onditions	ASC *can* be used in place of ASD (Autism Spectrum Disorder) - the use of the term 'disorder' implies that there is something inherently wrong and undesirable about being autistic. That said, **using the word, 'autism' is preferable**, as 'conditions' still has medicalized

			connotations that are not always applicable to autistic lives. For more on this, see the appendix.
risk (of autism)	**increased likelihood, increased chance**	Describing probability of autism	'Risk,' much like the more obviously negative word 'danger,' implies that whatever you are about to describe is inherently negative and to be avoided. On the other hand, 'likelihood' or 'chance' is value neutral - you can have a chance of a positive happening just as much as a negative.
special needs	**additional needs, support needs (or preferably describing a specific support)**	Requirements for equipment, help or interventions that enable people to live the life they want	The use of the word 'special' is likely to be experienced as patronising, like something an adult might tell a small child; additionally, the needs an autistic person has should not carry the connotation that they are extraordinary or burdensome, which is implied in 'special.'
challenging behaviour, disruptive behaviour, problem behaviour	**distress behaviours, e.g. meltdown and shutdown;** **stimming; soothing** **self-harming behaviours**	'Meltdown' is the community-preferred term used to describe behaviour that is uncontrollable and sometimes harmful to self or others as a result of painful sensory overload 'Shutdown' is similar in that it occurs within a similar context, such as painful sensory overload, but involves shutting off responses to the outside world to avoid further pain - it can be conceptualised as an internalised meltdown 'Stimming' is what autistic people call the usually harmless repetitive behaviours they use to	Behaviour is simply a reaction to stimuli - while a behaviour *might* be perceived by observers as challenging, disruptive, or problematic, these descriptors fail to provide insight toward the internal processes that prompt the behaviour. For autistic people, these behaviours often serve a purpose and can have significant value to both the autistic person and those around them when understood in their context. Removing value judgements, and instead using common vocabulary and getting very specific about what the behaviours actually are is more helpful in every way. Use of these distinctions place these four categories of behaviour in the context of what they communicate, and also set aside their potential impact on

		stimulate the parts of their brain that allow them to narrow their focus on specific activities 'Soothing' is used by some autistic people to describe the usually harmless repetitive behaviours that they use to self-soothe, calm, and decompress during or after moments of stress	non-autistic onlookers. This helps to better understand what the problem *actually* is, and prioritises autistic needs over non-autistic comfort. Note: in much of the literature, *stimming* is used to encompass both self-stimulating and self-soothing behaviours, but some autistic people distinguish the two. For more information on these four autistic behaviours, see the appendix.
Deficit-led terminology or generalisations, for example: ● empathy "gap" ● deficient, deficiencies (especially when discussing subjective issues, such as social and/or emotional) ● 'Participant cannot…'; 'participant struggles with…'	**Strengths-led or neutral terminology, for example:** ● autistic skills ● 'Strong in _____, needs support in _____' ● 'Participant is not yet able to…' participant sometimes / occasionally has difficulty with' ● Participant has identified X as a skill they want to develop further	Strengths-led, neurodiversity-affirmative terminology asks people involved in autistic support, research, and advocacy to lead with the strengths of autistic people. Strengths-led approaches are a way of considering any marginalised identity. This approach asks those in positions of power to recognise and support the strengths of the group and the individual to an equal or greater extent than they focus on addressing the problems within the group or individual. For more information on strengths-led approaches and their application, see the appendix.	Strengths-led approaches have been used in other academic spheres to support positive outcomes among marginalised groups. In the field of biomedical research, they can be a way to approach and formulate questions about autism and autistic people's outcomes without bringing ableist ideas of 'curing autistic traits' into the picture. Strengths-based approaches take the agency and humanity of autistic people as a given, rather than looking at autism as, at its core, a deficit to be remedied. For researchers, a strengths-led approach can be the first step to identifying novel approaches to research questions; for clinicians, this approach lays the ground for identification of appropriate supports that can open up more positive outcomes for individuals and their families.
Medicalised descriptors, e.g. patient, PPIE, 'healthy control'; 'autistic symptoms'	**participant, autistic participants; non-autistic participants; 'autistic traits'**	Any autistic person or group of autistic people being discussed in research that is not *directly* related to a health concern should be	Autistic people are not *necessarily* patients, even if participating in a research study. If an autistic person has reached out to a clinician for help with a health concern, then they can be

		referred to as participants. Autistic *traits* relate to the way autistic people engage with the world; *symptoms* denote problems associated with a medical condition, which an autistic person may or may not have.	accurately referred to as a patient. For accuracy's sake, consider whether words like 'symptoms' and 'patients' fit the work you are doing before use. When describing co-occurring conditions like epilepsy or insomnia, they may be the best fit. When describing autistic traits like repetitive behaviours, they likely are not.

Appendix - Other Resources

Why use community-preferred terminology in research?

From *Autism in Adulthood*: "Avoiding Ableist Language: Suggestions for Autism Researchers" by Kristen Bottema-Beutel, Steven K. Kapp, Jessica Nina Lester, Noah J. Sasson, and Brittany N. Hand

Person First vs Identity First Language

From Autism Self-Advocacy Network (ASAN): An article detailing the implications of person-first vs identity first language

Autism, Neurodiversity and the Neurodiversity Movement

For an accessible primer on the concept of neurodiversity, see this overview by LEANS, a project from the University of Edinburgh.
From *Metanarratives of Disability*: 'The Metanarrative of Autism' - Sonya Freeman Loftis, Professor of English and disability studies scholar at Morehouse College. For another Disability Studies focused view of the cultural narratives of autism from this scholar, see *Imagining Autism*
From *Human Development*: 'Conceptualising Autistic Masking, Camouflaging, and Neurotypical Privilege: Towards a Minority Group Model of Neurodiversity' - from Beth Radulski, graduate researcher in Sociology at La Trobe University

Autism, Stratification, and Eugenics

From *Pediatrics*: 'Eugenics and the Origins of Autism' - Jeffrey P. Baker (Professor of Pediatrics at Duke) & Birgit Lang (Professor of German at University of Melbourne, historian of psychoanalytics, gender, sexuality, and disability)
From *Time* Magazine: 'Asperger's Syndrome, the Nazi Regime and the Dangerous Power of Labeling People' - Edith Sheffer (historian and European Studies senior fellow at UC Berkeley)

Support Descriptors vs Functioning Descriptors

From *Autism*: 'The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis' - Alvares GA, Bebbington K, Cleary D, Evans K, Glasson EJ, Maybery MT, Pillar S, Uljarević M, Varcin K, Wray J, Whitehouse AJ (2020)
From the National Centre for Mental Health: 'The Fallacy of Functioning Labels' - blog post by advocate Kat Williams, an autistic parent of autistic children

ASD vs ASC vs Autism

(NB: the following articles are both from 2015 - preferred terminology shifts quickly and these are both shared in order to give interested researchers an idea of how long these particular terms have been advocated for by researchers and community members.)

From INSAR: 'ASD vs. ASC: Is One Small Letter Important?' - Transcript of presentation given by Simon Baron-Cohen advocating for move away from use of 'ASD' in 2015

From *Autism*: 'Which terms should be used to describe autism? Perspectives from the UK autism community' - Lorcan Kenny, Caroline Hattersley, Bonnie Molins, Carole Buckley, Carol Povey, and Elizabeth Pellicano (2015)

Meltdowns, Shutdowns, Stimming, and Soothing

From Bristol Autism Support: blog post on shutdowns and how they differ from meltdowns

From Autism Awareness Centre: 'Shutdowns and Stress in Autism' - article aimed at educators

From Psych Central: Blog post on the utility of stimming behaviours to autistic people

From *Autism*: '"People should be allowed to do what they like": Autistic adults' views and experiences of stimming' - Stephen K Kapp et al (2019)

From the May Institute: An article written from an ABA perspective on the 'harms' of stimming and how to train autistic people out of them

Strengths-led Language, Approaches, and Mindset

From Autistica: a primer on Strengths-Based Approaches and Autism

From Harvard Medical School: a blog post from a parent on the value of a strengths-based approach for her autistic son

From *Autism in Adulthood*: 'An Expert Discussion on Strengths-Based Approaches in Autism' (2019)

From *Nature*: 'A capabilities approach to understanding and supporting autistic adulthood' (2022)