WHICH TERMS SHOULD BE USED TO TALK ABOUT AUTISM?

THE U21 AUTISM RESEARCH NETWORK

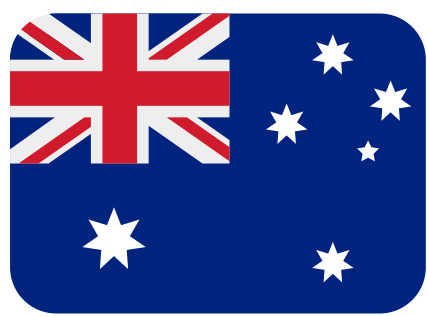*A report from the U21 Autism Research Network*

We asked 654 autistic adults across the globe about their language preferences. Here's what they said...

The participants were from 30 different countries across the globe

Although the majoirty were from six different countries

Australia

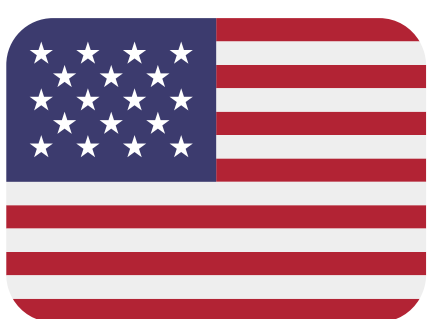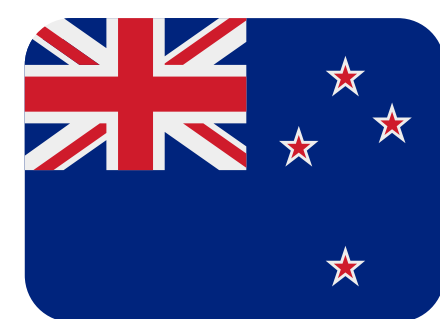**Canada**

UK

USA

Ireland

New Zealand

What did the participants say?

1

ASK THE AUTISTIC PEOPLE YOU INTERACT WITH ABOUT THEIR LANGUAGE PREFERENCES

" Even if you think you know the correct terminology, ask. We are not a monolith "

In situations where you can't ask about personal preferences, we recommend that you consider:
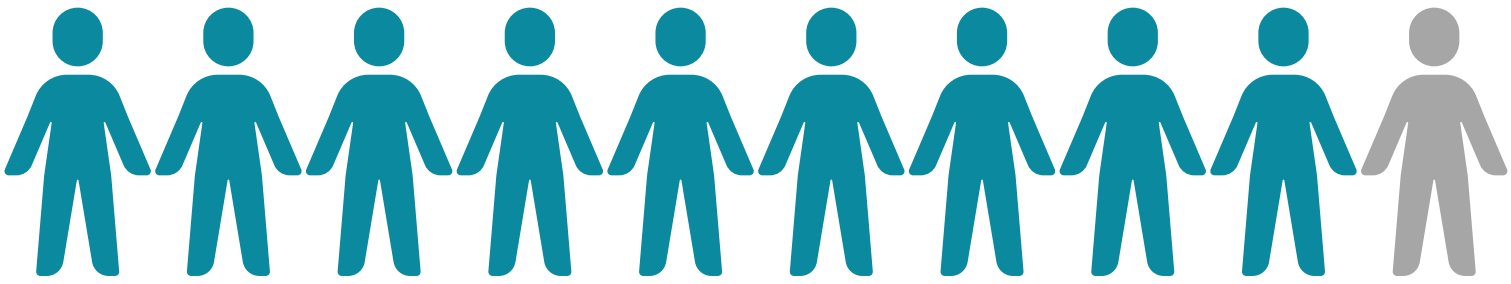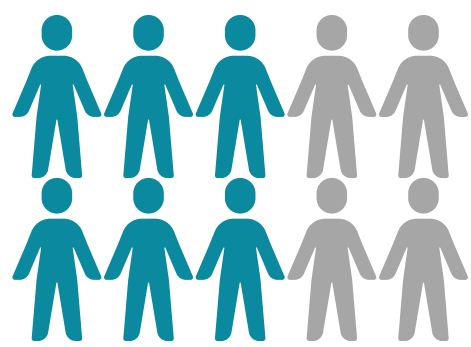
1 Which terms are liked by the majority of the autistic community

2 The ideologies underlying certain language choices (e.g., neurodiversity, avoiding ableism, etc.)
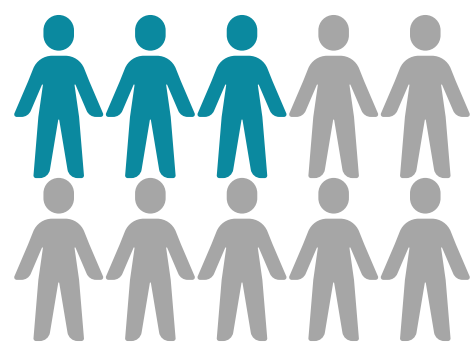
So which terms are liked by the majority of the autistic community?
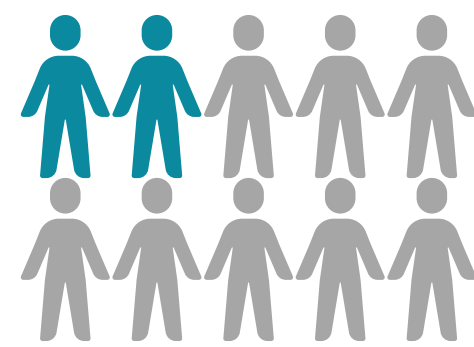
9 OUT OF **10** liked the term "Autism"

6/10 liked "Autism Spectrum Disorder"

3/10 liked "Autism Spectrum Condition"

2/10 liked "Asperger's syndrome"

"I dislike Asperger's as a term, not just because of the troubled history of the namesake, but also because I believe it segregates us. The point of Asperger's originally was to pin us down into 'higher' and 'lower' functioning labels and I massively object to that."

A large proportion of participants said that they disliked this term due to its ties with functioning labels (see page 7) and eugenics, and it no longer being used as a diagnostic term.

However some people may use this term as they feel it comprises a core part of their identity since their diagnosis or to distance themselves and to manage the stigma associated with autism.
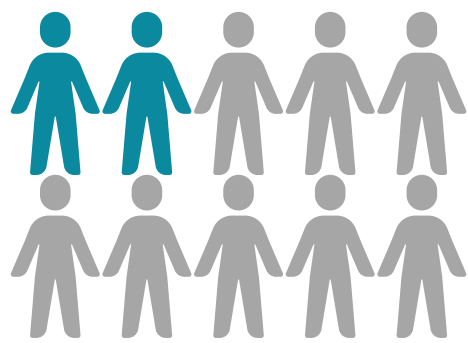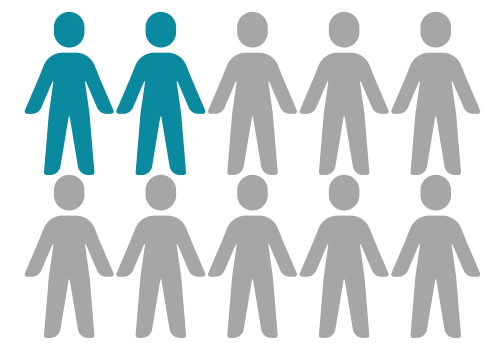
8 OUT OF 10

MOST POPULAR
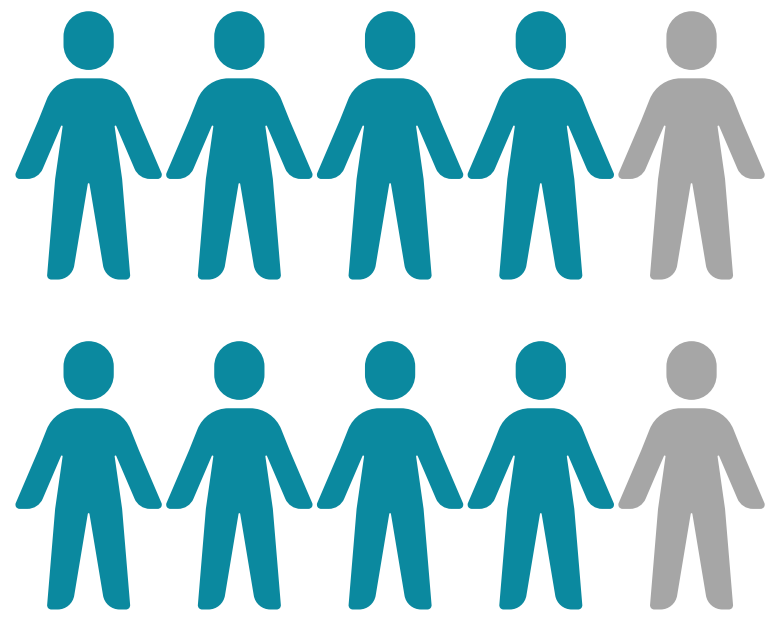
liked the term "Autistic person"
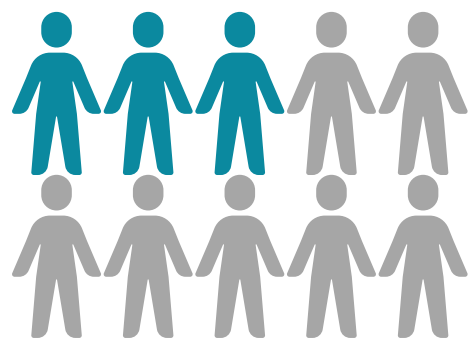
3/10 liked "Person on the spectrum"

2/10 liked "Person with autism"

2/10 liked "Aspie"

A large number of respondents said that person-first language (e.g., "person with autism") should not be used as autism cannot and should not be separated from them. These participants suggested that language should be identity-first (e.g., "autistic person") as autism is an integral part of who they are, just like their ethnicity, gender, or sexuality.

> I dislike "person with autism"... because it's a diagnosis, not a physical item/possession... I can't just "put my autism down" and suddenly not be autistic. It's not a handbag.

70%
liked the term "Neurodivergent person"

The term "neurodivergent" encompasses a range of other conditions (e.g., dyslexia, ADHD, etc.) and therefore is not specific to autism. Participants commented that they use this term when referring to themselves more generally or to multiple neurodivergences.

SPOTLIGHT ON "AUTISTIC"

67%
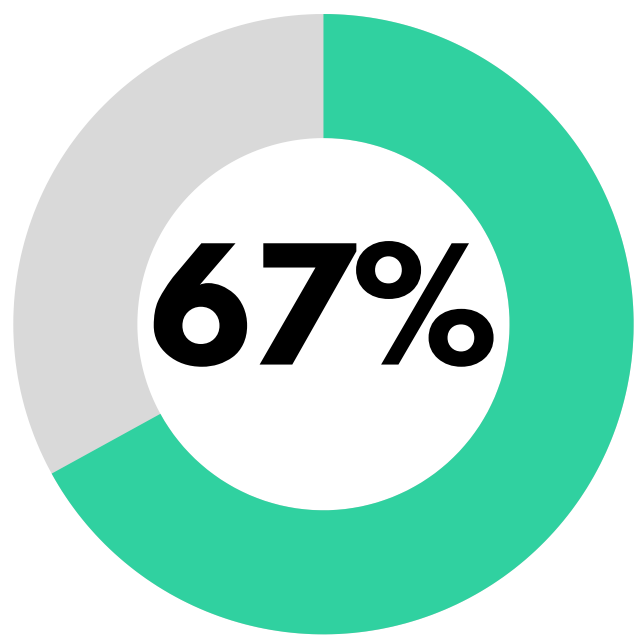
liked the term "Autistic"

E.g., "an autistic goes to my school"
"6 autistics go to my school"

> I do generally try to avoid noun omission and use terms like "Autistic people" and "autists" over "autistic" as a noun as this omission of noun is often used to subtlety dehumanize marginalized groups (e.g., "blacks" vs "black people"...).

The participants also highlighted that whilst they didn't mind autistic or neurodivergent people using this term, they didn't like when neurotypical people did.

> I do not like it when neurotypical people call a group of autistic people "autistics", as this gives them the option to dehumanize us. I believe only autistic/other neurodivergent people should say this.

However many respondents highlighted that using "autistic" as a noun (e.g., "an autistic", "lots of autistics") is reductive, derogatory, and dismisses their personhood.

> I don't like the term "autistic" as a noun though. I'm not an autistic. I'm a person

Our recommendations

✓ Use "autistic" as an adjective
E.g., "autistic person", "they are autistic"

✗ Don't use "autistic" as a noun if you are neurotypical
E.g., "an autistic", "two autistics"

WHAT ABOUT FUNCTIONING LABELS?

"High-functioning" "Low-functioning"

"Severe autism" "Level 1/2/3 autism" "Profound autism"

INACCURATE
As so-called "functioning" varies across time and situations

DIVISIVE
As they unnecessarily segregate autistic people

HARMFUL
As they lead to "high-functioning" individuals missing out on support, and "low-functioning" individuals being infantalized or ignored

> Because I am seen as 'high-functioning', it means people are less likely to give me accommodations that I need to be successful... Likewise, people labelled 'low functioning'... have their strengths and abilities minimized. They aren't allowed to advocate for themselves and are denied basic agency. We are all *just autistic* We are all completely different from each other. Grouping us by how outsiders percieve our level of ability is innacurate and harmful

Rather than using functioning labels, it is better to use clear brief descriptions e.g.,
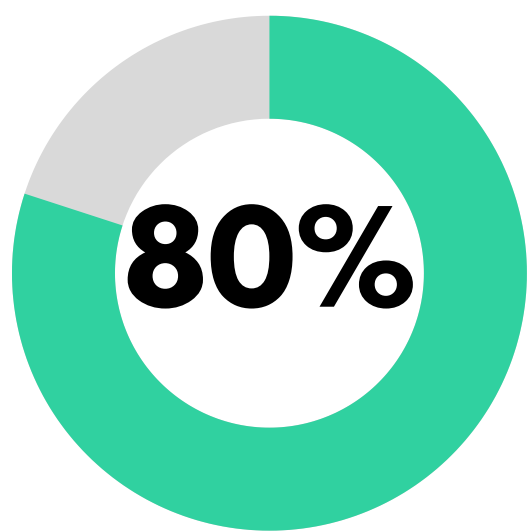
"autistic person with high IQ"

"autistic person with an intellectual disability"
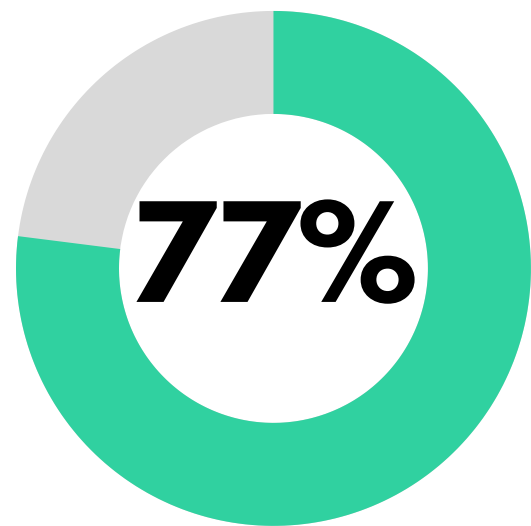
"autistic person with minimal verbal language"
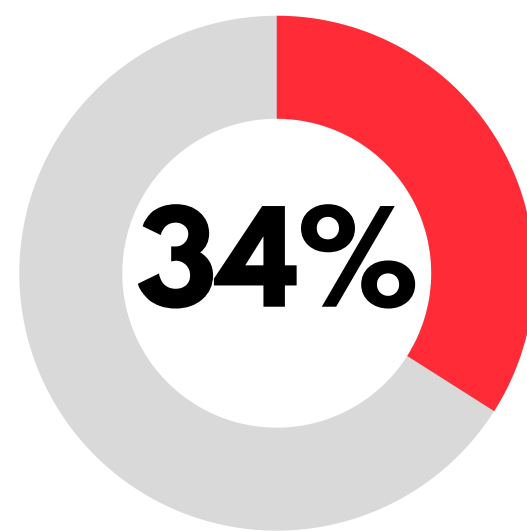
TERMS THAT TREAT AUTISM AS A PART OF NATURAL DIVERSITY

PATHOLOGIZING DEFICIT-BASED MEDICALISED LANGUAGE

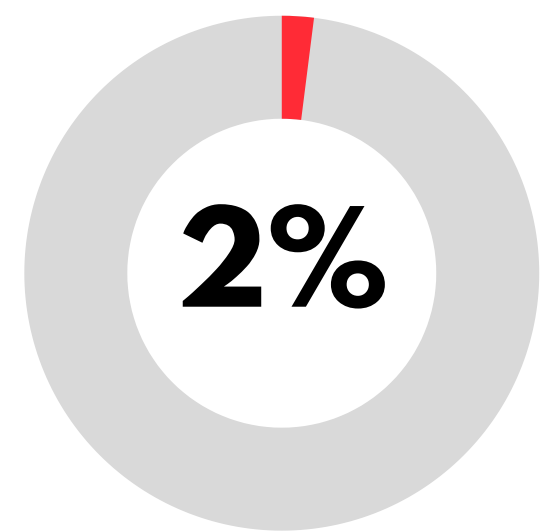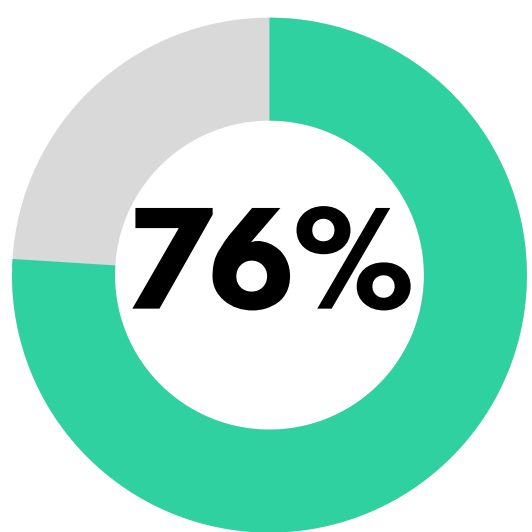**80%**
"Neurological difference"

77%
"Differences"

34%
"Disorder"

2%
"Disease"

76%
"Challenges"

75%
"Difficulties"

23%
"Impairments"
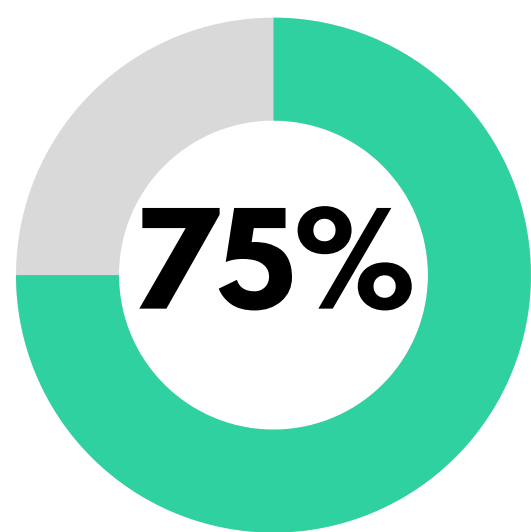
12%
"Deficits"

"My brain formed a bit differently and that doesn't make me sick or disordered. It only appears this way because of the pressures and expectations placed on individuals by our current societal model"

"A lot of autistic traits are needlessly pathologized because they're useful indicators for diagnosis, but just because it's diagnostically relevant doesn't mean it's an impairment"

What did participants think about referring to autism as a disability?
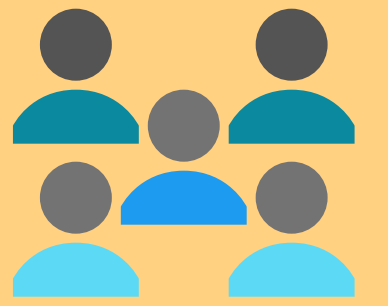
6 OUT OF 10
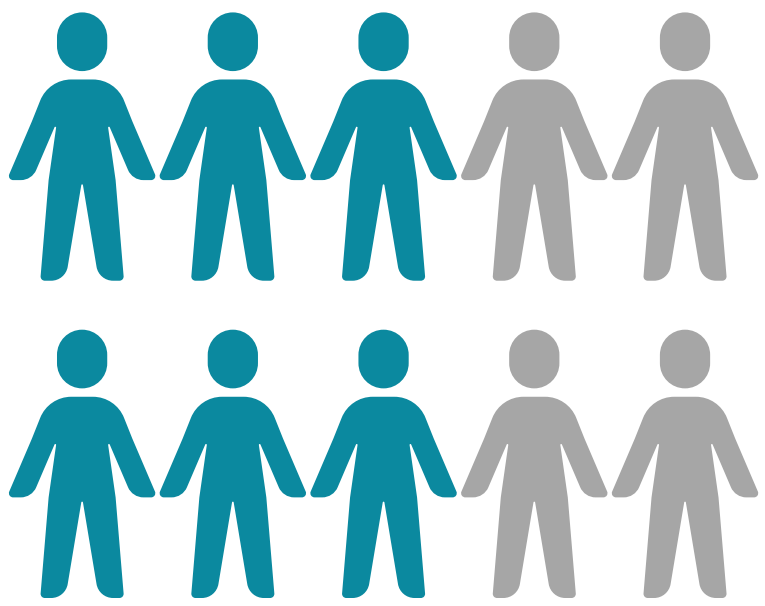
liked to refer to autism as a "Disability"

Gaining accommodations and community

66 I like using the term disability as it can be used to get accessibility under the equality act, since autism is a disability and it is illegal to discriminate against people based on disability. It has helped me a lot when getting accommodations at university and when trying to make education and healthcare more accessible. It also links us to the disabled community which is much larger than the autistic community so we get access to a lot more information and support. 99

In particular, participants liked the social model of disability.

Many respondents noted that a large proportion of their "difficulties" arise from being situated in a neurotypical world not built for them. These participants also responded that if the world was adapted to their differences and support needs, then many of their difficulties, or even all of them, would disappear.

66 Most "challenges", "difficulties" and "problems" only arise when I as an autistic person have to communicate with a world designed by and for neurotypical people. 99

Whilst there was a recognition of the problematic structure of an ableist society, participants still noted that for some autistic individuals legitimate difficulties may remain even after accommodations.

66 Autism is a disability, both in social model terms, i.e. that often we are disabled by it because of society but also that there are inherent aspects of being autistic that disable us that an ideal society wouldn't erase 99

66 99 I have a disability but not every autistic person is disabled by autism. I would say that for them it's merely a neurological difference

REFERRING TO NON-AUTISTIC PEOPLE

75%

MOST POPULAR

65%
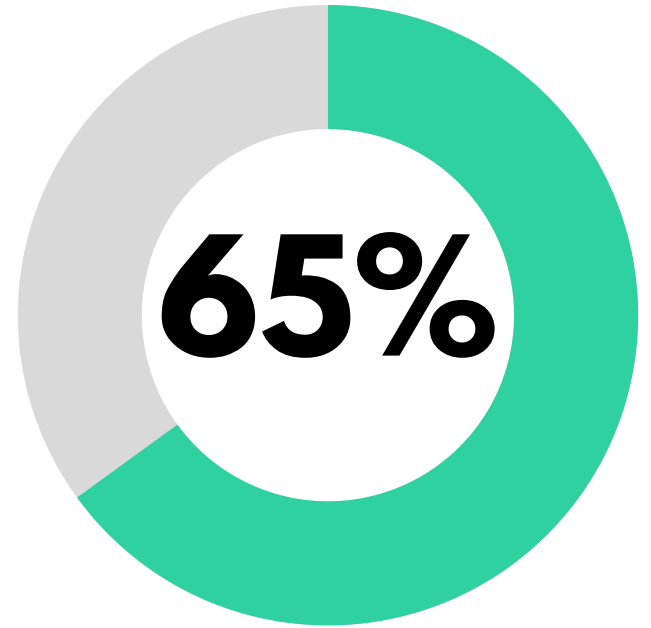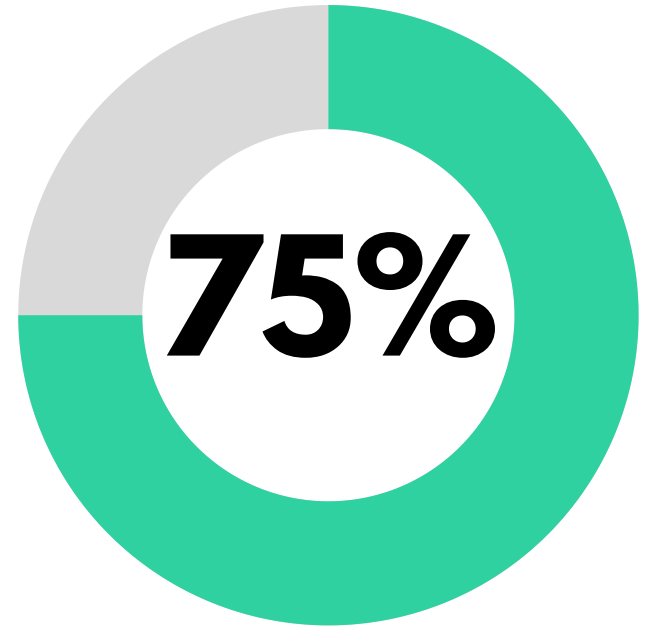
liked the term "Neurotypical people"

Neurotypical means not neurodivergent (e.g., no autism, ADHD, dyslexia, etc.)
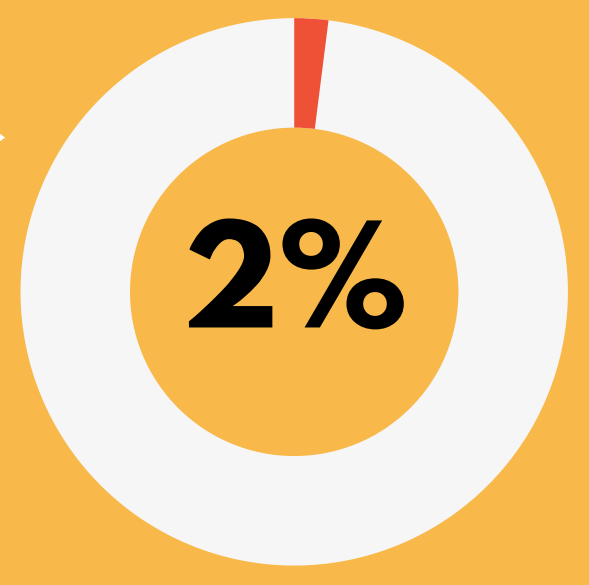
liked the term "Non-autistic people"

Non-autistic means not autistic.

LEAST POPULAR

50%

10%

2%

liked the term "Allistic people"

liked the term "Typically developing people"

liked the term "Typical people"

"

Language I do like is language that empowers us and allows us to self-identify... language that acknowledges our autism as being an integral part of us, language that allows us to express that we are different, not less, and most importantly, language that the autistic community develops ourselves instead of words that are forced onto us by non-autistic people

"

THE U21 AUTISM RESEARCH NETWORK

THANK YOU!

Thank you to the participants who took part in this study - we are really grateful for your time! Special thanks go to the Birmingham Psychology Autism Research Team Consultancy Comittee for their input.

READ THE FULL ACADEMIC ARTICLE AT: HTTPS://DOI.ORG/10.1002/AUR.2864

TO LEARN MORE ABOUT OUR NETWORK VISIT WWW.U21AUTISMRESEARCHNETWORK.COM

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