

Autism Awareness Survey 2024



Aim:

to gather data on how autistic people, and those who support autistic individuals, perceive public awareness and understanding of autism.



There was involvement of autistic staff members at all stages of development, including review from members of the National Autistic Society's Autistic Colleagues Network (ACN).

Data Collected:

Informed consent to carry out the survey was given by all participants.

- demographic data
- 17 targeted questions relating to key survey topics
- quantitative and qualitative data collected

The survey ran from 3rd-16th June 2024

The survey was advertised via social media, targeted emails and word of mouth.



Public understanding of autism

Finding support and understanding

Behaviour of the public

Key Survey Topics

Impact of the public

Public assumptions of autistic people

Changing perceptions

Eligibility Criteria:

Autistic

OR

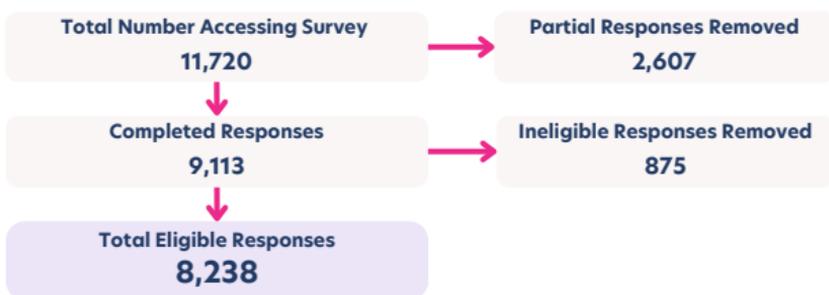
Provides support to an autistic person

Lives in the UK

AND

Aged 16+

Engagement Figures



Participants

Autistic Participants



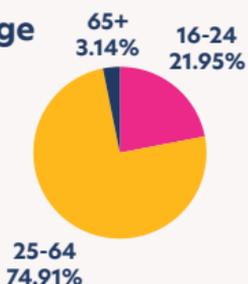
Autistic Respondents

4,231

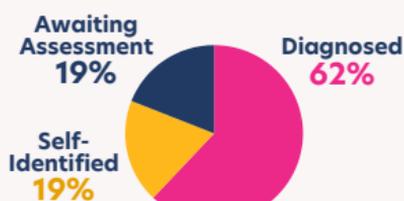
Most commonly represented:

- Female
- Aged 25-64 years
- No, or minimal, support needs

Age



Diagnostic Status



Location

- Northern Ireland 1.61%
- Scotland 8.08%
- Wales 6.31%
- East Midlands 6.92%
- West Midlands 7.94%
- East of England 7.51%



- London 9.55%
- Yorkshire and the Humber 8.51%
- North East England 4.09%
- North West England 11.53%
- South East England 17.23%
- South West England 10.73%
- Outside the UK 0%

Non-Autistic Participants

88% of non-autistic respondents



were parents or carers of an autistic person.

Due to this, we have referred to the non-autistic group as **parents/carers** to reflect the majority of the relationships involved.



Non-Autistic Respondents

4,007

Most were aged

25-64

and support a child or young person

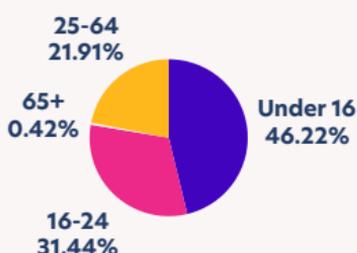
The autistic person they support:

Most commonly:

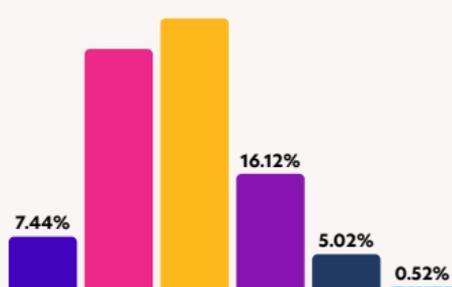
- Male
- Under 16 years
- Needing a lot of day-to-day support



Age of the person they support



Support Needs



- They have no or minimal support needs
- They need some support with day-to-day tasks
- They need a lot of support with day-to-day tasks
- Their support needs change a lot
- They like to describe their support needs in a different way
- I don't know

Limitations

Although a large number of people completed the survey, as with all surveys, there are limitations to the conclusions that can be drawn from the findings and how far these can be generalised.

These include:

- Key differences in the demographics of the autistic people in the two respondent groups (majority female with no/minimal support needs vs. majority male with high support needs). Any comparison of the two groups must take this into account;
- All data collected in the survey is self-reported and subjective - it reflects the participants' perceptions of experiences and events, and their interpretation of the questions in the survey;
- The sample may not reflect the views of autistic people who are less-represented in research or surveys, such as those from minority ethnic groups or those who have minimal or no speech;
- In the autistic group many were not formally diagnosed (38%);
- Participants were a self-selecting sample - they may represent a specific (and potentially biased) sample which could limit the generalisability of results across a wider autistic population.

Key Findings

● Autistic Participants

● Parents/Carers

Public Understanding of Autism

"Most people I meet have heard of autism"



% of participants that agree with this statement



"Most people I meet have a good understanding of autism"



% of participants that agree with this statement



Respondents were asked if the people they meet show that they are aware of some specific autistic experiences.

The figures below show the % of respondents who selected **'very few people I meet'** or **'no-one I meet'** is aware.

High % = Low Awareness

Need for extra time to process spoken information



Masking



Sensory seeking



Repeating words/phrases/noises



Talking loudly, or formally



Confusion by certain language or phrases



Noticeable distress such as 'meltdowns' or 'shutdowns'



Sensory sensitivity



Using few or no words



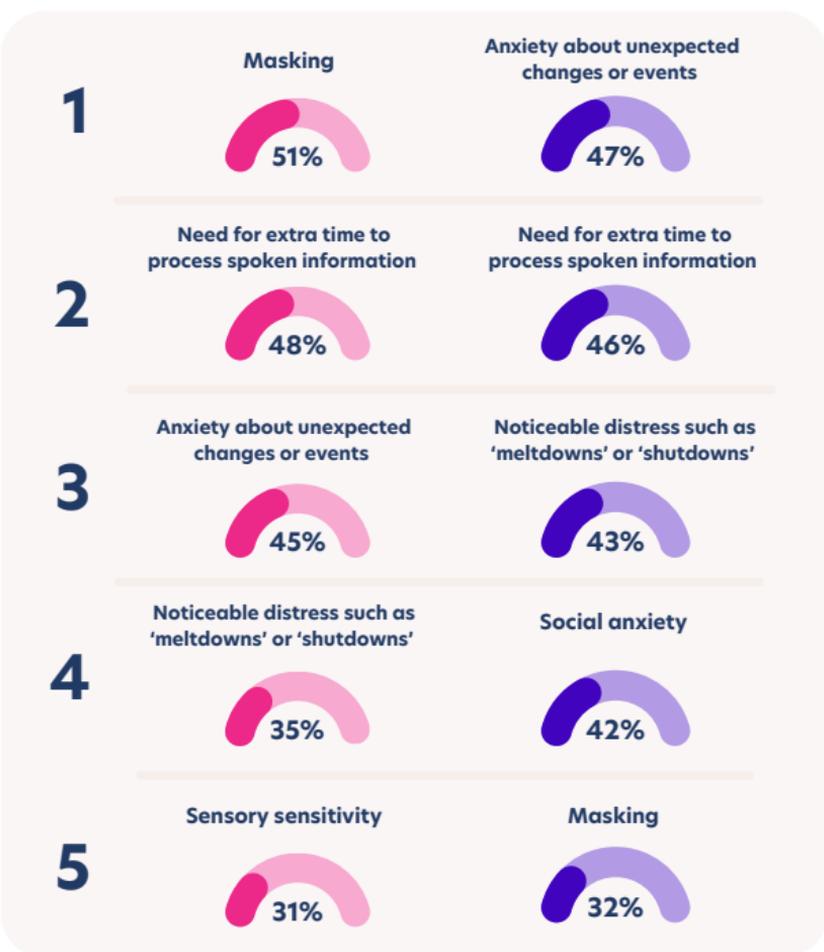
Stimming



Improving Awareness



The top five things that respondents wished other people were more aware of:



Disclosure



"How do members of the public usually respond when made aware that you are/the person you support is autistic?"

Reaction to disclosure	Autistic Participants	Parents/Carers
Positive Reaction	12%	35%
Neither positive or negative	27%	34%
Negative reactions	25%	23%
Don't tell the public	31%	8%
Don't know	4%	1%

Changing Perceptions



Both groups shared the same top three priorities of things they most want people to understand about autism:

"The idea that 'We are all a little bit autistic' is untrue and dismissive of our challenges"



"Autistic people should not be underestimated - autistic people have the potential to achieve so much more than society allows"



"Autistic people should not have to 'look autistic' to prove that they are"



Of least concern were:

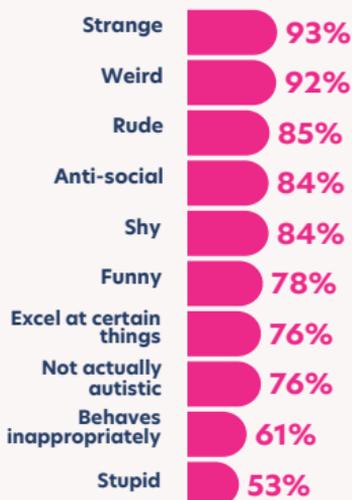
- understanding around autism terminology/language
- understanding that not all autistic people have a special skill, such as being good at Maths.

Public Assumptions

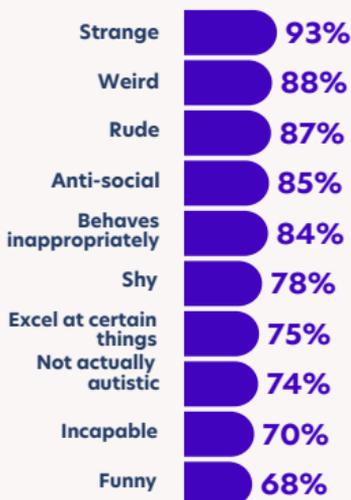


Respondents reported they had either **'more than once'** or **'many times'**, been described as, or assumed to be:

Autistic Participants



Parents/Carers



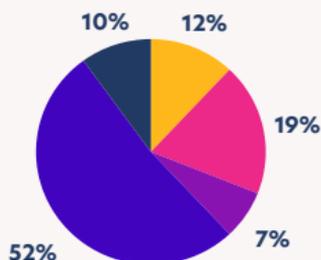
Key Findings

Behaviour of the Public

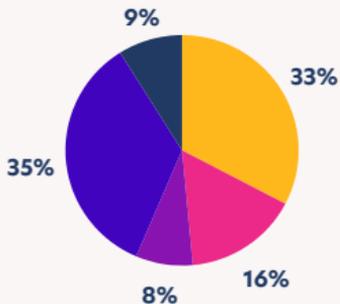


Respondents were asked how they are treated by the public when they go out:

Autistic Participants



Parents/Carers



- Experience a friendly response
- Treated no differently to anyone else
- Experience an unfriendly response
- I don't think people know I'm/they're autistic
- Don't know/Don't go out



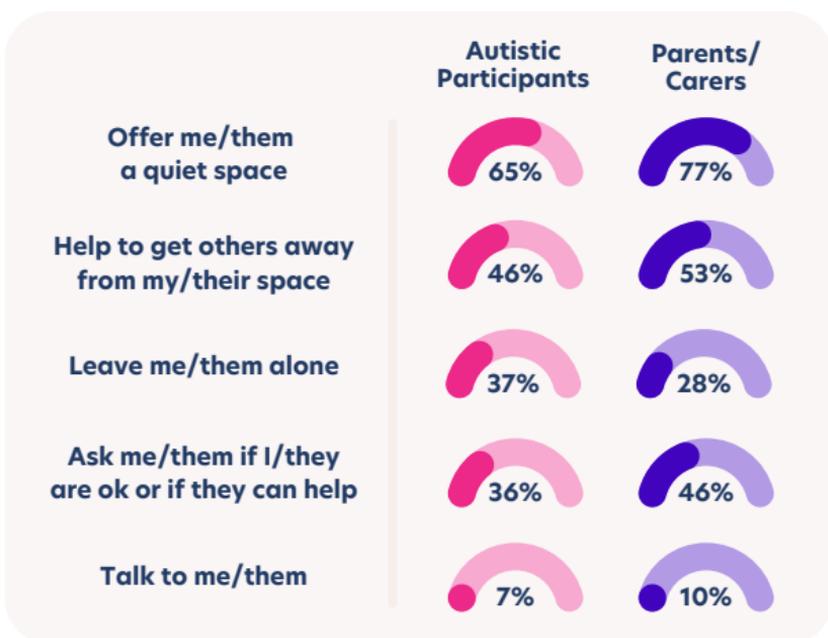
"How often do members of the public react in the following ways when you, or the person you support, are showing noticeable distress e.g. sensory overload or a 'meltdown'?"

	Autistic Group (most selected response)	Parent/Carer Group (most selected response)
People leave me/ them alone	Often 44%	Often 53%
People ask if I/they are ok or if they can help	Rarely 29%	Rarely 34%
People offer me/ them a quiet space	Never 53%	Never 44%
People stare	Often 35%	Often 62%
People tut, shake their heads, or make disapproving noises	Don't Know 33%	Often 37%
People actively avoid me/ them or get out of the way	Don't Know 33%	Often 38%
People ask me/ them to leave the places I'm in	Never 54%	Never 41%
People get aggressive with me/ them	Never 42%	Never 44%
People mock or taunt me/ them	Sometimes 25%	Sometimes 34%

Behaviour of the Public

Q

“When you, or the autistic person you are with, is visibly anxious, experiencing sensory overload, or having a meltdown, what would you like members of the public to do?”



Both groups reported that the best thing a person could do to help an autistic person who is experiencing distress was to **offer a quiet space away from people**.

Despite this, **44-53%** reported that being offered a quiet space when they have been distressed had **never happened**.

Q

“What else should the public do?”

Both groups shared the same top three priorities:

1

Make small changes in their environments e.g. at work/ public spaces that could have a big impact on autistic people.

78%
of all respondents

2

Educate themselves about autism.

69%
of all respondents

3

Become more open-minded in the way they think everyone should behave.

68%
of all respondents

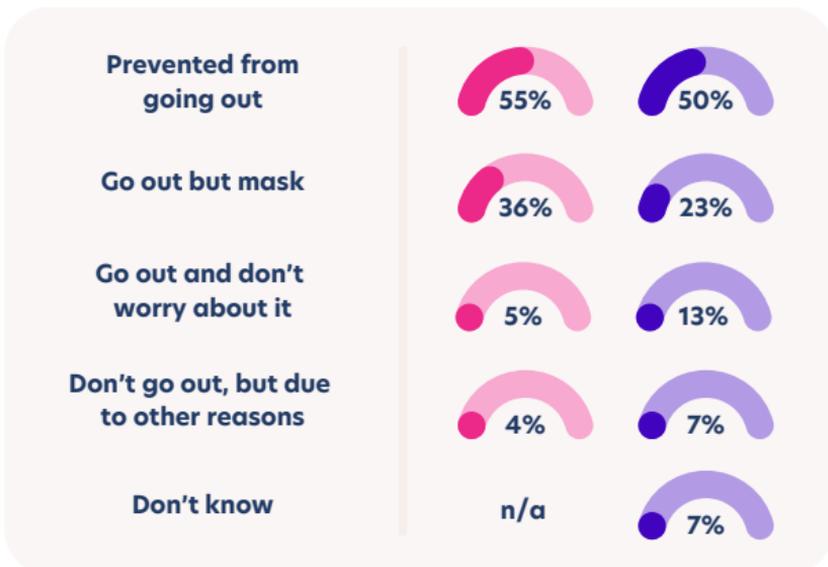
Key Findings

Impact of the Public

● Autistic Participants
● Parents/Carers



Respondents were asked if they ever stay at home because they are worried about how people they meet will treat them:



Both groups report a **significant impact** on autistic people's ability to leave the house due to worries about how **other people will treat them** (50-55% of respondents).

Only 5-13% of autistic people reported that they do not worry about going out.



"If you/the person you support feel(s) socially isolated, which phrases most reflect how you/they feel about this?"

Statement	Autistic Participants	Parents/Carers
"I/they don't mind it"	29.71%	25.39%
"I/they would like to have more friends"	44.53%	53.17%
"I/they feel lonely"	47.24%	43.33%

While around ¼ of each group reported **'not minding'** their social isolation, in both groups higher numbers reported that they **'would like to have more friends'** (45-53%) or that they **'feel lonely'** (42-47%).

Feeling Understood



Both groups reported on who they felt had the best understanding of autism amongst the people in their life:

Autistic Participants

- Friends (42%)
- Partners (32%)
- Parents/Carers (27%)
- Other (22%)
- Other Family Members (19%)

Parents/Carers

- Parents/Carers (91%)
- Educators (25%)
- Other Family (25%)
- Health and Social Care Professionals (24%)
- Grandparents (21%)

The **difference in demographics** between the two groups likely accounts for the differences in responses for this question.

The majority of the non-autistic group were answering on behalf of their **autistic child**; the majority of the autistic group were **adults**.

Feeling Supported



Both groups also reported on who they felt had been the most **positive and supporting**:

Autistic Participants

- Friends (46%)
- Partners (38%)
- Parents/Carers (35%)
- Other Family Members (21%)
- Other (13%)

Parents/Carers

- Parents/Carers (93%)
- Grandparents (33%)
- Other Family Members (29%)
- Educators (27%)
- Friends (22%)

Over **90%** of the parent/carer group reported that most understanding and support came from **parents/carers**.

For the Autistic group this was **more evenly distributed** across friends; partners; and parents/carers.



Respondents were asked if they had ever experienced any of the following due to other people's **attitudes or perceptions** of autism.

The table gives the % of 'Yes' responses for each category:

	Autistic Group (most selected response)	Parent/Carer Group (most selected response)
1	Poor mental health 90%	Social isolation 81%
2	Social isolation 84%	Inability to attend leisure activities 78%
3	Loneliness 80%	Loneliness 74%
4	Inability to attend leisure activities 77%	Poor mental health 72%
5	Lost friendships 74%	Lost friendships 66%
6	Poor physical health 63%	Inability to attend education 56%
7	Unable to leave the house 59%	Unable to leave the house 54%
8	Fallen out with/isolated from member of their own family 58%	Poor physical health 46%
9	Inability to attend employment 55%	Inability to attend required support 42%
10	Inability to attend education 49%	Fallen out with/isolated from member of their own family 42%

Both groups reported the same top 5 negative impacts resulting from poor public attitudes and understanding of autism:

- 1 Poor mental health
- 2 Social isolation
- 3 Loneliness
- 4 Inability to attend leisure activities
- 5 Lost friendships

Conclusions

Despite some shortfalls outlined in the limitations section, these survey findings are significant in capturing a large number of people's experiences.

They demonstrate a poor public understanding of autism and the significant and far-reaching negative impact this has for autistic people and the people who support them.

There were relatively few reports of positive experiences both in the Autistic and the non-autistic groups. However, on average, positive experiences were reported at a slightly higher frequency by the non-autistic group i.e. by the parents and carers of autistic individuals.

Instead, the findings were dominated by reports of negative experiences including:

- **Poor public understanding of autism; of autistic behaviours and experiences;**
- **Frequent, negative assumptions made about autistic people and their behaviour;**
- **A lack of understanding and appropriate help given to autistic people when needed (e.g. when visibly distressed);**
- **Experiences of taunting, mocking, and overt disapproval at distressed behaviours;**
- **Negative reactions to disclosure.**

There is a clear message from the survey data that much needs to be done to educate and motivate the general public so that they can accept, empower, and support autistic people, both children and adults, in the ways that they want to be supported.

It is also clear that it is often simple things that can make the biggest difference to autistic people:

- **To feel accepted as an autistic person without judgement or assumptions;**
- **To be able to feel safe when leaving the house and entering public spaces;**
- **To be given the opportunity to reduce loneliness and social isolation;**
- **To be offered help to access a quiet space when distressed;**
- **To be treated with kindness and understanding.**