

Autistic person

Disease

Autism

Aspie

Disability

Identity

Allistics

Challenges

Controls

Neurotypicals

Deficits

Impairments

Spectrum

NOMENCLATURE

Brain

PERFORMANCE



None of the proposed autism terminology was endorsed by 100% of participants.

Is there a universally accepted term

to refer to Autism?

By ICIAR ITURMENDI-SABATER

'Autism', 'Is autistic', 'Neurological/Brain difference', 'Neurodivergent', 'Challenges' and 'Neurotypical' are amongst the most common terms used by autistic English speakers to distinguish between autistic and

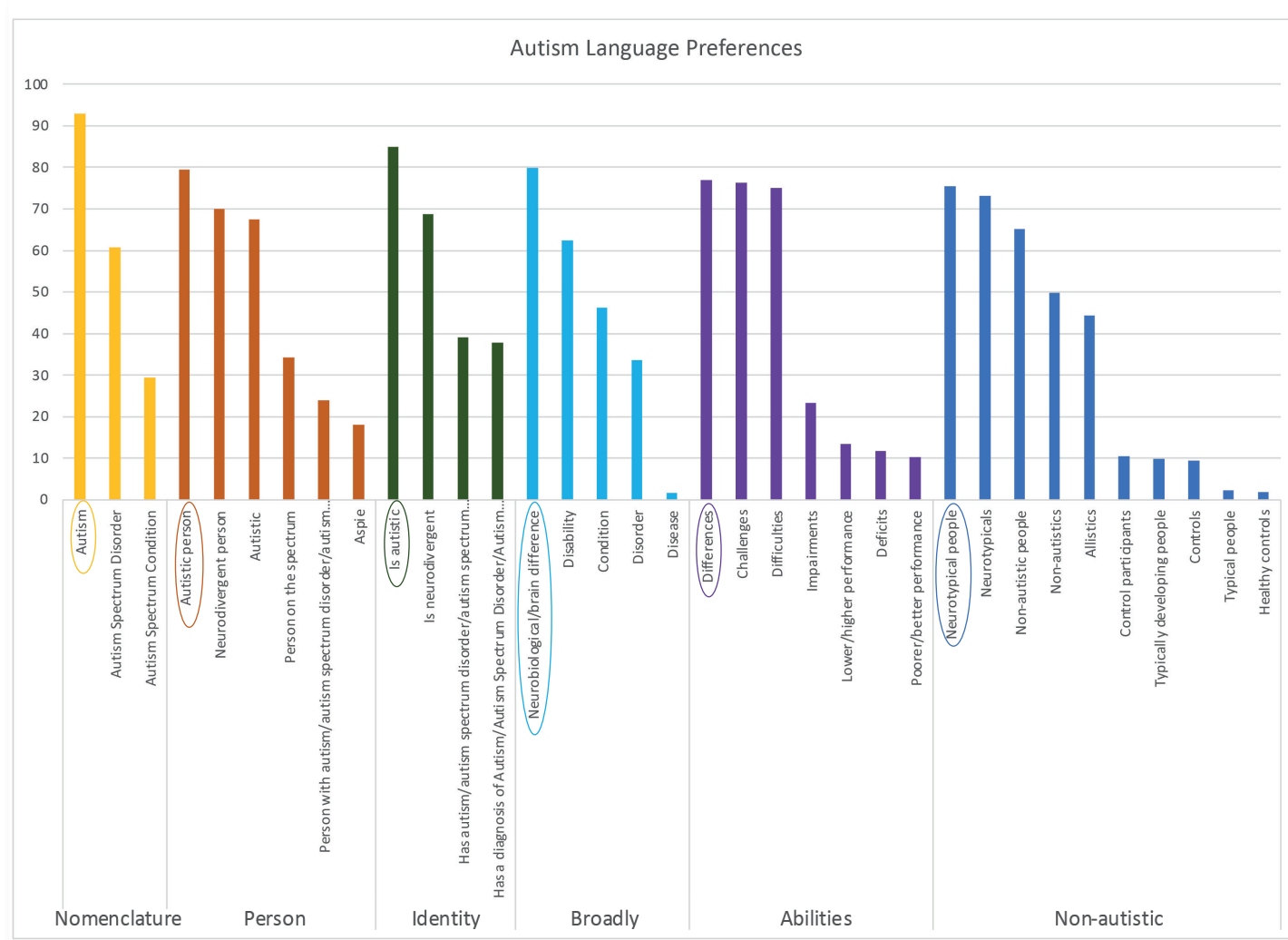
non-autistic people. Yet there is no universally accepted way to refer to autism; this is what a recent study published in November 2022 in the journal Autism Research found. The study examined the language

preferences of over 650 English-speaking autistic adults internationally (1).

Two previous studies investigating autism-related language preferences had found that although 'Autistic' and 'Autistic person' are the preferred ways to refer to autism in the UK and Australia, over 40% of autistic individuals in the UK did not endorse these terms (2,3). The reasons behind these diverging preferences remain unknown, and autistic persons, researchers and clinicians continue to wonder whether such language preferences may vary across cultures.

To answer these questions, Connor Keating at the University of Birmingham conducted a large study

across English-speaking countries: Canada, the US, Ireland, Australia, New Zealand and the UK. The mixed-method nature of the study (see the Science FAQ article in this issue about research methods for more details) allowed them to *quantitatively* analyze which terms are more popular over others, and to further *qualitatively* examine participants' responses to why they may choose one term over another to refer to autism. Keating's team consulted with a group of autistic community members to develop their survey. They then asked 654 autistic adult participants which terms they were *happy to use* when talking about autism, describing themselves or others as autistic, referring to someone's autistic identity, talking about



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the challenges associated with autism, and when talking about non-autistic people.

Across countries, respondents most frequently endorsed the term 'Autism' to generally refer to the condition, 'Is autistic' and 'Autistic' to refer to an individual and their identity personally, 'Neurobiological/Brain condition' to describe autism broadly, 'Differences' or 'Difficulties' to name specific autistic abilities, and 'Neurotypical people' to refer to non-autistic individuals. Yet **none of the proposed autism terminology was endorsed by 100% of participants as a word they would be happy to use** (see **Figure page 3**). In general, these preferences did not vary between countries.

When it comes to the reason for their preferences, different themes became clear.


The first of these themes had to do with using language to unify versus separate autism into various subgroups. This is a current hot discussion topic in the community of autistic individuals, care providers and researchers.

Some argue that those autistic individuals having greater support needs, intellectual disabilities and very limited language (4), should constitute a separate group, which were not represented in Keating's study sample. In 2021, the term 'Profound autism' was proposed to refer to this subgroup (5). Those in favour of differentiating between autistic persons by their support needs argue that if this distinction is not made, research efforts and services may end up only geared towards autistic persons with lower support needs, overshadowing those with high support needs (6).

Others oppose the idea of adopting labels such as "Profound autism" or "high-level autism" to differentiate subgroups along the autism spectrum, a view that seems to be reflected in Keating's study. From this perspective, autism is understood as a constellation of individual characteristics that make each autistic person unique. Consequently, splitting the autistic population in two would generate a false split, leaving those in the middle unrepresented. Thus, terms such as 'Profound autism', 'Low/High functioning autism' and 'Asperger Syndrome' are considered misleading and offensive by some (7). Importantly, this view is held by autistic individuals with a diverse range of support needs, intellectual and language abilities, including members of ethnic, sexual and gender minorities (8).

Another identified theme was that the use of these categorical terms may lead to lack of recognition of autistic potential and over-focusing on 'difficulties,' 'challenges' and 'deficits'. In their opinion, avoiding these negatively valued terms does not mean underfunding research that attempts to explain the causes underlying these differences, nor her giving less priority to treatment and clinical care (1). Instead, it is argued that using neutral terms to refer to subgroup differences prevents language-driven stigmatization (9). In contrast, others propose that any term used to refer to autism could be potentially stigmatizing, and that we as language users can challenge stigma depending on the meaning we give to our words (10). Whatever meaning is implied through word choices, Keating's study participants emphasized that chosen language should convey that autistic persons 'are different, not less'.

To recognize the unique characteristics of each person on the spectrum avoiding negative connotations, participants proposed to use concise and specific language to refer to the abilities or challenges of each autistic person, rather than general labels. For instance, instead of using the term 'Profound autism', we could just refer to the person as an autistic individual with intellectual disability, language difficulties and high support needs. Using accurate descriptors adapted to each person can help value individual identities. While some of the participants responding to Keating's survey highlighted that autism is a core part of their identity, others emphasized that their autism does not define them. **An overarching theme across responses was the importance of making autistic voices prevail.** Thus, listening to each individual's language preferences, or asking the individual's preferences when in doubt is an easy way to respect everyone's identity.

Differences exist on how people select their words to refer to autism, and language choices reflect the way we understand the condition. This diversity of views may be seen as a debate that is dividing and polarizing the field. But another perspective is that this may be a fruitful discussion leading to a richer, integrated way to understand autism. 

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