Consultation Report: How we speak about autism across county council and NHS services in Cumbria

Overview

The language county council and NHS services in Cumbria use when speaking about autism is often inconsistent, with terms such as Autistic Spectrum Disorder (ASD) or Condition (ASC), autism or autistic being used interchangeably.

Cumbrian young people and their families have told us they are uncomfortable with the inconsistencies.

National guidelines have been published which recommend using the terms autism or autistic, rather than ASD or ASC. This stance has been supported by organisations such as Autistica and the National Autistic Society.

Cumbria County Council and the NHS conducted a consultation to find out how Cumbrian residents would prefer services to speak about autism in the county.

The consultation was written in co-production with National Autistic Society Young Ambassadors, Maya Stretton, Leah Benjafield and Pavan Bhamidipati, parent carers of autistic children and young people from Special Education Needs and Disabilities Alliance Cumbria (SENDAC) and SEND professionals employed by Cumbria County Council and the NHS.

Methodology

The qualitative consultation consisting of two sections and ten questions was approved and endorsed at SEND Improvement Board on Tuesday 28 September 2022 by 23 SEND professionals from the county council and NHS services at all levels of governance.

The autistic and neurodivergent community, parent carers, friends and family of autistic people and professionals who work in services that support autistic children and adults were invited to complete the online consultation.

Between Wednesday 28 September 2022 (launch date) and Wednesday 9 November 2022 (close date), the consultation was live on the Cumbria SEND Partnership database (4,435 subscribers), social media to Cumbria's SEND Local Offer Facebook page (a following of 1,426), SENDAC's Facebook page and closed groups (a following of 725), Cumbria County Council Facebook (a following of 34,000) and Twitter page (a following of 28,100), and an information page created on the Cumbria SEND Local Offer Website.

Communications teams from Cumbrian NHS Integrated Care Boards (ICBs) and Foundation Trusts supported the promotion of the consultation with their service users on social media, via newsletters and internal communications to employees.

34 Cumbrian organisations or charities that state they provide services or support autistic people were invited to take part in the consultation and share with their services users. The

list of recipients was constructed in co-production with parent carers, SENDAC representatives, Cumbria County Council and NHS SEND professionals.

Cumbrian schools were invited to take part in the consultation via the Cumbria Schools Portal and the Cumbria Association of Secondary Headteachers (CASH) and Primary Headteachers Association (PHA) database.

The profile of the consultation was raised via two press releases that achieved coverage in Cumbria.

Furthermore, Barbara Kewn (SEND Consultant) and Nicola Wood (SEND Communications and Engagement Officer) delivered presentations on the consultation to a Mental Health Champions forum and at a NHS Cumbria Speech and Language Therapy event.

Respondent profile

A total of 569 respondents shared their views in the autism terminology consultation.

Over half of respondents (55%, 313) are aged 35 to 54, with 11% (54) of respondents under 25 and therefore may receive support from the Cumbria's SEND Partnership.

Table 1: Respondents age

Base size: 569

Age	% and count
0 to 4	1% (5)
5 to 11	1% (3)
12 to 16	2% (9)
17 to 25	7% (37)
26 to 34	17% (99)
35 to 44	29% (164)
45 to 54	26% (149)
55 to 64	14% (80)
65+	4% (23)

A large majority of respondents identify themselves to be a friend or family member of an autistic person (77%, 439), with one quarter of all respondents stating they identify as autistic (25%, 141).

Respondents were able to choose multiple categories therefore the percentages do not add up to 100.

Table 2: Respondents' self-described profile

Base size: 569

Respondent profile	% and count
Friend or family member of an autistic person	77%, 439
A parent carer of an autistic child, young person, or adult	52%, 298
A professional who works in a service that supports autistic people	50%, 284
Identify as neurodivergent	31%, 175
Identify as autistic	25%, 141

Analysis

Respondents were asked to rate the following terms used to describe autism out of five (one for dislike the use of the term very much, to five, like the use of the term very much):

- I am autistic/my child or young person is autistic/an autistic person
- I have/my child or young person has autism/a person with autism
- I have/ my child or young person has/ a person has ASD
- I have/ my child or young person has/ a person has ASC
- I have/ a child or young person has/a person has traits or symptoms of autism
- I am/ a child or young person is/ a person is neurodivergent
- I am/ a child or young person is/ a person is on the spectrum

Each term received a weighted average score; a score closer to five is a term respondent like very much and closer zero, a term they dislike very much.

With a weighted average score of 3.78, the most liked term amongst all respondents (463) is 'I am autistic/my child or young person is autistic/a person is autistic', with 'I have/ my child or young person has/ a person has ASD' the least preferred term (weighted average score of 2.20).

Table 1: Weighted average score of terms used to describe autism

Base size: 463

Respondent profile	Weighted Avg.
I am autistic/my child or young person is autistic/an autistic person	3.78
I have/my child or young person has autism/a person with autism	3.34
I am/ a child or young person is/ a person is neurodivergent	3.21
I have/ a child or young person has/a person has traits or symptoms of autism	2.47
I have/ my child or young person has/ a person has ASC	2.38
I am/ a child or young person is/ a person is on the spectrum	2.36
I have/ my child or young person has/ a person has ASD	2.20

Respondents were then asked to choose out of the list of terms, the one they prefer **the most** when speaking about autism.
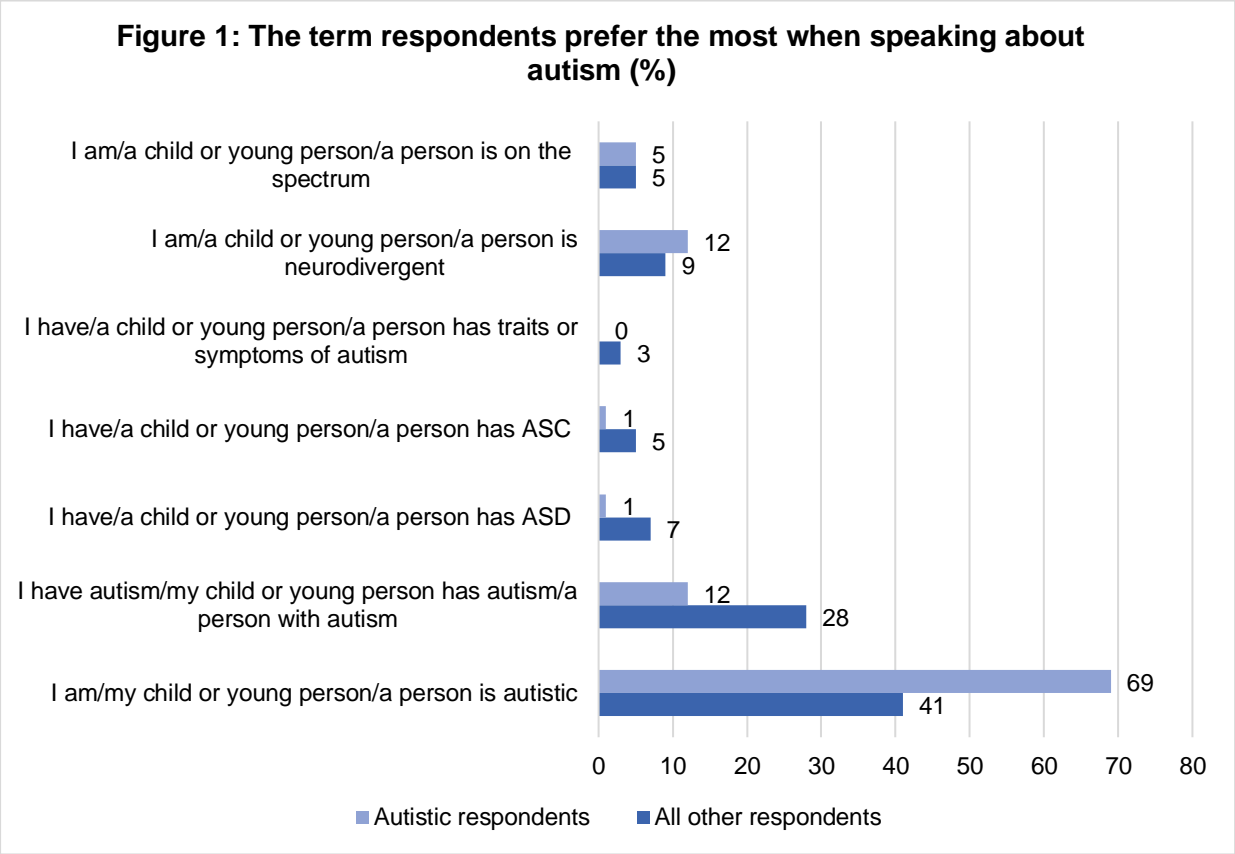
Almost half of all respondents (49%, 227) prefer the term 'I am autistic/my child or young person is autistic/a person is autistic'.

Sub-group analysis shows:

The term 'I am autistic […]' is **favoured by autistic respondents**, with over two thirds (69%, 90) and similarly, by 66% (103) of neurodivergent respondents.

One quarter of all respondents prefer the term 'I have autism/my child or young person has autism/a person with autism' (24%, 110). This reduces to 13% (21) with neurodivergent respondents and 12% (16) with autistic respondents.

Figure 1 compares autistic respondents' most preferred term with of all other respondents. This 'all other' group includes parent carers, family and friends, professionals and those that identify as neurodivergent.

Figure 1: The term respondents prefer the most when speaking about autism (%)

Term	Autistic respondents	All other respondents
I am/a child or young person/a person is on the spectrum	5	5
I am/a child or young person/a person is neurodivergent	12	9
I have/a child or young person/a person has traits or symptoms of autism	0	3
I have/a child or young person/a person has ASC	1	5
I have/a child or young person/a person has ASD	1	7
I have autism/my child or young person has autism/a person with autism	12	28
I am/my child or young person/a person is autistic	69	41

Respondents were then asked if there are any other terms they prefer to use when speaking about autism that have not been listed as an option in the consultation.

A large majority felt all terms for autism were covered, however it is clear some respondents identify differently and have alternative preferences.

A small number of respondents prefer 'Asperger's' or 'Asperger's Syndrome' as it is the term used at their diagnosis. Though it should be noted that Asperger Syndrome has now been reclassified under autism spectrum disorder and is no longer an official diagnosis.

Slang terms for autism and Asperger's were referenced such as 'tistic', 'tism' and 'astie'.

Other respondents referenced a specific 'difference' relating to autism such as 'sensory processing needs', that they are 'high functioning' or have 'social anxiety', with some focusing on broad terms relative to need such as, 'particular', 'specific', 'additional' or 'special', rather than being labelled as autistic.

The main theme identified in the comments is identity should be put first before any diagnosis, disorder or medical condition. Children, young people or adult's names should be

used in first instance, or an individual should be asked what language the person prefers to use or identifies with.

One respondent referenced autism to be a 'superpower' and individuals need to be empowered by professionals or services to identify and communicate in the way they prefer.

> **Respondent quote:**
>
> *"Treat everyone as an individual and see where it takes you."*

A full list of comments in response to this question are available in the form of an excel document and are available on request from hayley.stewart@cumbria.gov.uk.

Respondents were asked to think about the term(s) for autism they dislike and describe how it makes them feel when they hear them being used.

92% (395) of respondents' comments had a negative sentiment (8%, 33 neutral).

The percentage of negative sentiment comments increased to 95% (122) with respondents that identify as autistic, with terms they dislike making them feel 'as though autism is a disease, or something [they] "carry around" with [them] rather than a fundamental part of [their] being.' Words such as 'depersonalised', 'uncomfortable', 'stigmatised' and 'as though [they] are a problem' were also mentioned.

Negative feelings towards the terms disorder and condition were frequently referenced by autistic respondents and they appear to have the most negative impact on their wellbeing as they 'assume limits on their ability and potential':

> **Autistic respondents' quotes on the terms disorder and condition:**
>
> *'It makes me feel like being autistic is a problem/something to be ashamed of/something wrong when it isn't.'*
>
> *'Even though I consider "having autism" a perfectly valid term to be used is a less-preferred term to me because [it] feels as though it's only adjacent to the person or is attached to the person. Autism is intrinsic to an individual's personality, so "is autistic" feels more accurate.'*
>
> *'I don't favour disorder – it makes me feel there is something wrong with me.'*

It is important consider that some respondents who favour the term 'have autism' do not believe autism is intrinsic to them and feel negatively towards being labelled as autistic first.

For example, one respondent stated 'I am being told autism is all I am, I don't think it is, I am me and then I have these feelings I find hard, which means I have lots of diagnosis, one of those is autism. It is something I have, not who I am.'

A full list of comments in response to this question are available in the form of an excel document and are available on request from hayley.stewart@cumbria.gov.uk.

Conclusion and recommendations

There is clear preference amongst all respondents (49%, 227) and more specifically, autistic respondents (69%, 90), for using identity-first terms when speaking about autism. For example, 'I am autistic/ a child or young person is autistic/ an autistic person'.

The findings therefore support Cumbria County Council and NHS services to adopt the use of identity-first language as consistent terminology when speaking about autism to better support service-users.

However, it is important to consider not all respondents believe autism is intrinsic to them, individuals self-identify and there are varying preferences.

Terms ASD and ASC have a negative impact on autistic people, their friends and family, making them feel defected, diseased and like something is wrong with them.

Based on the findings, three recommendations have been drawn.

1. Cumbria council and NHS services adopt identity-first language

It is recommended services adopt identity-first language as the preferred and consistent terminology used to describe autism in both verbal and written communications.

For example, 'I am autistic/ a child or young person is autistic/ an autistic person'.

2. Eradicate the use of the terms ASD and ASC unless speaking about an official diagnosis

Due to the negative impact the terms ASD and ASC have on autistic people, their friends and family, it is recommended current documentation is updated to eradicate the terms ASD and ASC. In addition the terms should no longer be used in verbal and written communications from Cumbria council and NHS services or employees.

Autistic Spectrum Disorder (ASD) will remain as the medical diagnostic term and therefore should still be used when discussing a diagnosis or within the formal diagnosis letter.

3. Identity must come first

Although there is a clear preference amongst respondents for identity-first language to be used when speaking about autism which offers an opportunity for services to adopt consistent terminology, it is evident identity should be put first before any diagnosis, disorder or medical condition.

When specifically speaking about autism, if an individual declares identity-first terms are not their preference, they should be asked how they would like to be identified, and their choice should be supported, respected and used whilst communicating with them.