The Language of Autism Project

(November 2022)

A bit about us...

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Investing in Children

NHS
North East and North Cumbria

Longstanding debate from 2010

• 2010 NICE	“many different terms”	Autism ✓	
• Autistica & NAS	Strongly advice	Autism ✓	~~ASD~~ ✗
• 2015 Kenny et al	Autistic people’s preferences	Autism ✓	~~ASD~~ ✗
• 2020 Bury et al	Autistic people’s preferences	Autistic ✓	~~ASD~~ ✗
• Autism Journal	Terminology guidance	Autism ✓	~~ASD~~ ✗

Autistic Spectrum Disorder (ASD) is still commonly used

Social media comments

Job titles

Team name

Email signatures/addresses

Publications

Informal reports

Case discussions

Conference presentations

Research titles

Website addresses

Educational reports

Name of an ‘autism friendly’ Café

Preferred terms to describe autism

Survey: Co-produced with the Extreme group

What do you think about the following terms from 1 (do not like) to 5 (like very much)?

1. Autistic Spectrum Condition / ASC
2. Autistic
3. Autistic Spectrum Disorder / ASD
4. On the autistic spectrum

Which term do you prefer most?

1. Autistic Spectrum Condition
2. Autistic
3. Autistic Spectrum Disorder
4. On the autistic spectrum
5. Other

Are there other terms you use to describe autism?

Participants	Autistic adults	Autistic young people	Parents & carers
573	106	9	386

Results

Liked the most

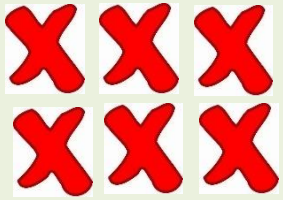
Everyone

Autistic people

Disliked the most

Everyone

Autistic people

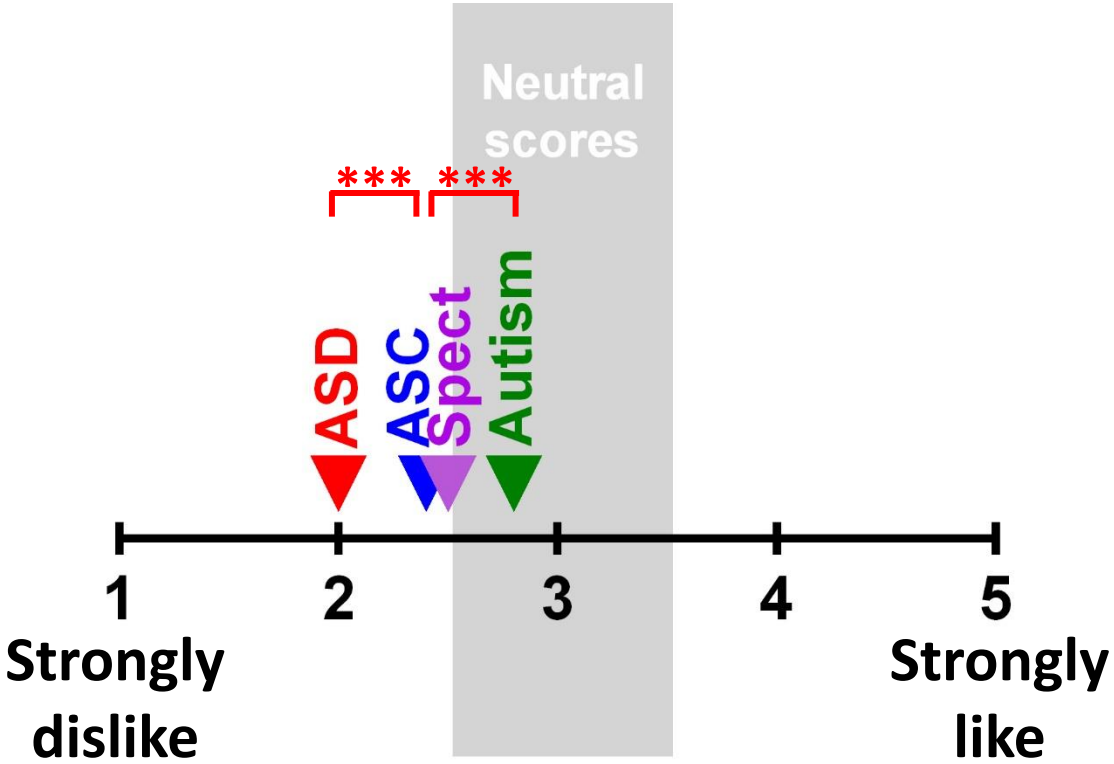


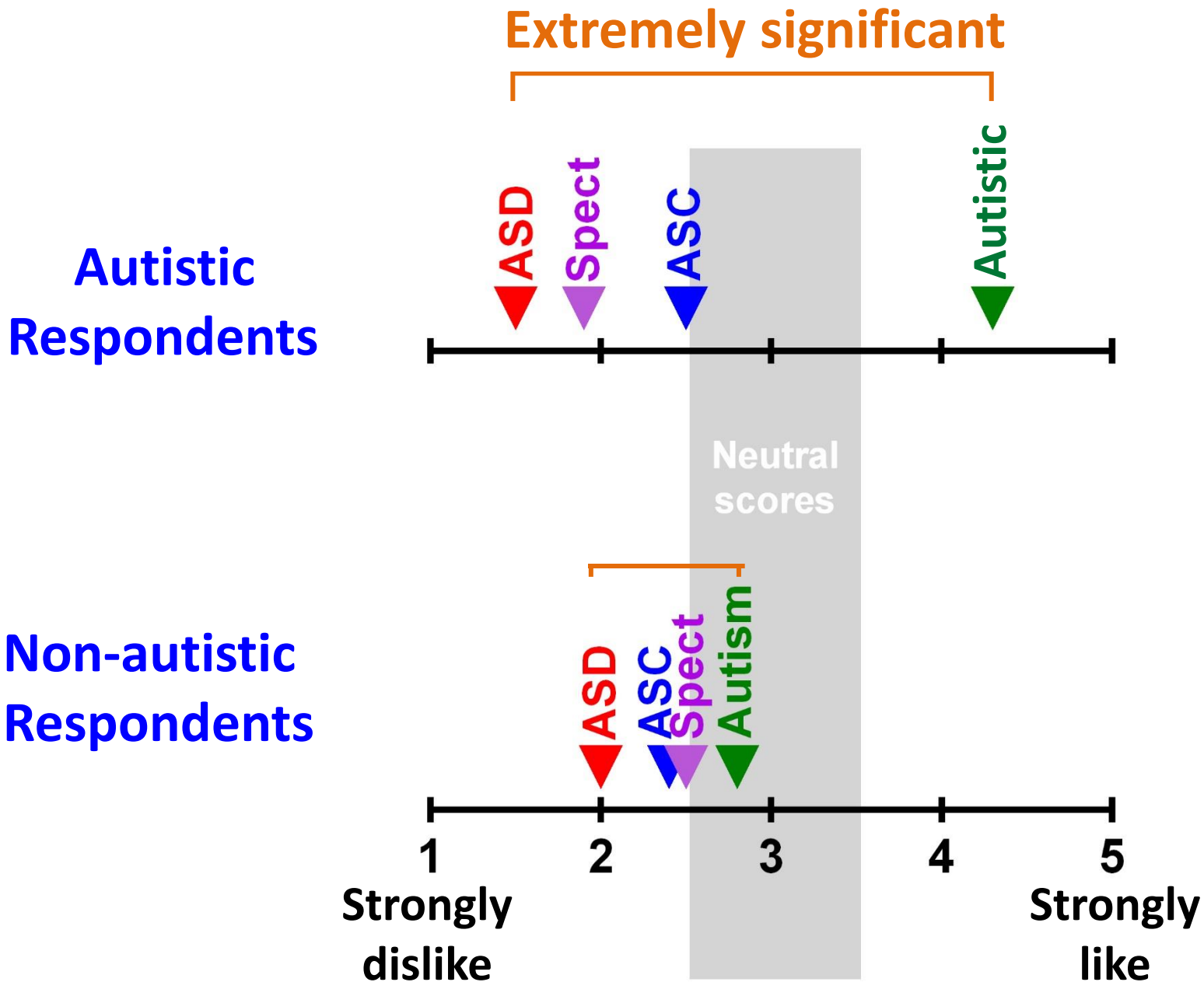
Preferred term overall

Everyone

Autistic people

Non-autistic Respondents




Extremely significant
Autistic Respondents
ASD
Spect
ASC
Autistic
Neutral scores
Non-autistic Respondents
ASD
ASC
Spect
Autism
1
2
3
4
5
Strongly dislike
Strongly like

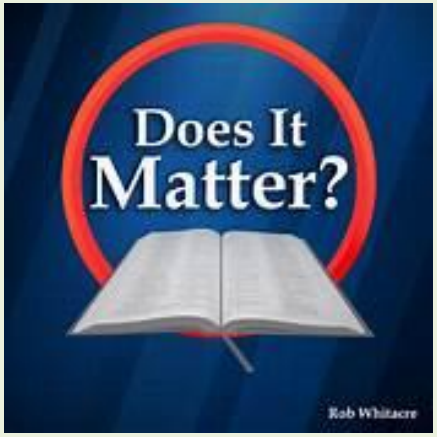
Language is powerful

'Disorder' = external value-judgement & highly negative

Language is dynamic

Imbecile, lunatics, moron, psychopathic inferiority.

Who *should* decide the words we use?



Cultural & societal understanding evolves

Homosexuality was a psychiatric disorder until 1973!

ICD-10: "Childhood Autism"

"Aspergers"

'No decision about me without me'

NHS have a duty to promote the involvement of patients/carers in decisions about their own care.

(National Health Service Act 2006)

We are not bound by ICD-10 terms

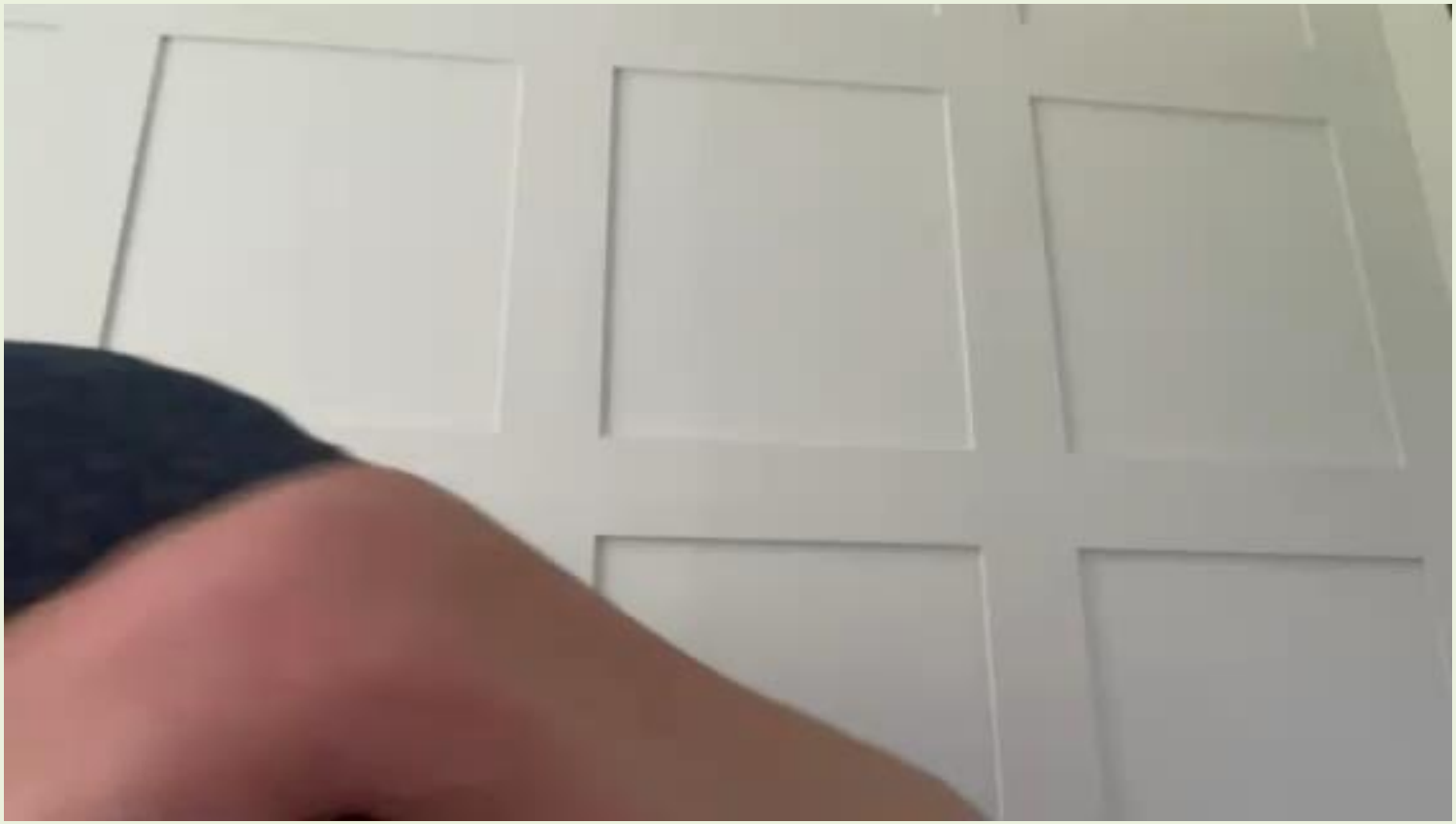
"Mental Retardation"

is the 'correct' term, but is *never used*.

ICD-10: "Childhood autism"

It's not just us asking these questions…

- Autism **acceptance** contributes to good mental health *(Cage et al)*
- **Positive autistic social identity** appeared to offer protective mechanisms against poor mental health (*Cooper et al, 2017)*
- Meaningful participation in autism research involves respect, authenticity, **assumptions**, infrastructure and empathy *(Sue Fletcher-Watson et al, 2019)*
- "**Self-determination** should be at the centre of any discussion…Autistic people should be directing the language used to describe autistic people" (*Botha et al, 2020)*
- Describing autism in negative ways "has a negative effect on how society views and treats autistic people and maybe even negatively effect how autistic people view themselves" *(Bottema-Beutel et al, 2021)*
- "Re-conceptualising autism as purely a 'developmental disorder' to recognising a **neurodiversity** perspective" *(Happe & Frith, 2020)*
- Qualitative themes reflected the **rejection** of stigmatising and medicalised language. (*Bury at al, 2020)*



“We are all made different. Autism is just one of those differences between human beings. Yes, it may be more challenging in the life of a person. It may put more barriers in their way but that's it. It's a difference, which is why we can't have any negative aspects of how we describe it, just as we can't for any other difference in human beings. It is important to me because I know some of my greatest, unique attributes derives from me being on the spectrum and I wouldn't be without them. Stuff anyone who tries to put a negative tint on that because I am great”

“Where next? As with everything else, education! Push forward, go forward with education about people on the spectrum. Make it as common as sliced bread and margarine and bubble-gum in society. Make it so that neurotypical people don't think twice when they hear someone has autism. That’s was I think!

Have we enabled change and delivered improvement?

Made it accessible

https://youtu.be/F03Dwp5YWw8
(approx. 1700 views)

Spread the learning

Asked for commitment

Everyone asked to reflect upon (and change) the language they use

Reflections

Should we describe people using language they find offensive?

***Who* should decide the words that are used to describe a whole community of people?**

Who cares the most about the language used?

***Who* has the power to change it?**

Freya

Might your practice change as a result of this project?

Let us know at Sli.do #3011036

Alison Wellon, Coordinator, Friends 2 Friends (F2F)

James Channon, Member of Friends 2 Friends, Friends 2 Friends (F2F)

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OPEN FORUM EVENTS