

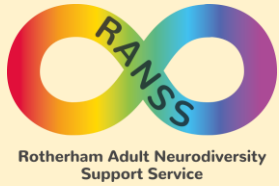


**Rotherham Adult Neurodiversity
Support Service**

Rotherham All Age Autism Strategy Engagement Findings

October 2023

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Background

Rotherham Parent Carer Forum & Rotherham Adult Neurodiversity Support Service (RPCF & RANSS)

RPCF is a registered charity governed by a Board of Trustees.

Rotherham Parent Carers Forum (RPCF) has a strong 13-year history of developing positive, effective working relationships with a wide variety of partners across the public, private and voluntary sectors within local children and young people's services. In equal partnership with RMBC, RPCF co-lead Genuine Partnerships, a community interest company created in 2010 to embed and implement the 4 Cornerstones of Coproduction, locally, regionally and nationally. Families living with Special Educational Needs and/or Disabilities are represented on several strategic and operational boards across health, education and social care and their role is to inform the development of services as active equal partners through sharing their knowledge and lived experience. RPCF work hard to ensure we understand the services that are available to families living with SEND across Rotherham and consequently has strong links with numerous other organisations across both the private and voluntary community and social enterprise sector and are active members of Rotherham's Children, Young People and Families Consortium. RPCF currently delivers on contracts and agreements with RMBC, ICB and DfE and all policies and processes for monitoring and evaluation are established.



In more recent years, RPCF have also welcomed the opportunity to extend these skills to work within adults services through our Rotherham Adult Neurodiverse Support Service (RANSS) and in particular are actively contributing to the All Age Autism Strategy, Learning Disability Strategy, Autism Partnership Board, SEND Preparation for Adulthood Board and have a current active partnership in South Yorkshire ICB , North East & Yorkshire ICS and NHSE long term plan Learning disability and Autism workstreams and communities of practice.

RPCF work regionally and nationally with partners to ensure the living experience of CYP, families and neurodivergent adults contributes to change for better outcomes.

Overview of Project

- RMBC were looking to commission a coproduction partner to facilitate and lead on the coproduction element of the All-Age Autism Strategy refresh, to be submitted to cabinet early 2024. RPCF, as a partner within the All-Age Autism workstream were invited to submit a proposal.
- RPCF have a successful history of coproduction and have developed a significant network of partners through equal partnership locally, regionally and nationally.
- The ethos and core value of RPCF & RANSS is to work in coproduction by embedding the 4 Cornerstones systemic approach, Welcome & Care, Value & Include, Effective Communication and Equal Partnership.

<https://genuinepartnerships.co.uk/>

1. Introduction

This report summarises the findings from a public consultation about the views and experiences of autistic people living in Rotherham and their parents and/or carers.

The format of this report has been chosen to enable increased accessibility in the following ways:

- Limit the amount of text on a page
- Ability to skip to the sections that people are interested in
- Facilitate it being broken up into subsections
- Facilitate conversion to text to speech videos

All the recommendations within this report are made by the autistic people and their parents and/or carers who contributed to the consultation. We would like to thank them for sharing their experiences and views with us.

2. Public Consultation & Engagement

2.1 Methodology

A public consultation was undertaken by Rotherham Parents Forum Ltd from 24th July 2023 - 10th October 2023. In developing the consultation, we were mindful of the specific needs of autistic people and their parents and carers. The following methods were used:

- A Microsoft forms document containing a range of open and closed questions was developed and published online. Text to talk videos reading the long pieces of text were provided as an option. Alternative methods could also be requested.
- 4 in-person focus groups also took place.
- A range of engagement events and contacts took place to make people aware of the consultation and how they could take part.

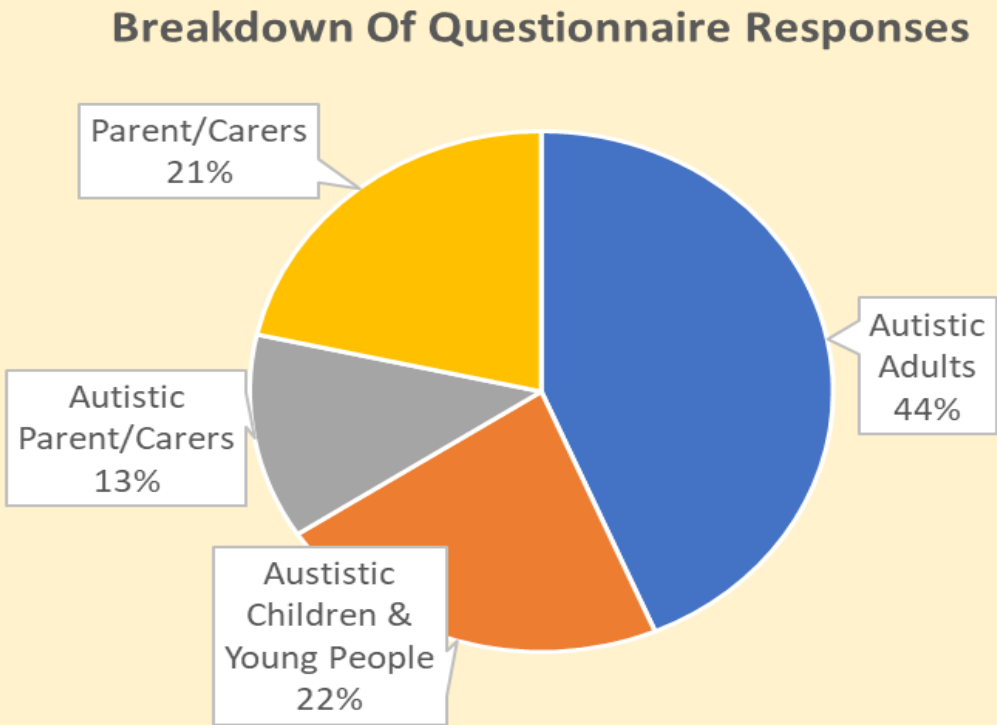
See appendix 1, 2 and 3 for further details.

An overview of the information collected is presented in this document and is compiled from a mixture of quantitative and qualitative information. Individuals could respond to some or all of the questions.

2.2 Breakdown of the responses

A total of 175 people provided their views and experiences, of which approx. 79% identify as autistic. No formal autism diagnosis was required so also includes people who self-identify or are questioning and their families. All focus groups were with autistic people and the questionnaire breakdown of responses is shown in the chart below.

Autism Strategy Public Consultation 2023 Responses	
Questionnaire	149 people
Focus Groups	26 people
Total	175 people



3. Data Analysis

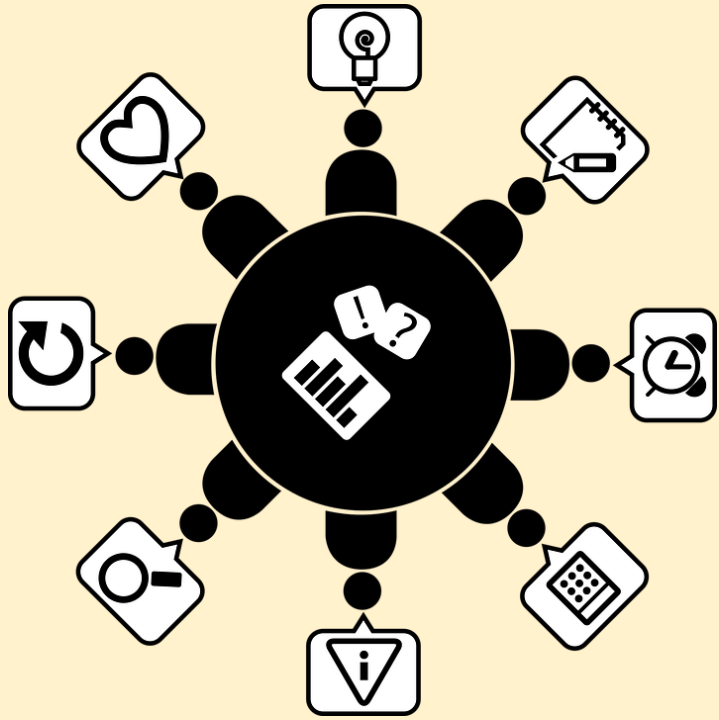
We analysed over 20,000 words of qualitative data. The questionnaire also collected quantitative data however, this was only used in a qualitative way to give context to the research and a voice for those who cannot use words to share their experiences.

We analysed the responses to identify themes which were then used to write this report.

4. Micro-Kindness

Micro-kindness refers to small, thoughtful acts or gestures that positively impact others in our daily lives. These acts can be as simple as offering a smile, holding the door for someone, or giving a genuine compliment. While they may seem insignificant individually, collectively these small acts create a ripple effect, fostering a sense of connection, empathy, and goodwill.

Throughout all the views and experiences shared with us, it was obvious just how important micro-kindness was. Many people's positive and negative experiences were often also based on the person/staff member that they had encountered and not solely about the service. Acts of micro-kindness evidently had a lasting impact and were greatly valued by those that shared their experiences with us.



Focus Groups

Focus Groups

In order to provide an alternative way for autistic people to express their views and share their experiences, we reached out to various organisations and service providers and extended an invitation to visit and engage in meaningful conversations with the autistic people that use their services. Additionally, we also held and advertised two focus groups.

In total, four focus groups took place with the following people:

- Nayi Zingadi – a community organisation who empower people with disabilities from ethnic communities
- Speakup For Autism – a self-advocacy group to give a voice to autistic people
- Autistic young people (under 18)
- Autistic adults (18+)

We used an informal discussion approach based around the themes of the questionnaire. The views and experiences shared in the focus groups have been included in the qualitative feedback sections of this report to keep anonymity.

Current Rotherham Autism Strategy

We also discussed the current autism strategy and overwhelmingly, people were not happy with the current strategy. They told us that:

- They did not like the categories of Starting Well, Developing Well, Moving on Well into Independence, Living Well and Aging Well. They were confusing, for example starting well is about children and young people being safe from harm but newly diagnosed autistic adults expressed how they were starting on a new part of their life as being a diagnosed/self-identifying autistic person.
- The current strategy feels very child and young person focused.
- The strategy is not available in a range of formats and languages.
- Parts of it on the website are incomplete.
- The implementation plan is not kept updated and is on a separate website page with no links from the strategy to the plan.
- The strategy and implementation plan are hard to find on the website, people could only find them via an internet search.

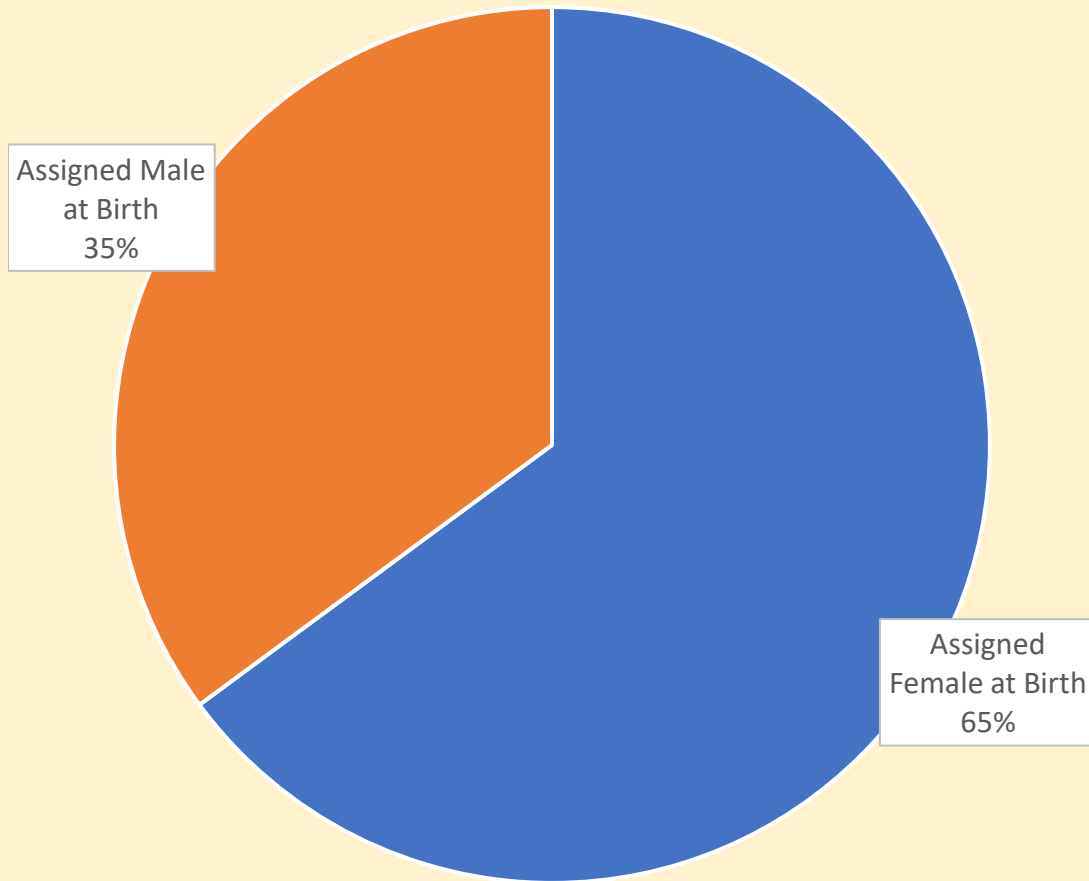
Demographics

Who shared their experiences with us.

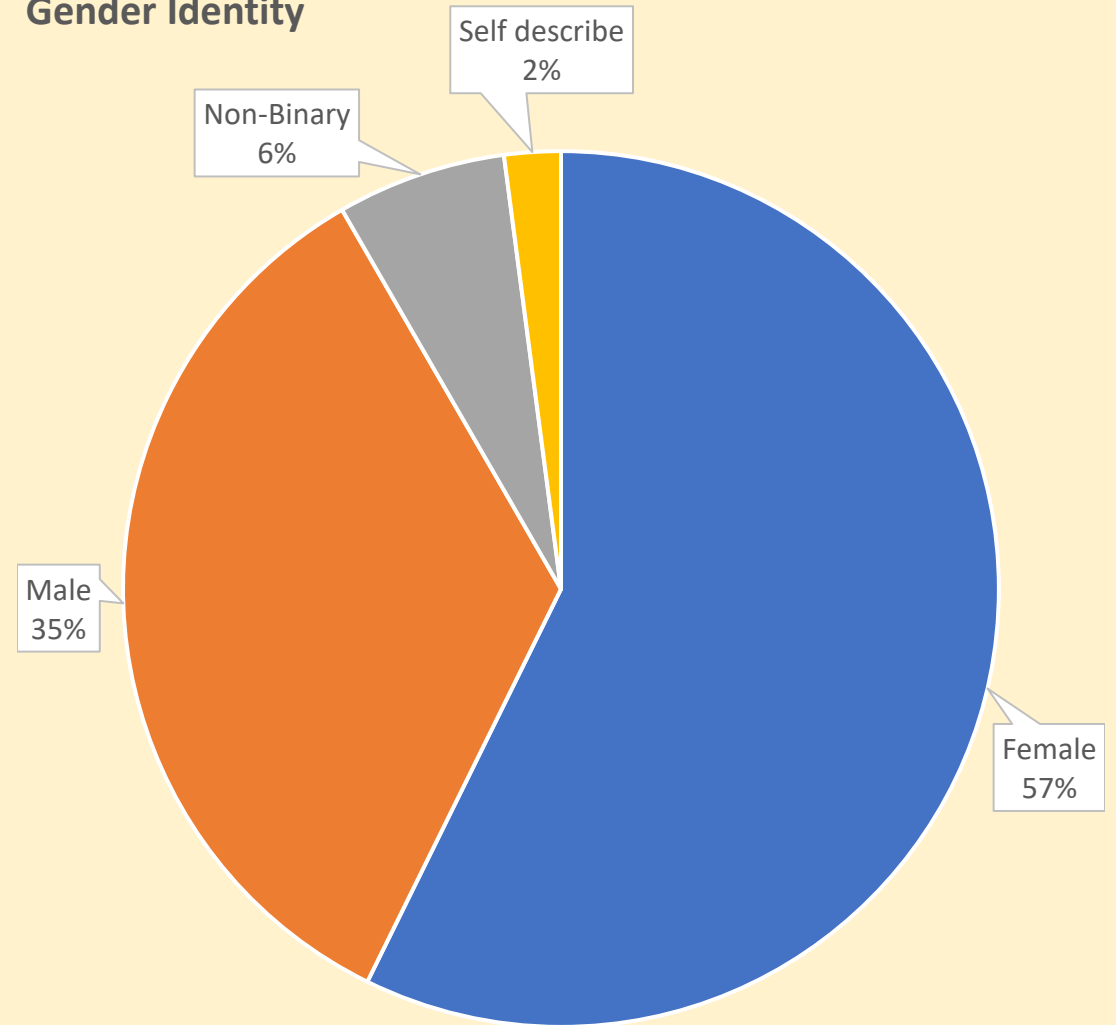


Questionnaire

Gender Assigned at Birth

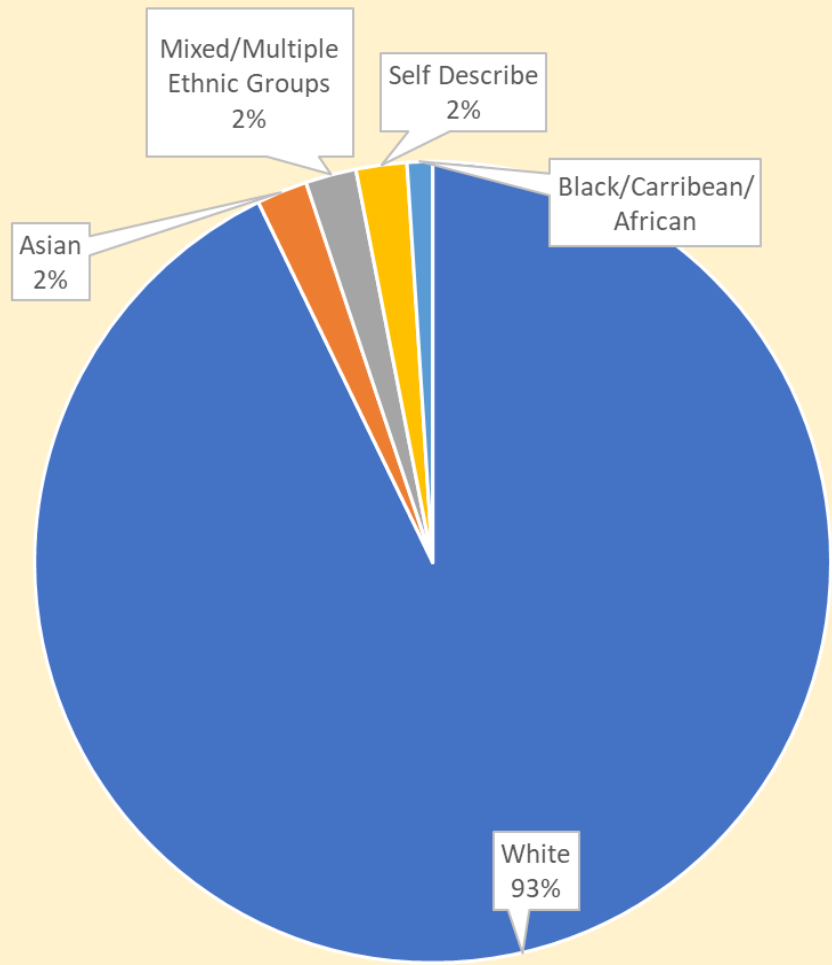


Gender Identity

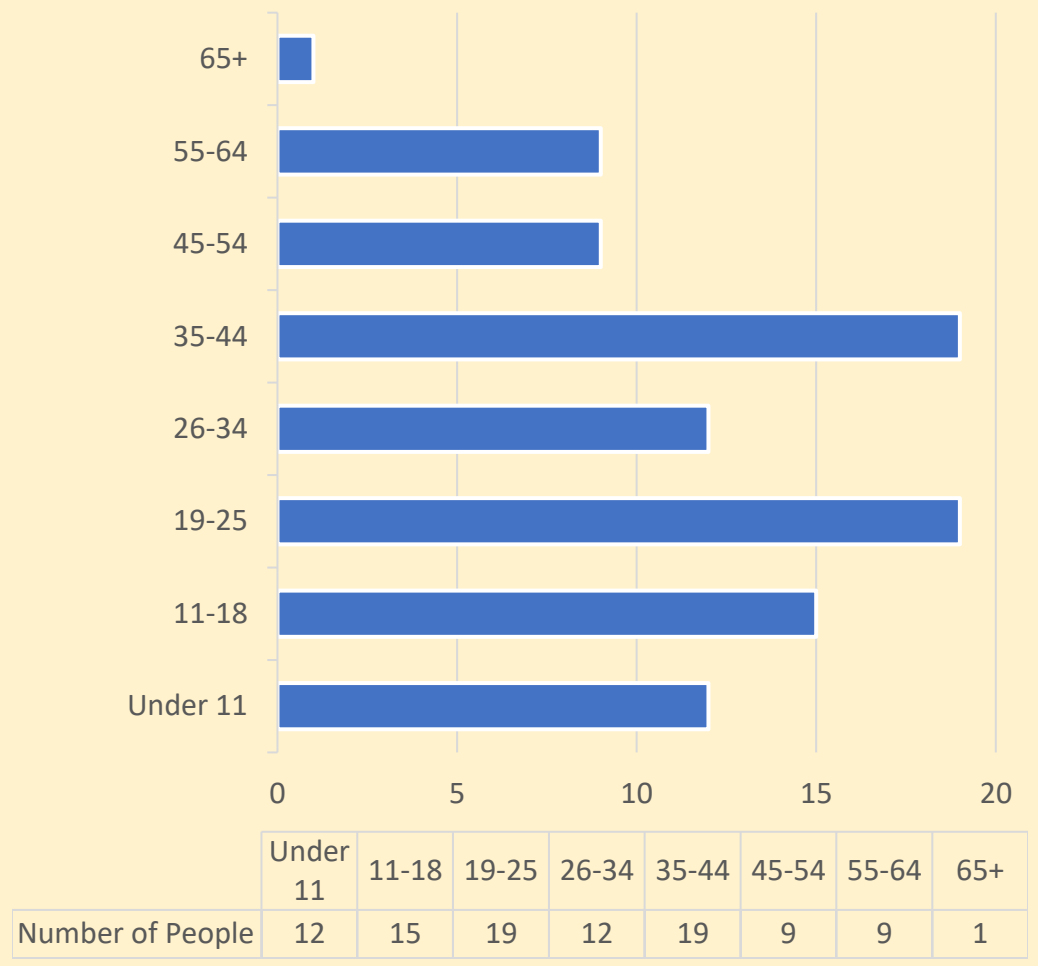


Questionnaire

Race/Ethnicity



Age



Starting Well

This section includes:

- Identification
- Assessment
- Diagnosis





Autism Diagnostic Experiences

Includes views and experiences of people who are not diagnosed but recognise or suspect that they are autistic.



Assessment and Diagnosis

We asked autistic people if they would like to share their experiences and views about diagnostic services. 82 people responded to this section of the questionnaire. They told us the following:

- 82% had a formal autism diagnosis
- 14.5% were waiting for an assessment
- 43.5% had difficulty being referred for an assessment
- 54% had been diagnosed as adults and 29% had been diagnosed under the age of 11 years
- 73.5% said that had been told what would happen during the assessment before it began
- 81.5% said that the staff appeared to have good knowledge about autism
- 94% said that they were treated with respect and kindness
- 78% said that they were kept informed about what was happening during the assessment process
- 83% said that they received a detailed diagnostic report
- Only 8% felt that a diagnosis had not helped them to better understand themselves

Co-occurring Diagnoses and Difficulties

We asked people if they had any co-occurring diagnoses and/or difficulties. 70 people responded saying that they did (approx. 86.5% of the people that responded to the diagnosis section). Of the people that answered this question, 88.5% told us that they had more than 1 co-occurring diagnosis or difficulty.

- 61% have mental health difficulties
- 46% have ADHD/ADD
- 40% experience sleep difficulties
- 29% have physical health difficulties
- 27 % have learning disabilities
- 24% have OCD
- 20% have an eating disorder
- 19% selected “other” which included PDA, specific learning difficulties, hypermobility and Fragile X

What Autistic Adults Told Us

Key Themes	Summary
Difficulty in Being Referred for an Assessment	Some GPs lacked understanding of autism leading to referral refusals/delays.
Waiting Times	Waiting times for autism assessments varied significantly, with some individuals waiting just a few months, while others waited for several years. Some people funded private assessments as a result.
Struggles with the NHS System	Individuals shared challenges with navigating the NHS system, including delayed diagnoses, referral issues, service criteria and lack of post-diagnostic support.
Communication From Services	- People reported a lack of communication whilst on the waiting list and communication breakdowns between services as problematic. For example, declined referrals without clear explanations. - Communication is always in English and full of jargon.

What Autistic Adults Told Us

Key Themes	Summary
Lack of Support	Many individuals highlighted the lack of support before, during and after the diagnosis and the significant impact it has.
Lack of Understanding	Particularly amongst females, people assigned female at birth and people from ethnic minority groups. Differences were often misunderstood or not considered at all.
Lack of Holistic Assessment	People reported having to undergo several diagnostic processes and lengthy waiting lists for commonly co-occurring difficulties and conditions to be assessed.
Impact of Delayed or Denied Diagnoses	The lack of a formal diagnosis had significant consequences on individuals' access to support and education.
Positive Impact of Diagnosis	Having a diagnosis was generally seen as a positive life-changing event, providing clarity and reducing the need to mask their true autistic self.

What Autistic Children and Young People Told Us

Key Themes	Summary
Difficulty and Delays in Being Referred for an Assessment	• There was a lack of clarity about who should make the referral, with some individuals and parents not knowing who to contact for the assessment. • Schools failed to recognise masking or other signs of autism. • Parents encountered institutional resistance or gaslighting, where they felt their concerns were not taken seriously, and they were met with scepticism or accused of being motivated by financial gain or personal issues. • In some cases, significant problems, such as school exclusions, were required for anyone to listen and initiate the referral process.
Long Waiting Times	• Due to the long waiting times and difficulties in getting referred, some parents resorted to private assessments to expedite the diagnosis process. • Can have a significant impact on mental health.

What Autistic Children and Young People Told Us

Key Themes	Summary
Lack of Support	Many individuals highlighted the lack of support before, during and after the diagnosis and the significant impact it has.
Lack of Holistic Assessment	People reported having to undergo several diagnostic processes and lengthy waiting lists for commonly co-occurring difficulties and conditions to be assessed.
Lack of Cultural and Religious Understanding	The diagnostic process can come into conflict with religious and cultural beliefs.

I had been trying to get a diagnosis since I was around 9 years old and was told that having a formal diagnosis would stop me from being able to get a job or further education in the future.

In reality, I was denied access to support I needed throughout school and my first year of university because I didn't have a formal diagnosis and I struggled to keep up with my peers

Support. There is no support waiting, or afterwards. What's the point of a diagnosis if there is no support?

My GP said autism was a childhood condition

I was glad I got a diagnosis. I could then stop pretending to be neurotypical. It was wearing me down trying to fit in. It made sense why I felt like I was from another planet

Improvements Suggested by Autistic Adults and Children and Young People

Recommendations	Summary
Reduce Waiting Times	• Increase resources and funding for diagnostic services to reduce the backlog of assessments. • Streamline the diagnostic process, possibly by merging assessments for related conditions like ADHD to save time and resources.
Support During and After Diagnosis	• Develop post-diagnostic support services to include peer support, mental health support, ADHD support, Occupational Therapy (including sensory), advocacy services and community support. It is important that these services work together. • Ensure a clear pathway for individuals to access these support services regardless of when or where they were diagnosed. • Provide support direct to children and young people to help them to understand themselves.

Improvements Suggested by Autistic Adults and Children and Young People

Recommendations	Summary
GP and School Education and Awareness	Develop training programs and resources for GPs and school staff to improve their understanding of autism, particularly in underrepresented groups.
Equality in Diagnosis	Promote policies and practices that eliminate discrimination in the diagnostic process.
Continuous Communication	- Staff to communicate openly and transparently with patients, addressing any questions or concerns. - Implement a feedback system for individuals whose referrals were declined, providing clear explanations and options for further action. - Communicate in a range of formats and languages.
Sensory-Friendly Environment	Create sensory-friendly waiting rooms and environments to accommodate sensory needs and improve accessibility.

Improvements Suggested by Autistic Adults and Children and Young People

Recommendations	Summary
Parental Involvement	• Parents often have valuable insights into the day-to-day experiences of their child and need to be believed and included in the assessment. • Pre, during and post diagnostic support for parents too.
Regular Updates	• Implement a system for regular communication or automated updates to individuals on the waiting list to keep them informed of their progress.

Developing Well

This section includes:

- Information & Advice
- Education
- Volunteering
- Employment



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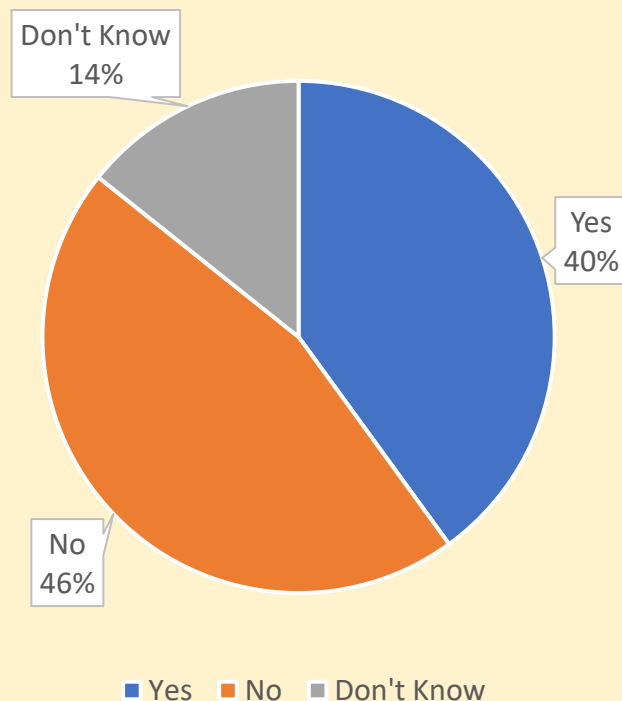
Information and Advice



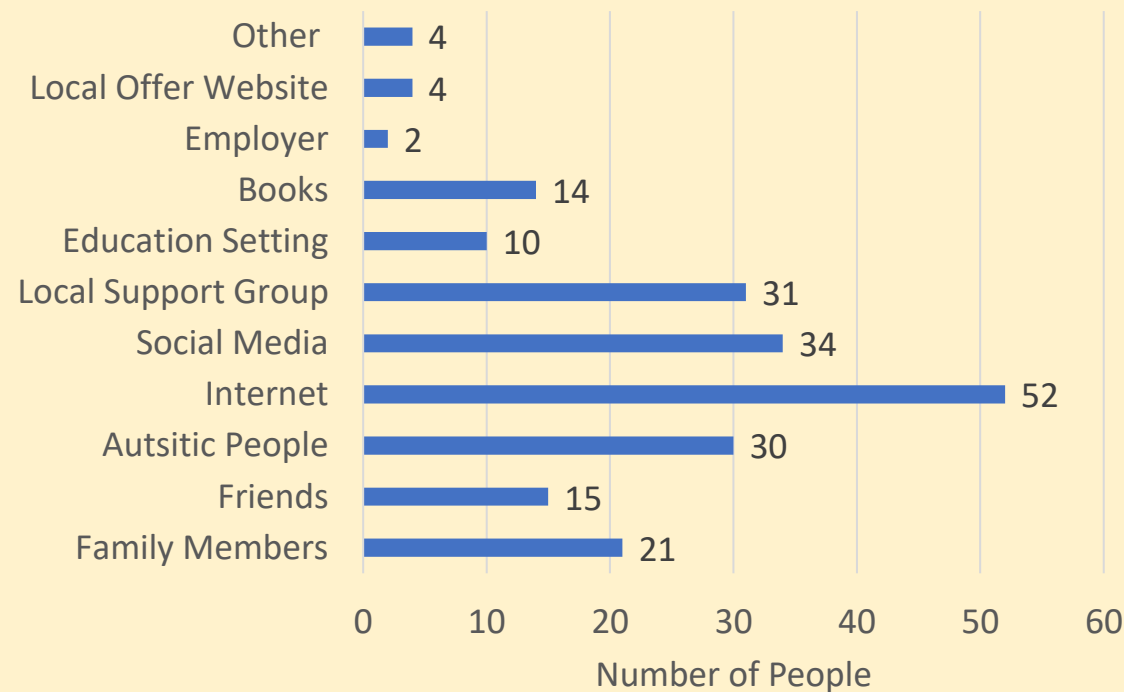
Information and Advice

We asked autistic people if they would like to share their experiences and views about accessing information and advice. 70 people responded to this section of the questionnaire. They told us the following:

Have You Been Able To Find The Information You Need?

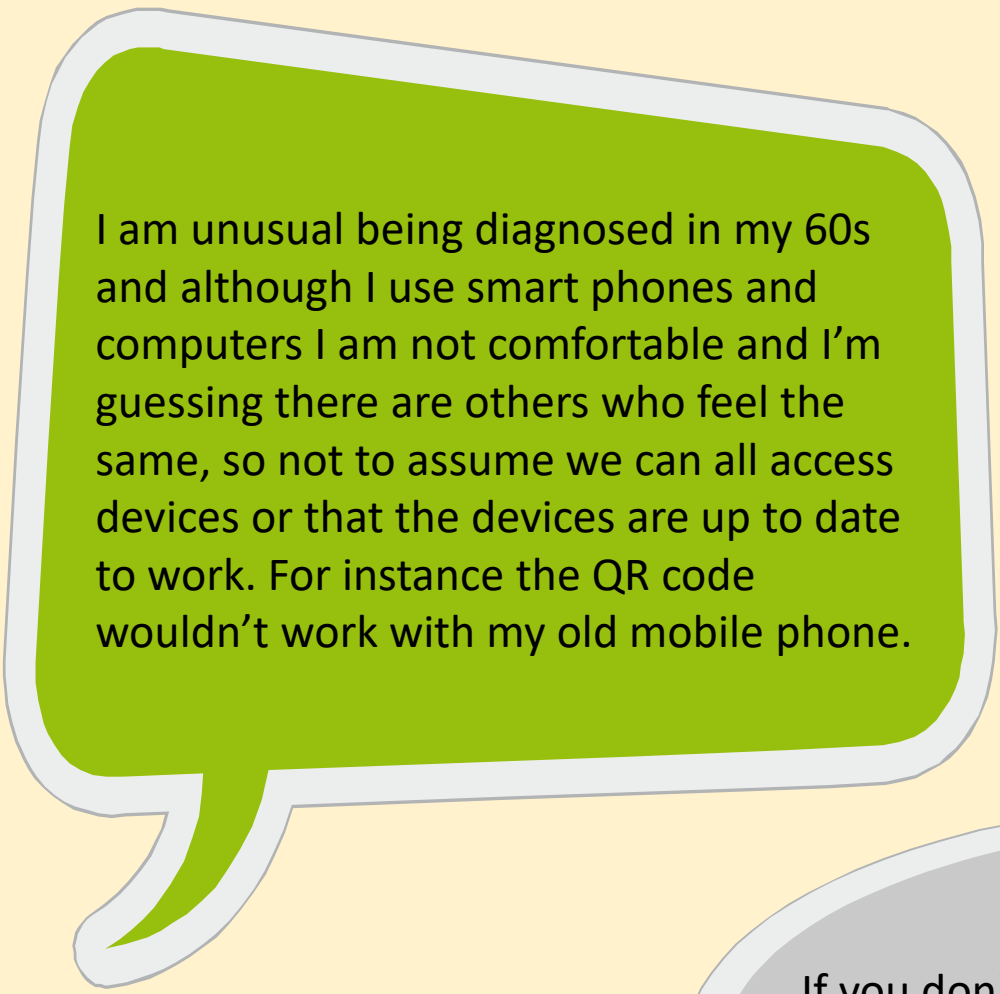


Where People Look For Information And Advice



What Autistic Adults, Children and Young People Told Us

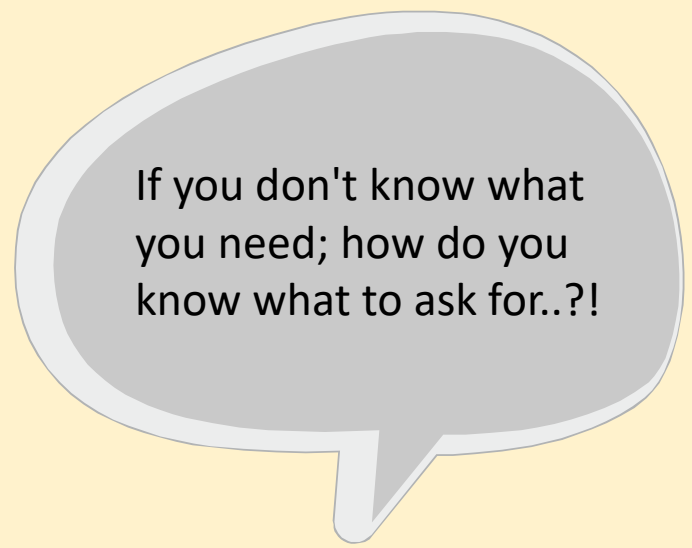
Key Themes	Summary
Accessibility of Information and Advice	• There is a reliance on technology to access information causing challenges for people who have difficulties with using and/or access to the required equipment. • Lack of alternative formats to communicate information such as easy read, videos and different languages. • Location of support services and groups also causes barriers to accessing information and advice. • A lack of information and advice available in schools.
Too Much Bureaucracy	• Administrative hurdles can be obstacles to receiving advice and support. Many autistic people experience challenges with executive functioning.
Knowing Where to Look For Information and Advice	• Difficulties knowing what information and advice is needed/helpful and also finding it.

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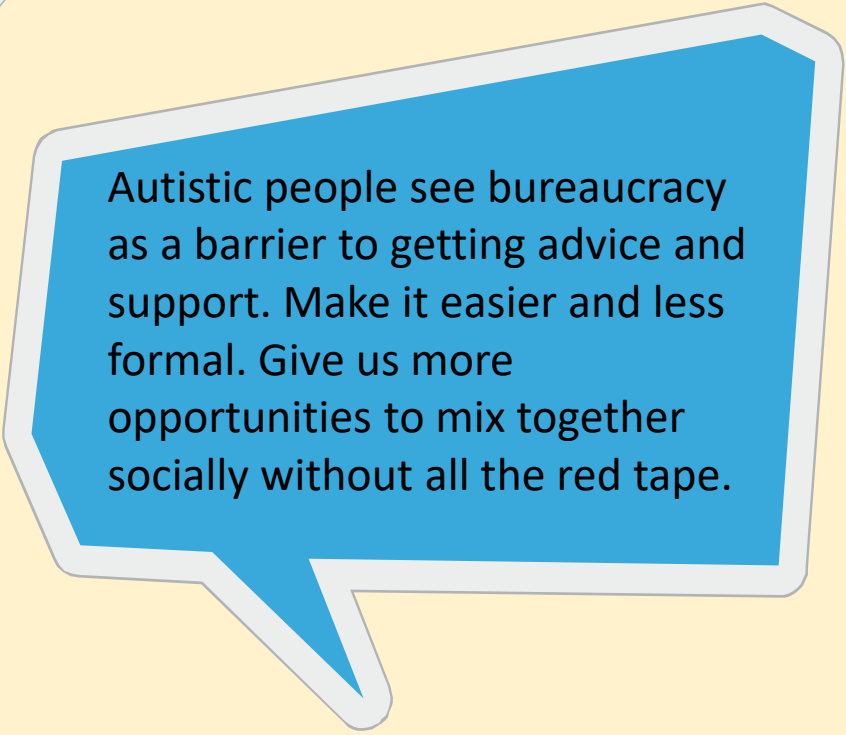
I am unusual being diagnosed in my 60s and although I use smart phones and computers I am not comfortable and I'm guessing there are others who feel the same, so not to assume we can all access devices or that the devices are up to date to work. For instance the QR code wouldn't work with my old mobile phone.

An orange speech bubble with a white border and a tail pointing towards the bottom left.

I found it really helpful when accessing this questionnaire that there were videos, I really struggle with having to read everything.

A grey speech bubble with a white border and a tail pointing towards the bottom left.

If you don't know what you need; how do you know what to ask for..?!

A blue speech bubble with a white border and a tail pointing towards the bottom left.

Autistic people see bureaucracy as a barrier to getting advice and support. Make it easier and less formal. Give us more opportunities to mix together socially without all the red tape.

Improvements Suggested by Autistic Adults and Children and Young People

Recommendations	Summary
One-Stop Hub for Assessment and Support	A one-stop hub that offers assessment, support, and education in one place to make it easier for individuals to access the help they need.
Localised Support	Provide more localised support to reduce barriers for people who have difficulty travelling.
Alternative Formats	Provide a variety of ways to communicate information such as easy read, videos, alternative languages, face to face, online and visiting existing community groups that people already trust
Information Pack for Late Diagnosed People	Create an information pack specifically tailored to late-diagnosed autistic individuals to better support their unique needs.

Improvements Suggested by Autistic Adults and Children and Young People

Key Themes	Summary
Support Lists	Create comprehensive lists of support services and how to access them to be available online, in person and by telephone.
Provide Information in Advance	Provide information about the service and what to expect in advance before they are referred to services to help feel better prepared for the contact.
Reduce Bureaucracy	Reduce bureaucracy and formalities when accessing advice and support services, making it easier for individuals to access support and interact socially.
Access to Training and Information Sessions	Provide training and information sessions for autistic people and their families.



Education

Schools, colleges, universities, adult learning/training and any other educational experiences

Education

We asked autistic people if they would like to share their experiences and views about education. 72 people responded to this section of the questionnaire. They told us the following:

49 people told us that they had attended education or training since 2018 of which:

- 63% had attended a mainstream school or college
- 19% had to attend a school or college outside Rotherham due to a lack of suitability/availability
- 72% felt that education staff did not understand about autism and how to support them

Of the people who attended education or training since 2018, 69.5% were still currently attending education or training in the following settings:

- 50% attend a mainstream school or college
- 29% attend a special school or college
- 9% attend university
- 9% attend adult training/learning
- 3% are educated at home

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Inadequate Support in Further Education	Adults felt that support in further education appears to be primarily directed towards young people, leaving adults struggling to access much needed help and support.
Inadequate and Unsuitable Support at Universities	- Students are only able to receive support if officially diagnosed. - Support was often unsuitable and/or inadequate resulting in significant difficulties including having to leave the course.
Lack of Staff Autism Knowledge and Understanding	- Misconceptions about autism, based on outdated and negative information, hindered appropriate support being available. - Lack of understanding and recognition of masking. - Forgotten about if do not cause staff any problems.
Lack of Recognition of Potential	Students were sometimes underestimated and discouraged from pursuing their academic aspirations.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Negative School Experiences	Many individuals shared experiences of negative treatment, bullying, and lack of understanding in schools by both other pupils and staff; causing or contributing to mental health difficulties including PTSD.
Pressure to Conform to Neurotypical Standards	Challenges in adhering to neurotypical educational standards and assessment methods that may not align with autistic individuals' learning styles and needs.
Sensory Environment	The educational environment can cause sensory distress, particularly during breaks and lunch time.
Failure to Follow Education, Health and Care Plans/School Support Plans	Some schools do not provide the support that is detailed in the plan causing distress for the child/young person.

What Autistic Adults, Children and Young People Told Us

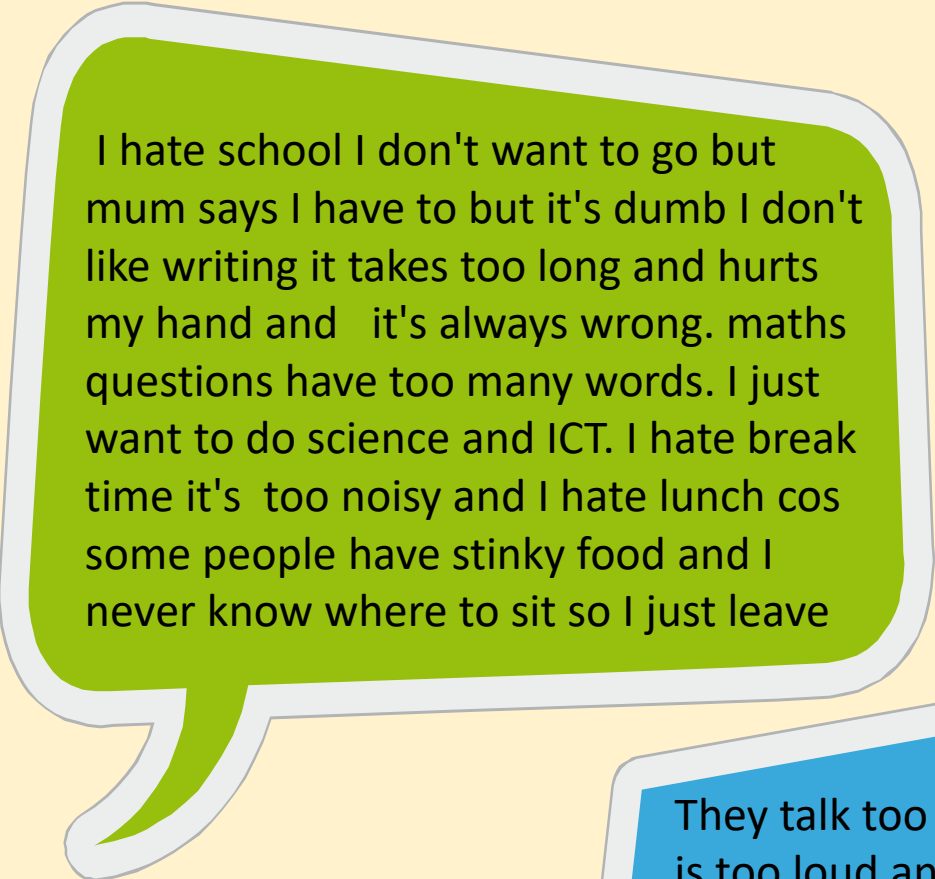
Key Themes	Summary
Special Schools	• Being told that a special school can meet their needs only to find out once there that they cannot. • Overcrowding and lack of alternatives • Low academic expectations • Limited academic curriculum • Not allowed to behave like neurotypical teenagers, e.g. having banter and holding hands etc.
Poor Communication Between School Staff, With Students and Parents	• There can be a lack of effective communication between parents and schools about support. • Teachers and staff may not fully understand or recognise the ways in which autistic children communicate leading to misunderstandings and misinterpretations of their behaviour. • Break downs in communication between staff members can lead to failing to provide the required support.

I had EHCP and they assumed and told me at college I wasn't capable of university, very distressing so family arranged cognitive assessment and my IQ said otherwise... I graduated with a 1st class honours, throughout only one tutor supported and believed in me... had a lifetime of people judging me and don't want to feel stupid anymore.

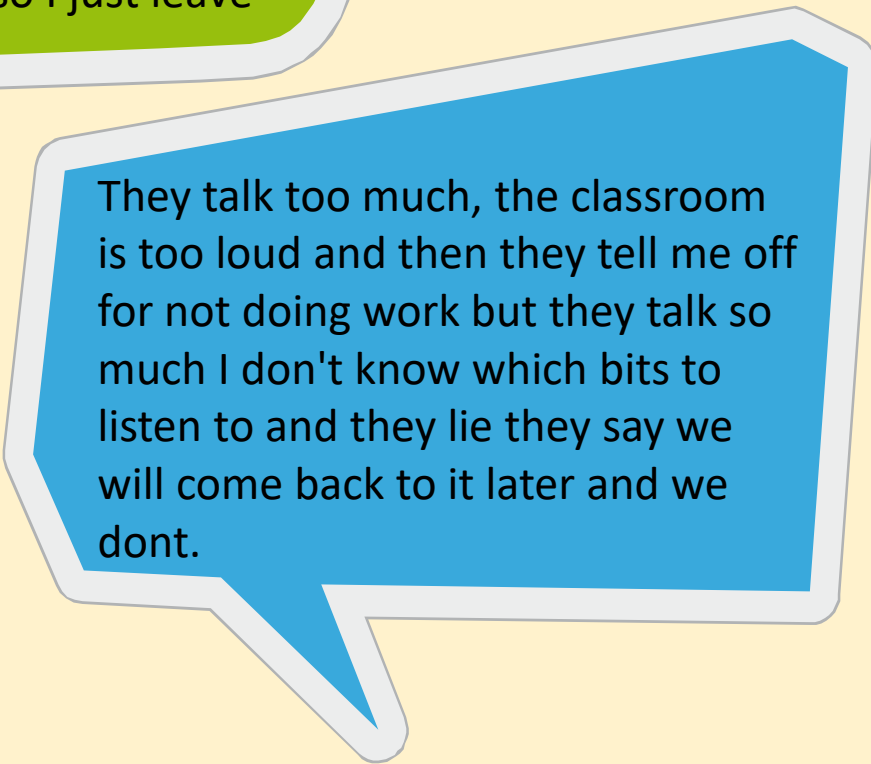
I was spoken to like a child, despite being 16-17. I was treated like I was being naughty when I couldn't go into a classroom due to the noise. I was regularly sent home and shouted at for behaviour I couldn't control

I found school incredibly hard and distressing most of the time... the mention of education now brings in anger upset and ptsd.

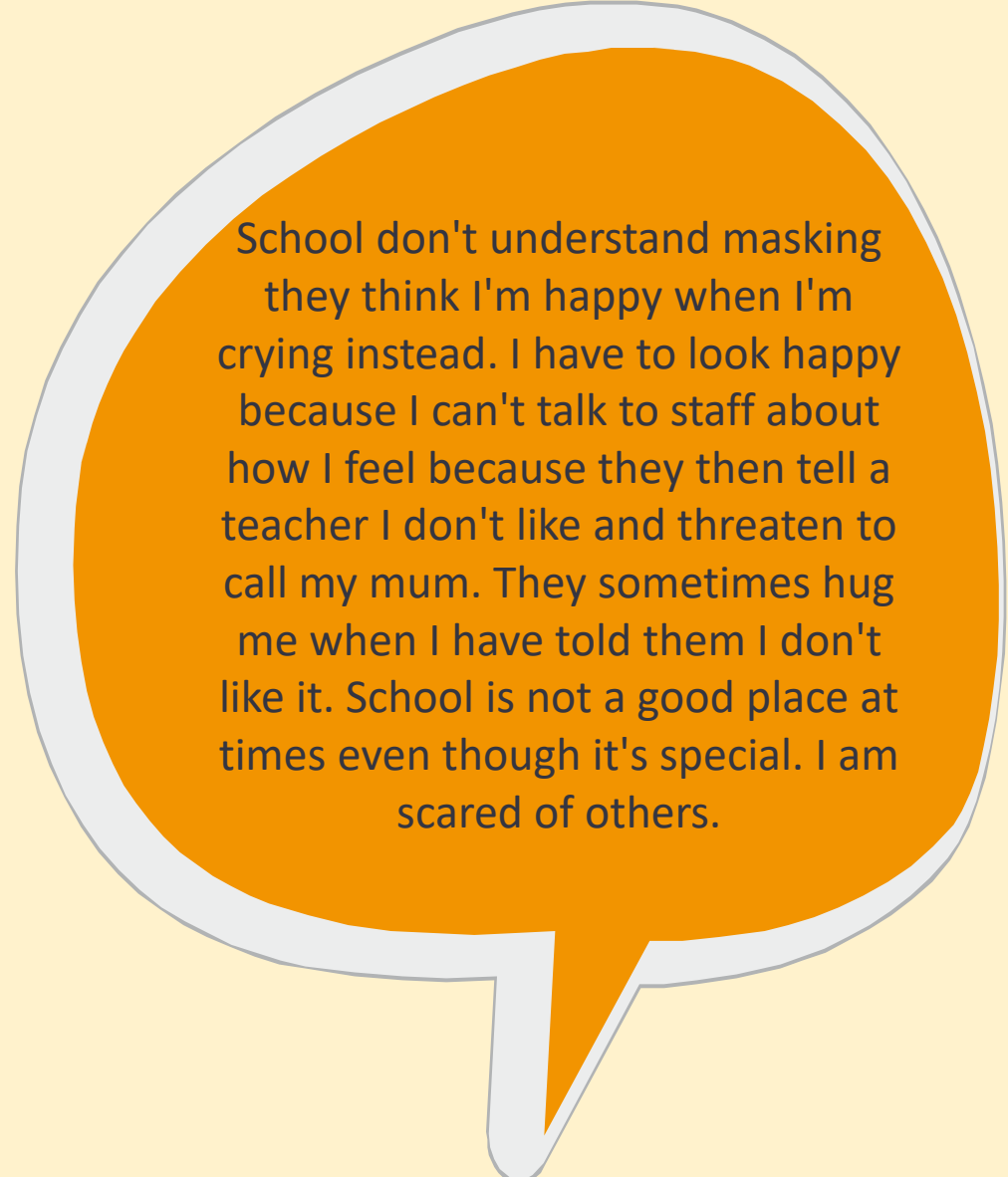
University gave me no support even less when covid hit and I was isolated, there were many times when I felt so low my parents had to bring me home for a week or so to keep an eye on my mood.

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I hate school I don't want to go but mum says I have to but it's dumb I don't like writing it takes too long and hurts my hand and it's always wrong. maths questions have too many words. I just want to do science and ICT. I hate break time it's too noisy and I hate lunch cos some people have stinky food and I never know where to sit so I just leave

A blue speech bubble with a white border and a tail pointing towards the bottom right.

They talk too much, the classroom is too loud and then they tell me off for not doing work but they talk so much I don't know which bits to listen to and they lie they say we will come back to it later and we dont.

A large orange speech bubble with a white border and a tail pointing towards the bottom right.

School don't understand masking they think I'm happy when I'm crying instead. I have to look happy because I can't talk to staff about how I feel because they then tell a teacher I don't like and threaten to call my mum. They sometimes hug me when I have told them I don't like it. School is not a good place at times even though it's special. I am scared of others.

Improvements Suggested by Autistic Adults, Children and Young People

Recommendations	Summary
Enhanced Support in Colleges and Universities	Improve the support systems for autistic students at colleges and universities to ensure that their specific needs are met with or without a diagnosis.
Update Autism Knowledge and Understanding	Educate schools, colleges and universities as well as support services with accurate and up-to-date information about autism to include masking and sensory processing differences.
Support for Mental Health and Wellbeing	Provide mental health and well-being support for autistic people, recognising the potential impact of educational experiences on mental health.
Autism Advocates Within Educational Settings	Advocates to support autistic students, raise awareness, highlight when needs are not being met or support not being provided, and challenge biases held by staff and peers.

Employment and Volunteering

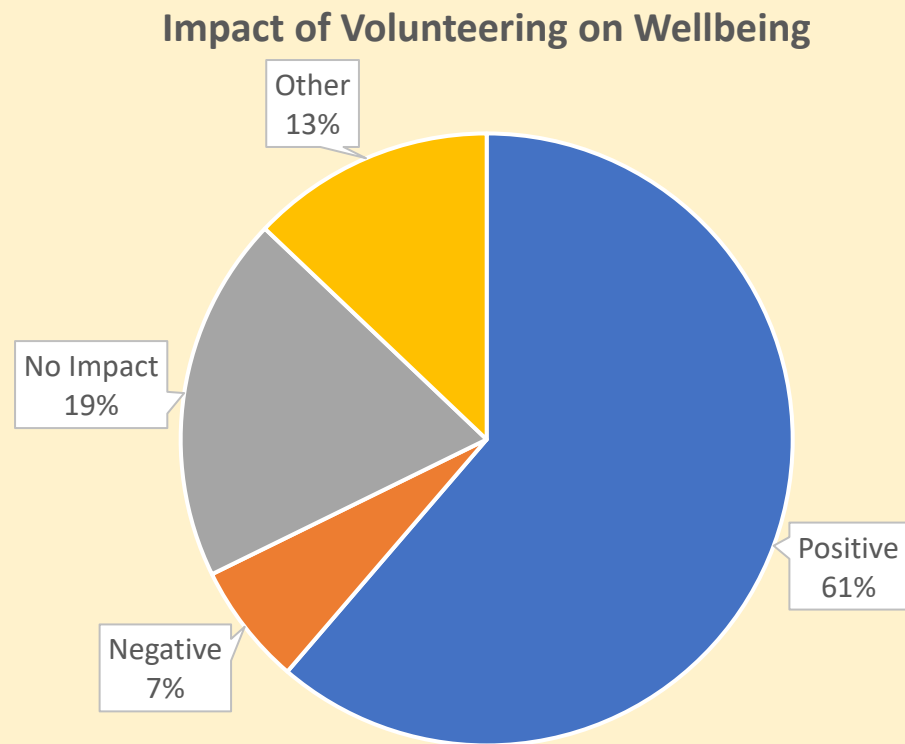
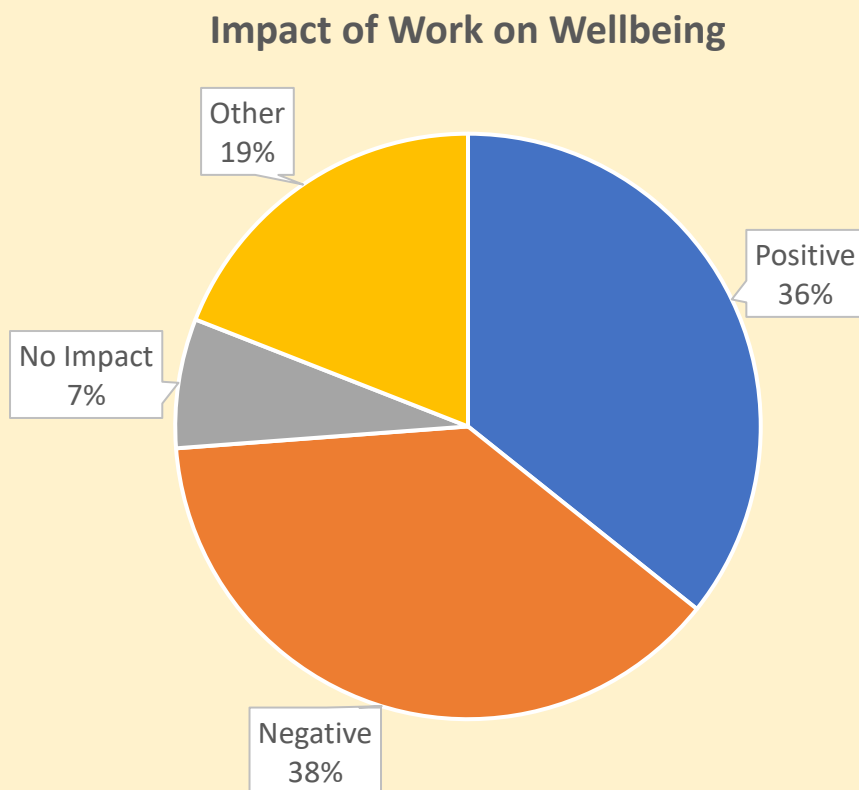


Employment and Volunteering

We asked autistic people if they would like to share their experiences and views about employment and volunteering. 49 people responded to this section of the questionnaire. They told us the following:

- 86% had been employed at some point in their lives.
- 55% were currently in employment, of which the majority worked fulltime (35 hours +)
- Most people had not received any help to find work and of those that had, the majority had been supported by family and friends
- 43% had never volunteered
- 36% had volunteered in the past
- 9% said that they would like to volunteer
- 6% were currently volunteering

We also asked people on whether they felt employment and volunteering had an impact on their wellbeing and they told us:



Where people have chosen the "other" option, it is mainly to say that it depends on the people and the environment as to whether it has a positive or negative impact on their wellbeing.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Sensory Overwhelm	Experience sensory overload in workplace environments. Loud noises, bright lights, and crowded spaces can be overwhelming and lead to stress, anxiety, and panic attacks.
Discrimination and Misunderstanding	Face discrimination and misunderstanding from colleagues and employers who may not be educated about autism. This can result in being treated unfairly, stereotyped and judged negatively.
Struggles with Social Dynamics	It can be challenging to navigate complex social interactions in the workplace which can significantly impact relationships with colleagues.
Rigidity in Working Hours	The rigidity of working patterns/hours can be problematic for those who benefit from more flexible working arrangements. Strict schedules may lead to burnout and decreased job performance.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Lack of Suitable Career Fit	Finding a suitable job that aligns with an individual's strengths and interests can be a significant challenge. Job fit is important to prevent harm and stress.
Bullying and Unsupportive Work Environments	Some autistic individuals report encountering bullying and unsupportive work environments, making it difficult to thrive in their chosen careers. These negative experiences can have a lasting impact on mental health.
Inadequate Support and Advice	- Access to support and advice to assist in job-seeking and navigating the work environment is limited or non-existent. This lack of support can hinder the ability to find suitable work and navigate workplace challenges effectively. - Lack of employment information and advice for people leaving school/college/university

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Burnout	Trying to conform to a neurotypical work environment, where the sensory and social demands are overwhelming can lead to exhaustion and burnout.
Valued Contributions	Autistic people can make valuable contributions in both volunteer and work settings, especially when provided with the right support and accommodations.
Volunteering and Work Experience	- Volunteering can be a positive experience, allowing more flexibility and alignment with personal interests and skills; contributing to a sense of purpose and fulfilment. - Volunteering and work experience has also helped people to explore potential career paths and interests.

I have had some jobs which have been excellent, and some that have discriminated against me and not been willing to work with me to help overcome some of the areas I find difficult. A service for autistic people (including self-id) to get advice around employment would be useful - I couldn't see how wrongly I'd been treated as it had a huge impact on my mental health.

I found that I got bullied at work I tried several different careers, but each time there would be someone who would upset me and I wouldn't be able to get over it. Then I would end up leaving.

Understanding that we are assets in a team but just might need extra support and reassurance.

Committing myself to working is exhausting and I have little energy to pursue my hobbies or build relationships outside of work, however I ... cannot afford to live if I don't work full time.

Improvements Suggested by Autistic Adults, Children and Young People

Key Themes	Summary
Education and Awareness	- Educate employers and colleagues about autism to foster understanding and reduce discrimination. - Raise awareness about the unique challenges faced by autistic individuals in work environments.
Flexible Work Arrangements	- Promote flexible working arrangements, such as home working, to accommodate sensory sensitivities and individual needs. - Allow for accommodations in the workplace to help manage sensory overload and reduce stress.
Peer Support and Mentoring	Establish peer support networks and mentorship programs to provide advice, guidance and emotional support for autistic individuals as they navigate their careers.
Safe Spaces	Create safe spaces within workplaces for autistic individuals to retreat when feeling overwhelmed.

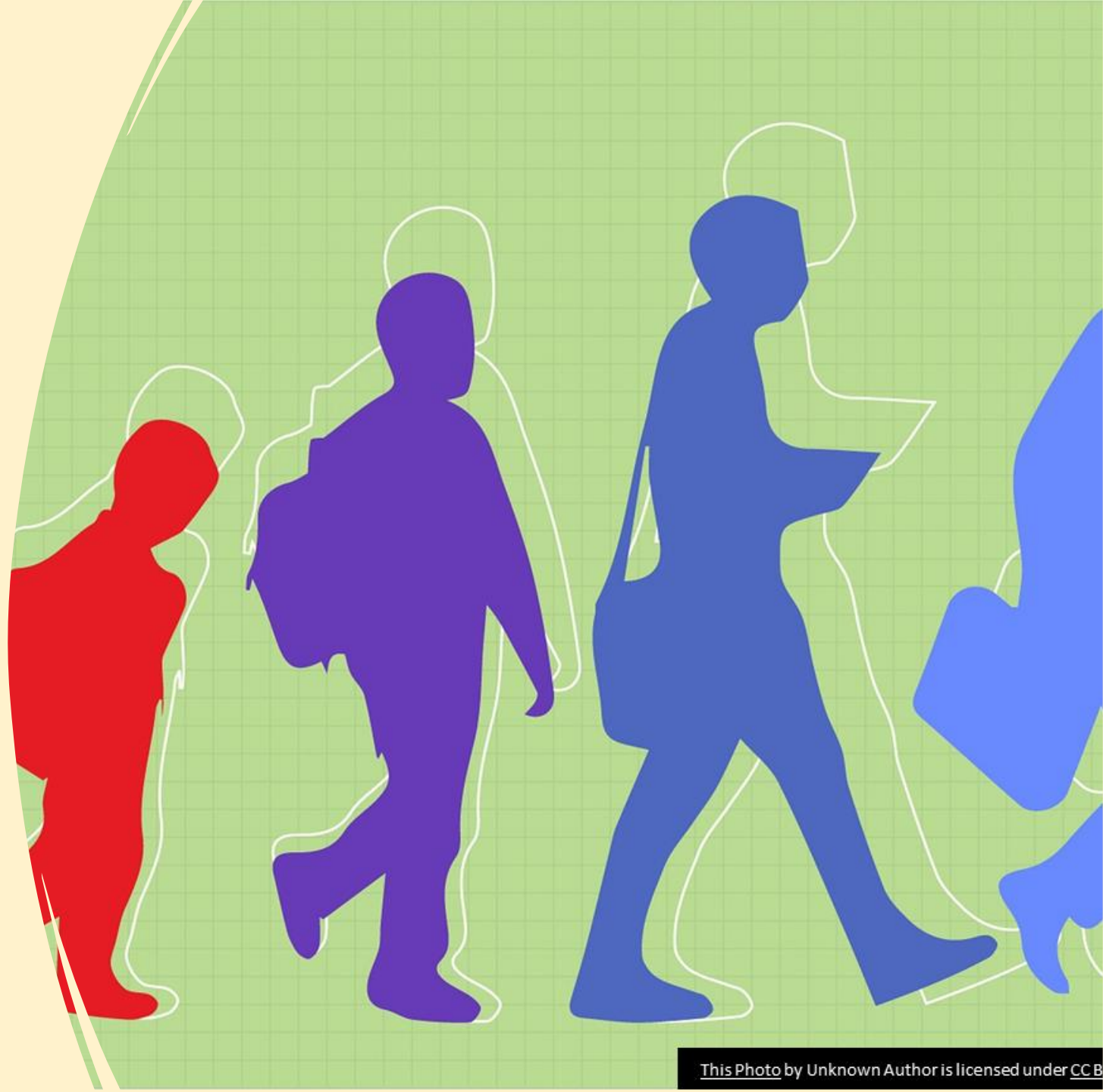
Improvements Suggested by Autistic Adults, Children and Young People

Key Themes	Summary
Mental Health Support	• Provide mental health support and resources to help address the psychological and emotional impact of workplace challenges and environments.
Employer Responsibility	• Support employers to recognise their responsibilities toward autistic employees and provide accommodations as needed. • Promote regular check-ins with autistic employees to ensure they are comfortable and supported in their roles.
Career Guidance	• Career guidance and support that helps autistic people explore their interests and strengths, and find the right career fit.
Value of Autistic Contributions	• For employers to recognise the unique abilities and contributions autistic people can bring to organisations,

Moving On Well To Independence

This section includes:

- Transitions to adulthood
- Housing





Transition to Adult Services

Transition to Adult Services

We asked autistic people if they would like to share their experiences and views about transitions from children's to adult services. 26 people responded to this section of the questionnaire. They told us the following:

- 33% had moved from children's to adult services since 2018

Of those that had transitioned since 2018:

- 66.5% received no information about transition
- 78% said that any information was not clear and accessible
- 33% had been involved in planning their transition
- 11% felt that their transition plan gave them choice and control
- 22% felt listened too
- 38% felt that their transition helped them to live the life they wanted

What Autistic Young People (Aged 19-25) Told Us

Key Themes	Summary
Lack of Transition Plans	- Many didn't receive transition plans, leaving them without guidance during the transition. - They were expected to navigate the transition independently, leading to feelings of distress.
Limited Services	Some received transition only related to education, lacking support for other essential aspects of their lives.
Rejection by Services	Referrals to NHS adult services were often rejected due to autism diagnosis, resulting in difficulty accessing care.
Complexity of Needs	Co-occurring conditions/disabilities, such as selective mutism, created barriers to services and led to individuals being considered "too complex" for support services.
Limited Choices	Limited options and choices that did not reflect individual preferences and needs.

What Autistic Young People (Aged 19-25) Told Us

Key Themes	Summary
No Opportunity for Transition Support	Some young people reported never having the opportunity to receive transition support due to being educated outside the school system e.g. home schooled.

I have had no support at all and have been referred to many NHS services by my gp but all referrals have been knocked back due to having autism. The mental health team discharged me after one appointment. I am deemed too complex for iapt support and the mental health team for mental health support due to having autism and selective mutism. The mental health team cannot help me because I struggle to speak so referred to speech and language who cannot see me because I have autism. They said to refer to the adult autism team. They cannot help me because I wasn't diagnosed by them and in the last two years. I am out of work and education and cannot get support from anyone

There was no transition help- due to being homeschooled- that should change! I've never had this opportunity

Entering adulthood is hard enough as a human being, but being autistic makes it worse as we are just expected to know everything and if we don't, we're expected to teach ourselves. This is hard for some autistic people like myself as I really struggle to learn things on my own and become really lost and distressed easily.

Improvements Autistic Adults and Young People Recommended

Key Themes	Summary
Develop Practical Independent Living Skills	Support to learn practical independent living skills. This includes skills related to daily life, such as managing household finances.
Holistic Support	Develop holistic support around health, social care, and education. These sectors should work together to prioritise and fund the necessary services.
Co-ordinate Services and Pathways	Create co-ordinated pathways that bridge the gap between child and adult services. These pathways should ensure smooth transitions and consistent care.
Assistance with Employment and Benefits	Support for finding employment opportunities or accessing benefits for those who may require financial assistance.
Expand Adult Services	Address the lack of services for autistic adults and young people to include offering services during evenings and weekends

Improvements Autistic Adults and Young People Recommended

Key Themes	Summary
Provide Clear Signposting	• Clear signposting for autistic people and their families, so they know where to access support and do not have to struggle or search for information.

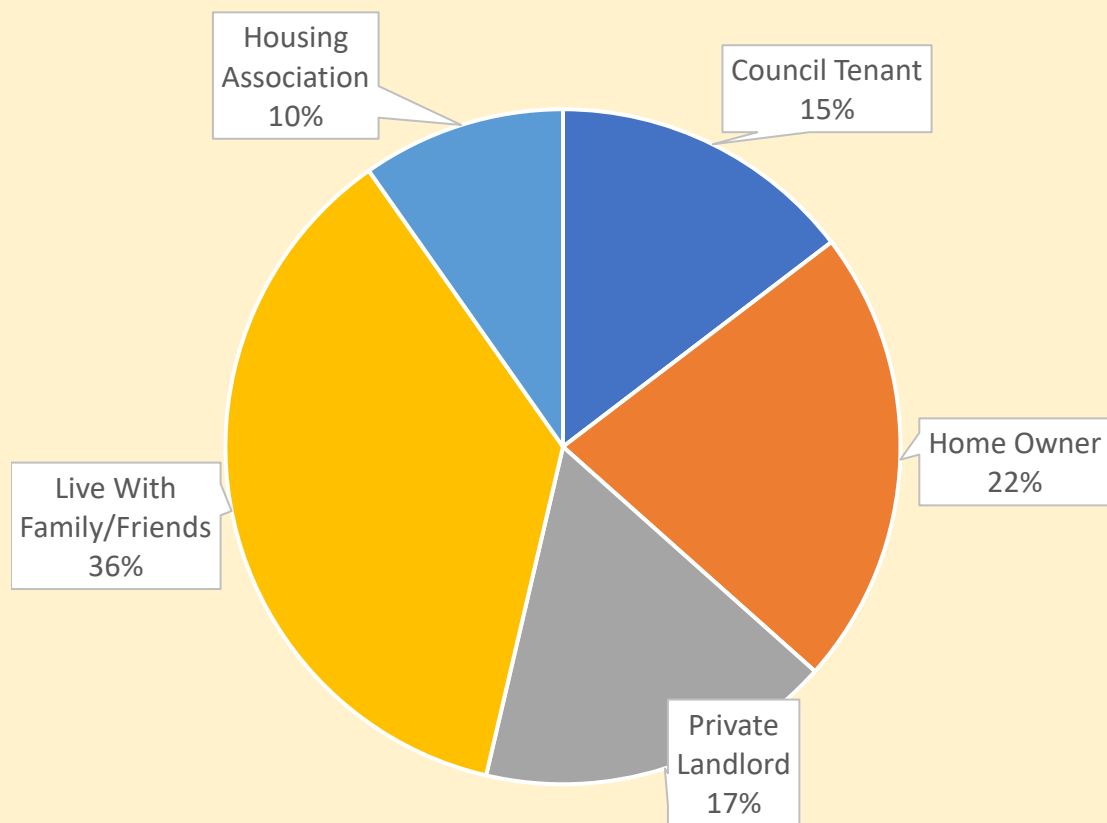
Housing



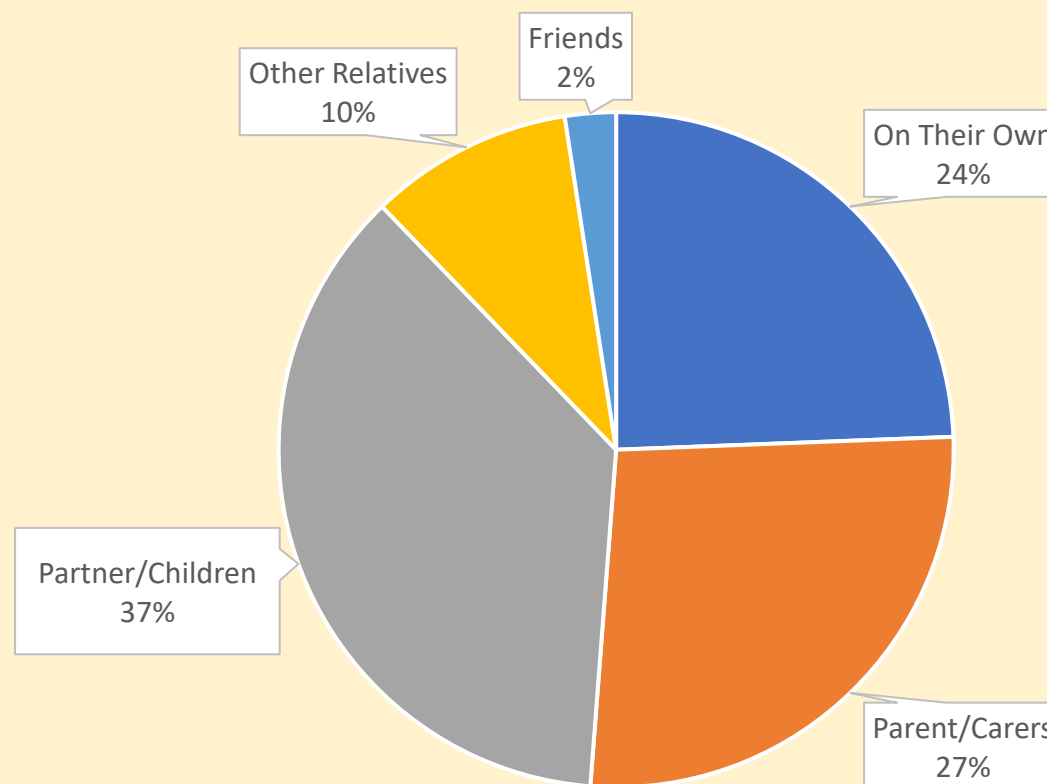
Housing

We asked autistic people if they would like to share their experiences and views about housing. 41 people responded to this section of the questionnaire. They told us:

Type Of Housing People Live In



Who People Live With



Housing Choice and Safety

We also asked people if it was their choice to live where they were living and whether they felt safe living there.

41 people answered these questions and 71% told us that they were living where they choose and 63% said that they felt safe.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Limited Housing Options	- Have to accept housing offers that are not suitable for their needs due to limited housing options. - Have to accept suitable housing that is not in an area they are familiar with.
Negative Perceptions	Autistic people can encounter negative stereotypes from landlords and housing services.
Sensory Difficulties	Noise from neighbours can cause significant problems and effect wellbeing.
Challenges Seeking Help	- Difficult to know where to go for help or support with housing situations. - Communication barriers to contacting services can leave people unable to access help, leaving them feeling isolated and without the assistance they need.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Lack of Accessible Information	Difficulties accessing information about housing, such as housing choices, buying a house, available services and financial implications, can complicate the decision-making process and the ability to secure suitable housing.

I hate being a council tenant but having a wheelchair means I get no choice. There is so little accessible accommodation you just have to take what ever you are offered. I would love to live in some where with support on site but have been dumped on an estate with all elderly people. Buses are only hourly and no accessible shops.

A lot of flats are inaccessible to autistic people due to the constant noise and potential of noise from others. Also being around so many people and yet being alone is extremely isolating and lonely

The housing officer was very sympathetic and understanding about my needs.

I struggled to get housing because I didn't have a guarantor or a job. This is really discrimination. I have had to live in social housing in a place where I don't necessarily feel particularly safe.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Provide Suitable Housing	- Create a range of housing options that take into account sensory processing differences, such as sound proofing. - Create properties with on-site support available for those who need it.
Provide Accessible Information and Support	It is important that information and support about all aspects of housing is provided in a range of accessible formats and is easily accessible.
Autism Training	Provide autism training to housing services and landlords to combat negative stereotypes and improve support and understanding.
Address Safety Concerns	Enhance safety and security in housing to alleviate the fear and anxiety autistic individuals may experience due to living in potentially unsafe or disruptive environments.

Living and Ageing Well

This section includes:

- Social Care
- Health and Wellbeing
- Daily Living and Local Community
- Criminal Justice





Social Care

Social care is support needed to live independently and can also be referred to as social services.

Social Care

We asked autistic people if they would like to share their experiences and views about social care. 38 people responded to this section of the questionnaire, of which 45% had requested a social care assessment since 2018.

Of those who had requested an assessment:

- 50% had requested an assessment from children's social care, 38% had requested an assessment from adult social care and 12% did not know who they had requested an assessment from
- 35% had been refused an assessment, the main reason being that they were told they did not meet criteria

Of those that had received an assessment:

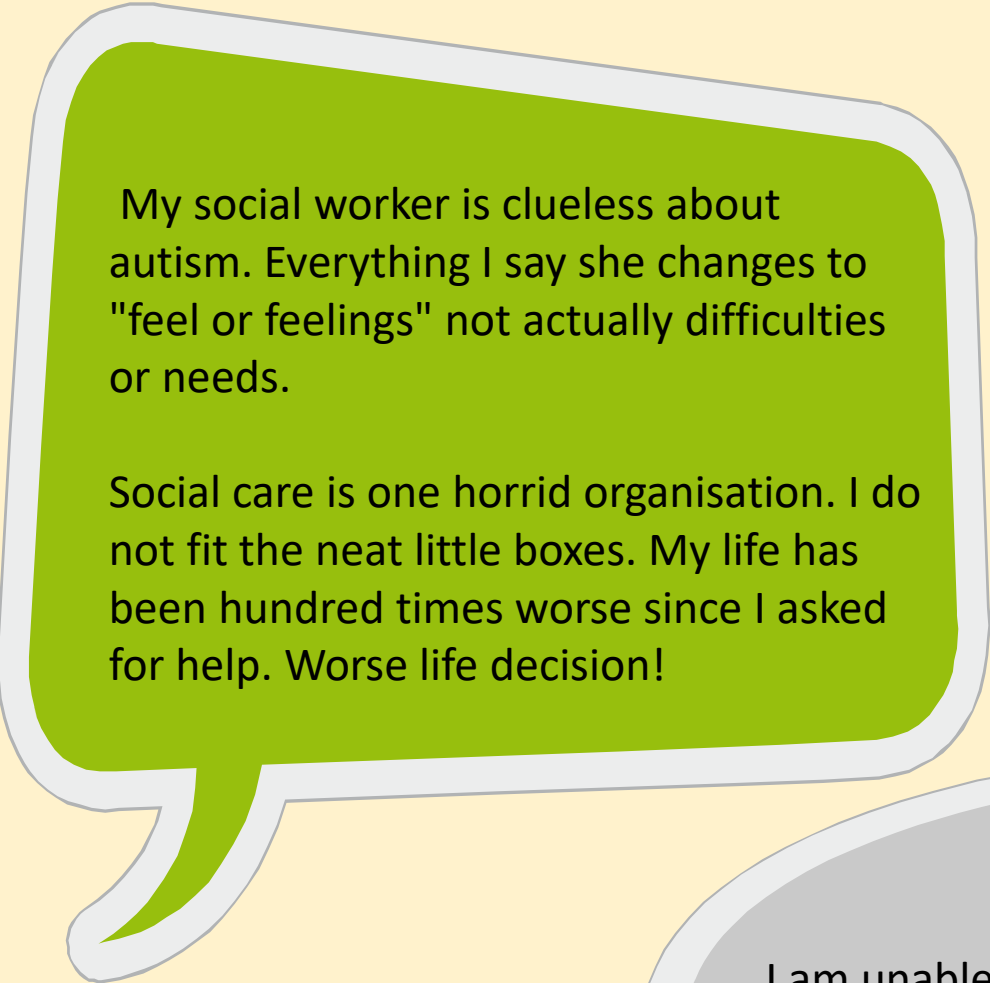
- 62.5% felt that the assessor did not understand about autism, 12.5% were unsure
- 62.5% felt that their views were not fully included and respected in the assessment
- 62.5% did not receive any new services or support as an outcome of the assessment
- 38% felt that the assessment made things harder for them, 38% said it made no difference and 25% said it improved things for them

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Lack of Clarity and Information	• Uncertainty about what social care involves, what they can help with and eligibility criteria, leading to confusion. • Difficulty in understanding, accessing and managing direct payments highlights the need for clearer information and support.
Inadequate Understanding of Autism	• Many social workers appear to lack a comprehensive and up-to-date understanding of autism and struggle to understand people's difficulties and needs.
Lack of Commissioned Services For Autistic People	• Many commissioned services cater to those who have learning disabilities and those who are physically able. • Lack of services/activities in school holidays
Barriers To Accessing Services	• Autistic people often face barriers as they don't fit into predefined categories.

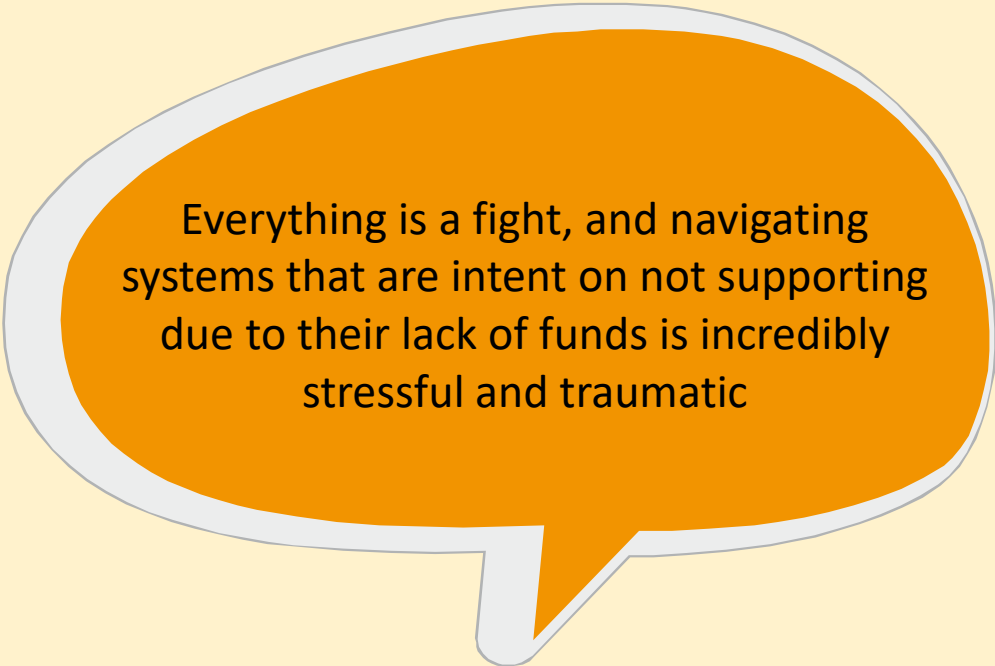
What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Difficulty Asking for Help	• Autistic parents worry about losing custody of their children if they sought support for themselves. • Communication differences and/or fear of negative consequences make it hard for some to ask for help.
Lack of Support and Communication	• There is a lack of support and communication following referral to social care resulting in feelings of abandonment. • Lack of regular communication from allocated social workers

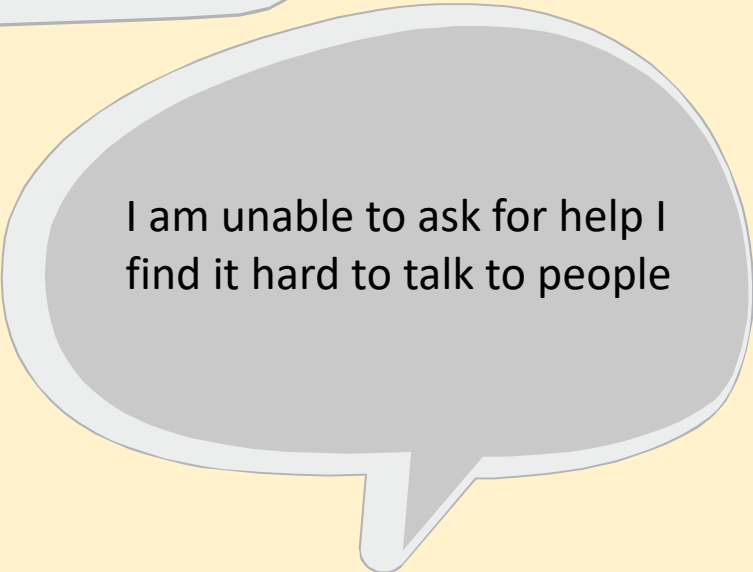
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My social worker is clueless about autism. Everything I say she changes to "feel or feelings" not actually difficulties or needs.

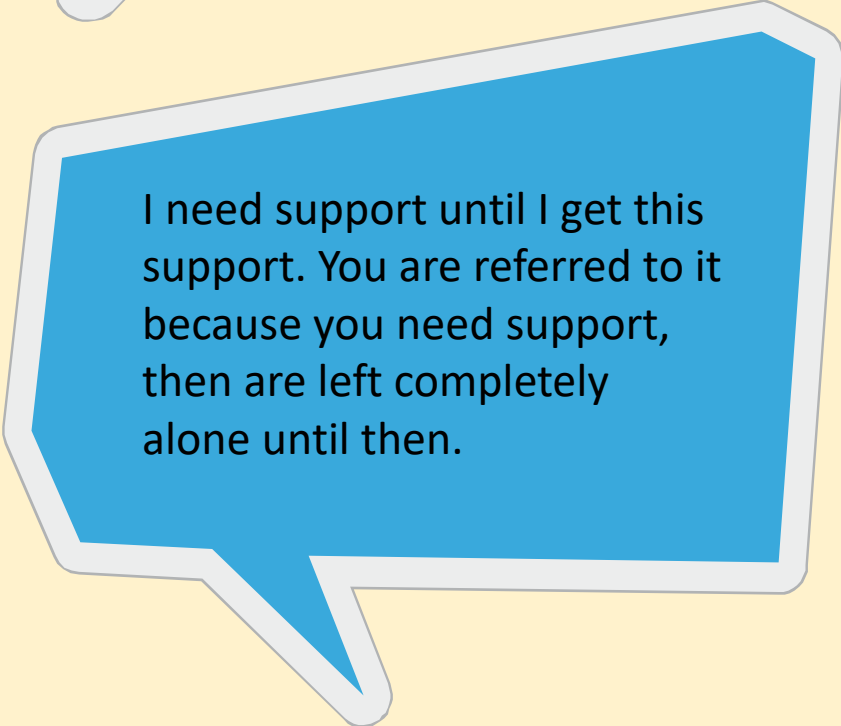
Social care is one horrid organisation. I do not fit the neat little boxes. My life has been hundred times worse since I asked for help. Worse life decision!

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Everything is a fight, and navigating systems that are intent on not supporting due to their lack of funds is incredibly stressful and traumatic

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I am unable to ask for help I find it hard to talk to people

A blue speech bubble with a white border and a tail pointing towards the bottom left.

I need support until I get this support. You are referred to it because you need support, then are left completely alone until then.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Clear Accessible Information	• Provide clear and comprehensive information about the social care system, its services, and potential outcomes for autistic people and families. • Streamline and clarify information about direct payments, supporting people to understand and use them.
Training for Social Workers	• Social workers need comprehensive training to better understand autism and the specific needs of autistic people.
Separate Autism Services	• Separate services for autistic people from those for people with learning disabilities to better cater to the unique needs of each group.
Inclusive Services	• Develop and provide services that are inclusive and accessible to individuals with physical disabilities.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Improved Communication	Continuous communication between individuals and social care, providing timely responses to enquiries and referrals.
Accessibility for Seeking Help	Recognise the challenges some individuals face in asking for help due to communication differences and work on creating a range of accessible methods for seeking support.
Reassurance	Address the fear individuals have around asking for support from social care. It is essential to provide information and reassurance to autistic people that these assessments are for support, not judgment.
Advocacy and Support for Individuals	Ensure that autistic people have access to advocates or support to help navigate the assessment process and provide guidance.

Health and Wellbeing



Health and Wellbeing

We asked autistic people if they would like to share their experiences and views about physical and mental health services. 62 people responded to this section of the questionnaire.

We asked what impacted on their ability to manage their health needs. They told us:

- 67% said sensory difficulties
- 58.5% said services are not autism friendly
- 48.5% said they find it difficult to leave their home
- 34.5% said a lack of support to access appointments
- 31% said finances
- 31% said forgetting appointments
- 27.5% said being busy at work
- 15.5% said family commitments

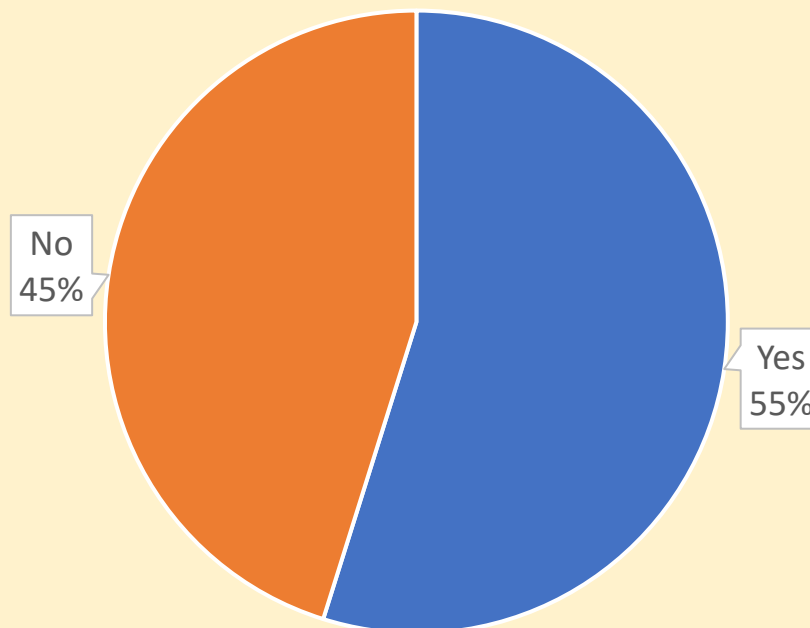


Physical
Exercise

Physical Exercise

We asked whether people took part in regular physical exercise, including walking or exercise in the home. 61 people responded to this section of the questionnaire. They told us:

Do You Take Part in Regular Physical Exercise

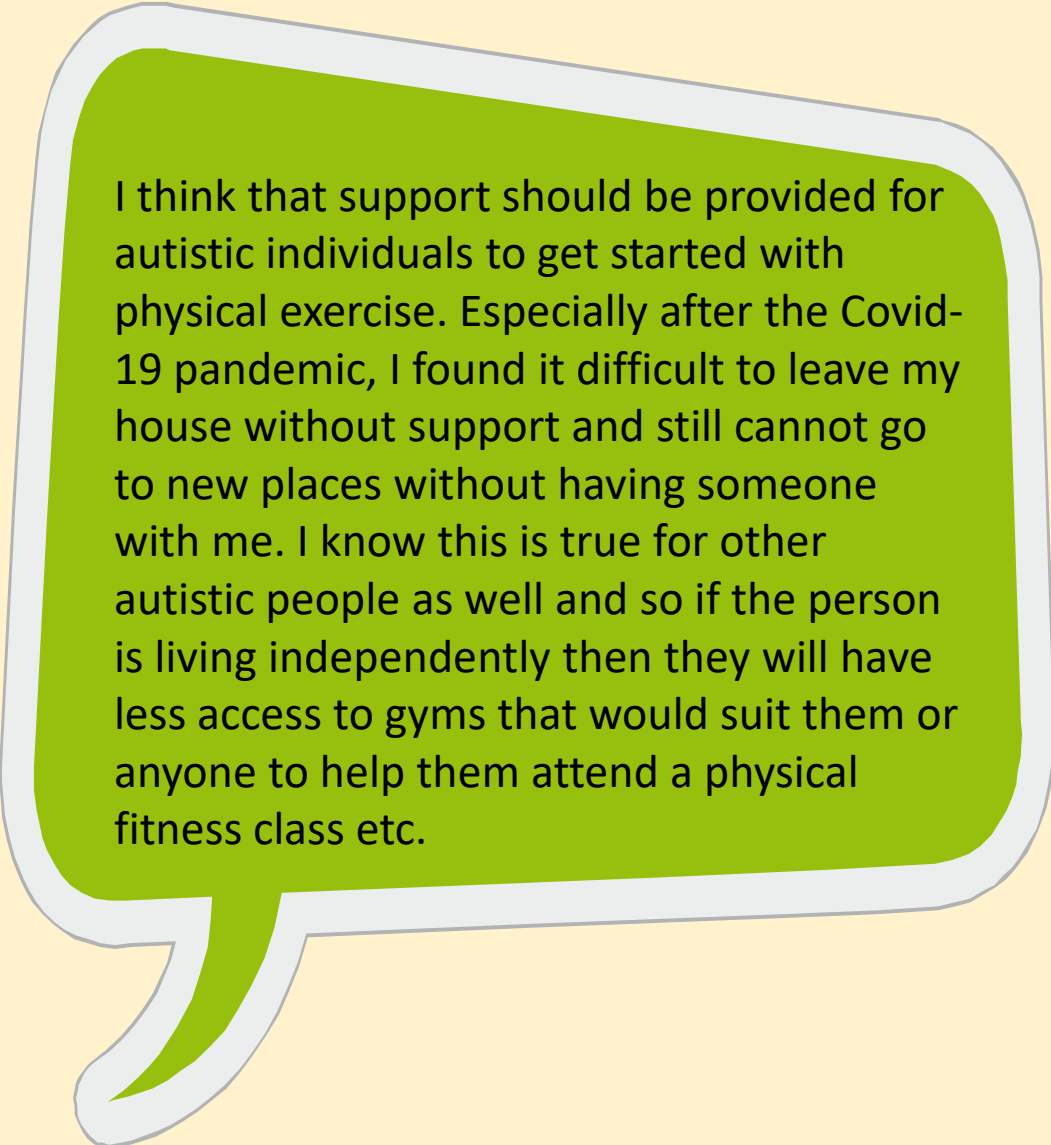


What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Challenges with sensory issues	• Bodily sensory issues such as feelings of heart racing, sweating, and pain during and after exercise. • Environmental factors, like noise from traffic and anti-social behaviour, can make outdoor activities difficult. • Gyms and swimming pools can be challenging due to sensory and social environments.
Barriers	• Physical difficulties/disabilities further complicate the ability to participate. • Location can also be a barrier.
Mental Health Difficulties	• Anxiety, lack of motivation and self-consciousness impacts on fitness levels and ability to participate in physical activities.

What Autistic Adults, Children and Young People Told Us

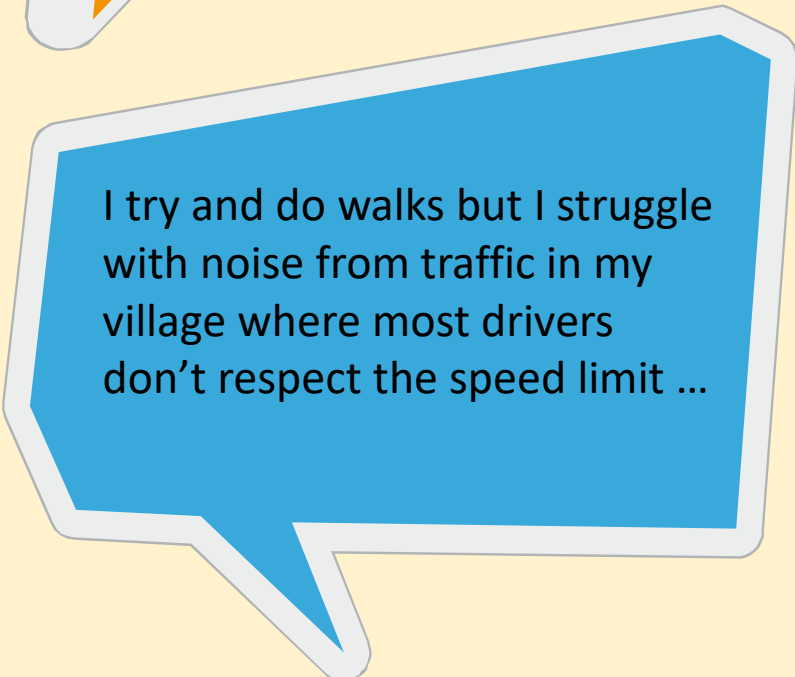
Key Themes	Summary
Availability of Support	• Support to access physical activities from another person is not readily available. • Parents can find it difficult to find the time and energy to provide the support required and not all young people want to attend things with their parents.
Lack of Autism Knowledge and Understanding	• Communication with staff can cause misunderstandings. • Staff can feel that they are not able to provide the right support due to a lack of confidence and knowledge.

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I think that support should be provided for autistic individuals to get started with physical exercise. Especially after the Covid-19 pandemic, I found it difficult to leave my house without support and still cannot go to new places without having someone with me. I know this is true for other autistic people as well and so if the person is living independently then they will have less access to gyms that would suit them or anyone to help them attend a physical fitness class etc.

An orange speech bubble with a white border and a tail pointing towards the bottom left.

It's always been recommended to me that exercise will help my mental and physical health and I am ignored when I describe the difficulties I have with this...mainly sensory (feelings of heart racing and sweating, pain during and after) and executive function.

A blue speech bubble with a white border and a tail pointing towards the bottom left.

I try and do walks but I struggle with noise from traffic in my village where most drivers don't respect the speed limit ...

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Create Autism-Friendly Sessions (Pools, Gyms etc)	• These sessions should have fewer participants, more space, quiet environments, and clear instructions. • Include sessions for autistic people who experience physical difficulties and difficulties.
Diversify Timing of Sessions	• Offer sessions at various times during the day and week to provide flexibility for diverse schedules.
Support	• Offer the option of having an autism trained person to support and facilitate engagement in physical exercise.
Accessible Information and Awareness	• Improve communication and information dissemination to ensure that autistic people are aware of available support and resources for physical exercise.

Accessing Health Services



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Accessing GP Appointments

We asked people questions about accessing GP appointments. 61 people answered this question. They told us:

- 16.5% felt their GP understood about their autism and it affects them
- 47.5% were able to book an appointment when they need one
- 10% felt that the practice staff understood about autism
- 92% were able to access the building
- 24.5% stated that reasonable adjustments were put in place when requested however, 54% did not know
- 51.5% stated that they have difficulty attending GP appointments

Accessing Hospital and Mental Health Services Appointments

We asked people questions about accessing appointments for physical health reasons since 2018. 49 people answered this question. They told us:

- 10% felt that staff understood their autism
- 12.5% stated that requested reasonable adjustments were put in place however, 37.5% did not know
- 54% stated that they have difficulty attending hospital appointments

We also asked people questions about accessing mental health services and appointments since 2018. 47 people answered this question. They told us:

- 25.5% felt that staff understood their autism
- 23.5% stated that requested reasonable adjustments were put in place however, 30% did not know
- 27.5% stated that they felt listened too
- 28.5% felt that they were able to get an appointment when they needed one

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Communication and Time Constraints	- Autistic people can struggle to effectively communicate their healthcare needs in short, rushed appointments. Especially where they are only allowed to discuss one concern. - They often feel they lack time to process information during appointments. - Difficulty in describing symptoms and feelings can result in dismissive attitudes from healthcare providers.
Dismissal of Symptoms and Misdiagnosis	Health concerns are often dismissed as autism related, or chronic pain without conducting thorough investigations, leaving autistic people feeling misunderstood and ignored.
Long Wait Times and Booking	Telephone booking systems and long waiting times for appointments creates barriers.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Accessibility	• The location of many health services can be a barrier, particularly for people who have difficulties with travelling. • Challenges related to the physical accessibility of buildings. • A lack of staff autism knowledge and understanding. • The sensory environment can be challenging.
Lack of Alternative Methods of Communication	• Following-up, remembering and understanding verbal information can be difficult.
Rigid Appointment Times	• It can cause distress when appointments are not running on time. • It can be difficult to arrive on time for an appointment due to anxiety/distress.

It's hard for us to communicate what is going on for us with comorbid conditions that are likely connected in 5 minute rushed appointments where you are only allowed to talk about one thing. I never really get time to process information before the appointment is over and I don't feel confident asking for what I need as I have had difficult and quite traumatic experience with healthcare. I don't feel like I am understood and get left to suffer.

Hospitals are scary places and very busy. I hate waiting to be seen as it is busy, normally there are kids running round making a noise which I don't like. I don't think the smell and how everyone is sat together close as I like space. Mum once asked if we could wait somewhere else they said no.

I liked it when the doctor from the hospital saw me at school I didn't have to wait I went straight from class in to see her and the room I recognised. They should do it more.

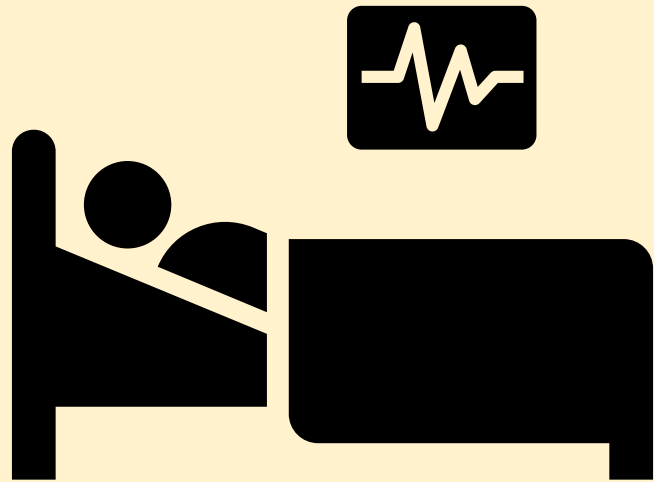
... they dismiss what I describe as not being typical symptoms which is possibly because I struggle to describe my symptoms and feelings. I'm left feeling like they don't care and my health needs are unimportant

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Frequent Health Checks	Offer frequent health checks to enable improved identification and monitoring of health conditions.
Extended/Flexible Appointment Times	- Allocate longer appointment times to provide autistic people with sufficient time to express their concerns and process information. - Provide some flexibility around arriving late for appointments due to the challenges many face in attending appointments.
Supportive and Understanding Staff	Autism training for staff to ensure they understand and cater to the specific needs of autistic patients.
Home Visits	Implement home visits as an option for those with barriers accessing a healthcare setting such as sensory processing difficulties, mobility difficulties and anxiety.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Online Appointment Booking	Allow for online appointment booking as phone calls are difficult/inaccessible for many autistic people.
Sensory-Friendly Environments	Create comfortable, quiet, and sensory-friendly healthcare settings that reduce sensory overload and anxiety.
Follow-up Communication	Follow up telephone calls and appointments with emails or text messages to help autistic individuals remember and understand the verbal information provided.
Patient Information	Ensure that autistic people are informed about the support available to them before each appointment and that any required support is readily available.



Hospital Admissions

Stays in hospital for 1 or more nights for physical or mental health reasons.

Hospital Admissions

We asked people questions about their experiences of staying in hospital for 1 or more nights since 2018 for physical health reasons. 31 people answered this question. They told us:

- 13% felt the staff understood about their autism
- 20% stated that reasonable adjustments were put in place when requested
- 16.5% said that they felt listened to
- 20% said they were kept informed about what was happening

We also asked people questions about their experiences of staying in hospital for 1 or more nights since 2018 for mental health reasons. 22 people answered this question. They told us:

- 4.5% felt the staff understood about their autism
- 9.5% stated that reasonable adjustments were put in place when requested
- 5% said that they felt listened to
- 5% said that they received the right support for them to move back home

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Inconsistent Care	The experiences of patients can vary significantly depending on the hospital and the staff.
Stress from Uncertainty	- Not knowing what to expect due to inconsistent care can cause significant stress/anxiety. - Uncertainty regarding the length of hospital stays can also cause significant stress/anxiety.
Autism Knowledge and Understanding	- There is wide variation of autism knowledge and understanding amongst staff. - Staff can make assumptions of needs based on a diagnosis as opposed to a discussion with the patient.
Reasonable Adjustments	- People do not know what is available to be able to ask for them. - People can find it difficult to ask.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Environmental Challenges	The hospital environment can cause significant sensory discomfort and distress. This can also negatively impact the patient's recovery.
Hospital Passports	Experiences of hospital passports were mixed with some people finding them useful and others not.

I do not like the hospital passports because they are fixed. I am an individual and unique. The best thing for me has been my communication grab sheet. It is short and quick for someone to read. Hospitals do not have a time to read a lengthy document. And staff see too many people to remember all what they read in a lengthy document.

I went to the hospital for stomach pains, although I didn't ask for anything to be adjusted, it would've been nice to have it offered to me.

I do not like it how staff assume I want a quiet room because I have autism. I am an individual and a quiet room is hell for me.

I have an autism passport for Rotherham hospital and my experiences have improved - particularly with the support of the LDA team.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Use of Short and Quick Communication Tools	A short document for the patient to carry that clearly explains their communication needs and is quick for staff to read.
Autism training for Staff	There is a need for improved knowledge and understanding of autism amongst staff to ensure that patients specific needs are met consistently and appropriately during hospital stays.
Clear and Consistent Communication	- Communicate with patients about their expected duration of stay, treatment plans and any changes, thereby reducing uncertainty and anxiety. - Improve communication between staff, departments and hospitals to ensure that patient needs are understood and effectively supported during hospital stays.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Proactive Offers of Reasonable Adjustments	• For patients to made aware of what reasonable adjustments can be put in place and to be asked what they need.
Sensory-Friendly Environment	• Staff training in sensory processing differences. • Identify patients sensory needs on admission/in advance. • Consider the lighting, noises from alarms etc, smells and food choices on offer.



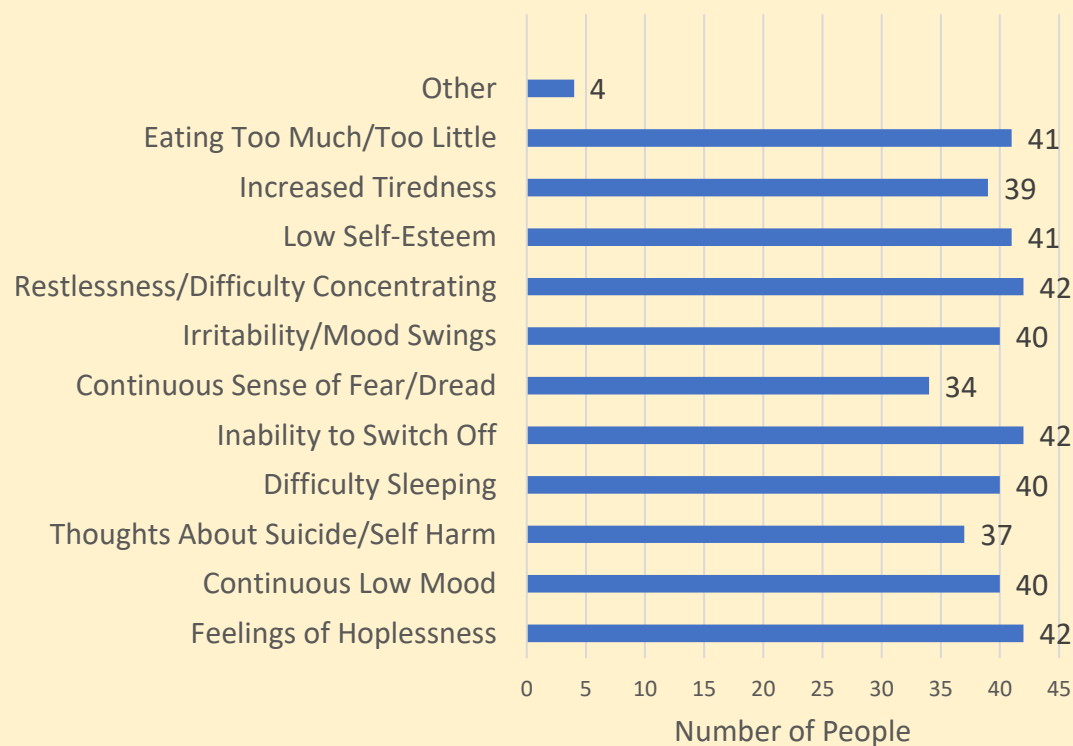
Mental Health and Emotional Wellbeing

Content warning – this section contains information about mental health difficulties, including suicidal feelings.

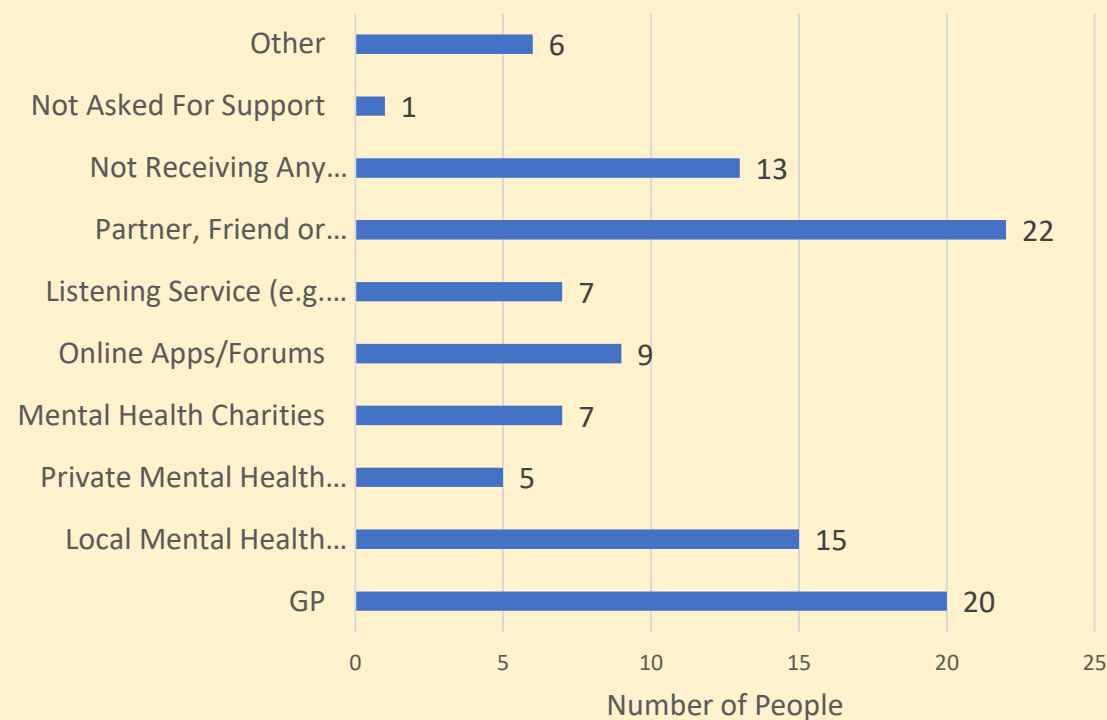
Mental Health Difficulties

We asked people questions about their experiences of mental health difficulties. We did provide a content warning for this section. 49 people answered this section as below:

Difficulties People Have Experienced



Where Do People Receive Mental Health Support



Seeking Support

We asked people what may prevent them from seeking help with their mental health. 45 people answered this question. The 6 main reasons that they told us (in order) were:

- Believe that services would be unable to meet their needs
- Concerns about long waiting times for services
- Do not feel comfortable discussing their mental health
- Do not know where to go to ask for help/support
- Do not believe that their difficulties are serious enough
- Are too embarrassed to ask for help

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Difficulty in Getting Mental Health Difficulties Recognised	- Staff can be dismissive or condescending once being autistic is mentioned; dismissing any difficulties as being an aspect of autism. - A lack of staff autism knowledge and understanding about how mental health difficulties can look in autistic people.
Lack of Holistic Support	No one looks at the whole picture and the complex interplay between co-occurring needs/difficulties and being autistic. For example, if therapy is offered it focuses on one thing only.
Narrow Therapeutic Offer	There is heavy reliance on CBT and talking therapies which can be difficult for many autistic people to access. There are also concerns around their effectiveness.
Waiting Lists	If people can manage to have a referral accepted, there are long waiting lists.

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
No-one to Talk To	Some people have no-one that they can speak too about their worries and difficulties,
Cultural and Religious Understanding	A lack of cultural and religious understanding can cause additional barriers.
Reliance on Parents	Children and young people feel that parents are relied upon to provide their support and therapy.

Support should be made more accessible for autistic people, I have had several rounds of CBT as well as other talking therapies and none of them have worked for me. As well as this, when I reached out for help I was put on a waiting list and then the therapists were only there to assist with individual issues such as thoughts of harm. They didn't care for helping me cope with my situation as a whole and dismissed my autism when I brought it up.

A lot of services don't cater to autistic people. We are told 'what do you expect'. Staff need to listen and accept that our limitations are there and they cannot be removed or 'exposed' out of us (e.g. being around noise constantly will not make you more tolerable towards it)

Mental health support and focused autism support. Some of my mental health conditions are directly linked to the autism, so they won't go away unless the autism is also addressed

Once you have a autism diagnosis everything is to be blamed on your autism. Mental health problems are too difficult to treat in autistic people. No one is qualified enough to deal with you. How do you think that makes you feel? Too damaged, too broken to fix.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Provide Holistic Support	Provide support that considers the whole person, taking into consideration their specific circumstances, communication styles and needs.
Autism Training	- It is important that staff are able to recognise and identify mental health difficulties and how they can present in autistic people. - Staff need to be able to adapt their approach and any therapies accordingly.
A Wider Range of Therapies	- Provide a wider range of therapies for all age groups that are evidenced as being beneficial to autistic people. - Include non-talking therapies in this offer.
Reduce Waiting Times and Barriers	- People are already struggling by the time they are referred and then expected to wait several years in some cases for the support that they need. - Remove the red tape that makes accessing services so difficult if you don't have the right diagnosis

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Training to Develop Cultural Knowledge and Understanding	• To ensure that staff are able to understand about autistic people from ethnic minority groups and how mental health difficulties can look and be perceived differently.

Daily Living
and Being a
Part of the
Local
Community

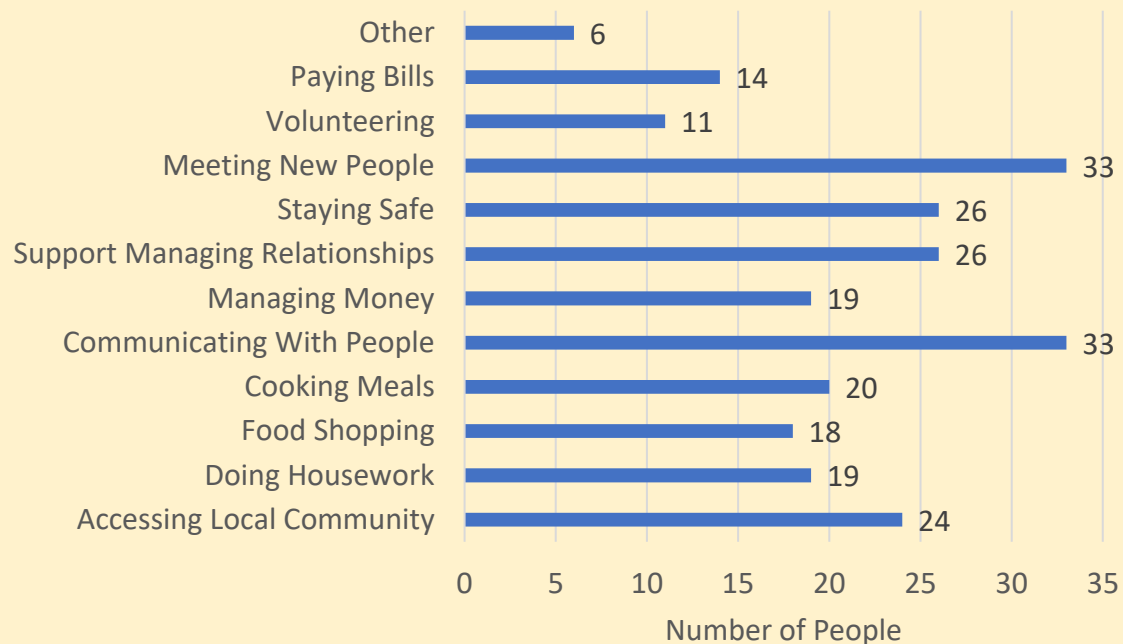


Daily Living and Community

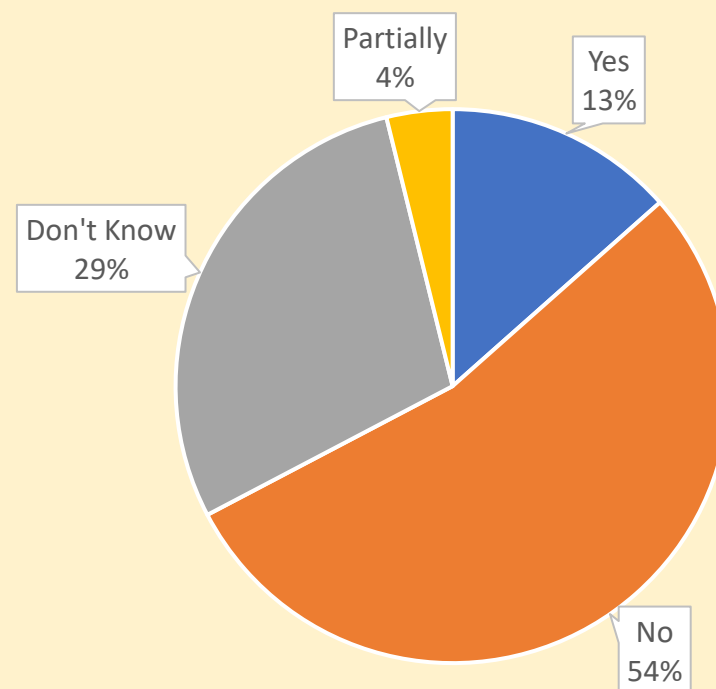
We asked autistic people if they would like to share their experiences and views about their day-to-day life and living in the community. 58 people responded to this section of the questionnaire.

We asked what support with daily living people felt they needed, and did they receive the support they needed. They told us:

Support Needed



Do People Receive The Support They Need



Daily Living and Community

We also asked people if they felt part of their local community and whether they felt lonely or isolated. 55 people answered this question, they told us:

- 74% do not feel part of their local community
- 58% felt lonely or isolated
- 65% do not use public transport

Of the people that do use public transport:

- 79% regularly use buses
- 37% regularly use taxis
- 37% regularly use the train
- 37% regularly use the tram

Daily Living

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Lack of Understanding	• Social interactions and accessing local services can be challenging due to the lack of awareness and understanding. • Some autistic people feel ashamed to disclose they're autistic because of societal attitudes. • Different cultural and religious understandings
Importance of Community Groups	• Community groups are seen as sources of support and play a positive role in the lives of autistic people. Not just autism specific groups.
Lack of Accessible Spaces and Local Groups	• Many of the groups and activities are held in places that are not always accessible to physically disabled autistic people. • The groups are generally not local to the people who attend or want to attend. • The groups and activities are often not held in the evenings and weekends.

Daily Living

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Lack of Social Activities	• People can have difficulty accessing social activities and events.
Groups for Ethnic Minority Communities	• People feel that there can be a lack of understanding about autism in some groups specific to their communities however, autism specific groups often have a lack of understanding about ethnic minorities.

Daily Living

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Community Awareness and Engagement	• Implement community awareness campaigns. • Offer courses or information sessions on autism in community centres to increase public awareness. • Provide support and training for non autism specific community groups to be more inclusive. • Engage with the ethnic minority communities to work with them on developing awareness and understating.
Autism Training	• Autism training for public facing staff.
Support Services	• Provide support workers to those who need them, including a level of flexibility so those who may seem to be managing well can access support during challenging times and prevent crises.
Transport	• Provide support for people to travel to the groups and activities that meets their needs.

Daily Living

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Support	• Support workers to help with daily living activities for those that need it. • Support for local community interest groups that are not autism specific to be more inclusive.
Create More Local Support Groups and Activities	• Create a range of local support groups and community activities for all ages to include evenings and weekends. • Provide social excursions, such as skateboarding, theatre trips etc.
Support for Community Groups	• Support community groups to develop their knowledge about autism and to help them feel more confident about including autistic people and increase accessibility.

Public Transport

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Sensory Difficulties	Sensory difficulties, such as noise, smells and crowds, can make public transport and bus and train stations, overwhelming and distressing.
Unreliability	The inconsistency and unreliability of public transport services, including frequent delays and cancellations, can cause anxiety and distress.
Lack of Accessible Information	Difficulties finding understandable information about using public transport such as timetables, how to pay, route changes etc.
Anxiety	Sensory issues, overcrowding, unpredictability, and the general environment of public transport can contribute to anxiety, making it inaccessible to many.
Cost	Public transport costs can be a barrier to using it.

Public Transport

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Clear and Accessible Information	- This includes details about payment systems, route announcements, and other relevant information. The recommendation is to ensure that information is easy to understand and readily available, reducing confusion and anxiety. - Announcing the next stop can help reduce anxiety and uncertainty, especially on unfamiliar routes.
Online Booking and Tracking	An online booking system that allows passengers to purchase tickets, see who the driver is and track the location would help reduce uncertainty and anxiety.
Quieter Areas and Times	- Create designated quieter areas on public transport and advise on specific times that are generally quieter. - Reduce the maximum capacity allowed at any one time on public transport.

Public Transport

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Autism Training	• To help staff be more aware and understanding of the challenges faced by autistic people.
Affordable Public Transport	• Improve the affordability of public transport, making it easier to access essential services and resources within the community.

I have tried to use buses with school when we do travel training and they are always rude to us. One driver once asked staff if we had escaped from the special school across the road cause we ran for the bus. The driver asked me to scan my pass but I had never done it before, instead of him showing me he took the pass off me and did it himself so the next time I still didn't know what to do.

There is a community centre on my street that could run courses or information sessions on autism and learning disabilities to make the public aware that we live among them in their community. I struggle to let people know I am autistic because I still feel ashamed.

I struggle so much with social interactions it makes it impossible to access local services

More fun activities for kids my age, its all play Arras and I'm too big for that now at 15. I want to hang at Dexx or skating with kids like me. I often feel lonely as I dont really have many friends at school and none out of school

Criminal Justice System



Criminal Justice System

We asked autistic people if they would like to share their experiences and views about criminal justice. 25 people responded to this section of the questionnaire.

48% of people told us that they had come into contact with the police, courts, prison or probation service either as a victim, witness or offender. They told also told us:

- 54.5% felt that they had been listened too
- 9% said that their needs as an autistic person had been understood
- 36.5% said that they felt safe during their contact
- 18% said that they were made aware of adjustments that could be made

We also asked if people were aware of the autism alert card. 95 people responded to this question

- 63% said that they were not aware of it
- 7% said that they had one
- 52% said that they would carry one

What Autistic Adults, Children and Young People Told Us

Key Themes	Summary
Misunderstandings	Communication differences can lead to misunderstandings and wrongful accusations.
Lack of Autism Knowledge	Lack of knowledge and understanding amongst staff can lead to making an already stressful situation even worse.
Access to Autism Alert Cards	- Evidence of an official diagnosis is required which causes problems to people not diagnosed or who do not have access to diagnostic paperwork. - There is a lack of awareness amongst autistic people about the card and how to use it. - The application process is challenging and not very accessible. - Carrying a card is not desirable to all autistic people.

I recieved support as a victim 3 times but they were not very helpful in the sense of when I got confused they questioned me as if I was changing my original statement which frustrated me as I felt like they didn't believe me

There should be access to an autism alert card not just for those diagnosed but for all autistic people. Statistically at least half of all autistic people choose not to be diagnosed, Why exclude them?

I've had one [autism alert card] since my diagnosis in 2013 but I dont know when I should use it or how to ...

Had a mental health crisis and they said horrible things to me. They may as well have just killed me

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Autism Training	• Training for staff on how to effectively communicate with and understand autistic people.
Support Person/Advocate	• A person to support autistic people during interactions with the police or in court to provide guidance, support communication, reduce stress and ensure that the individual's rights are upheld.
Improvement to Autism Alert Cards	• Simplify and streamline the application process. • Make it available to all autistic people regardless of official diagnosis. • Increase awareness of the card and how to use it amongst the autistic community.
Alternatives to Autism Alert Cards	• Pre-written alert cards or forms may not adequately capture individual needs and experiences. Explore alternative personalised approaches or tools to support autistic people in their interactions with the criminal justice system.

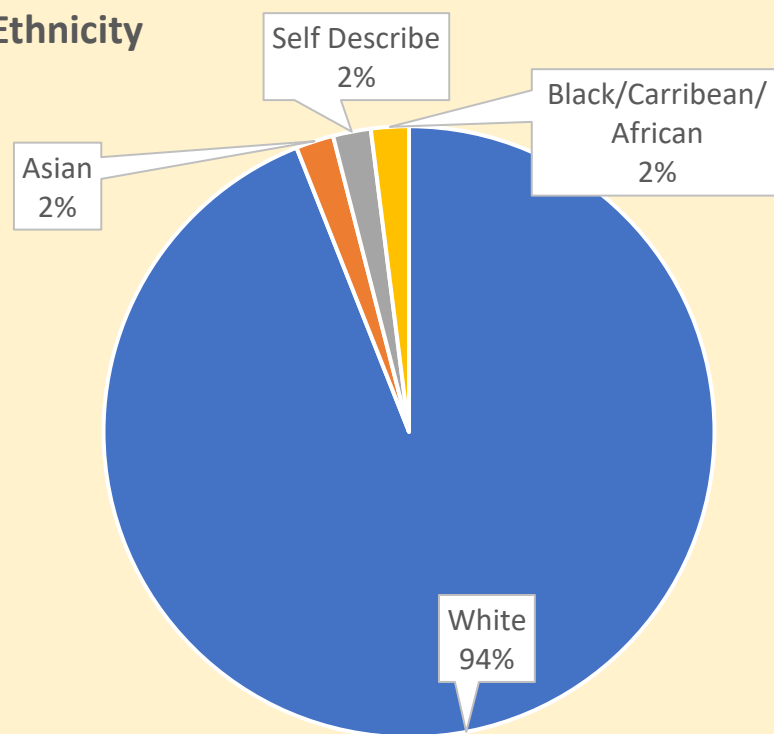


Parents and Unpaid Carers

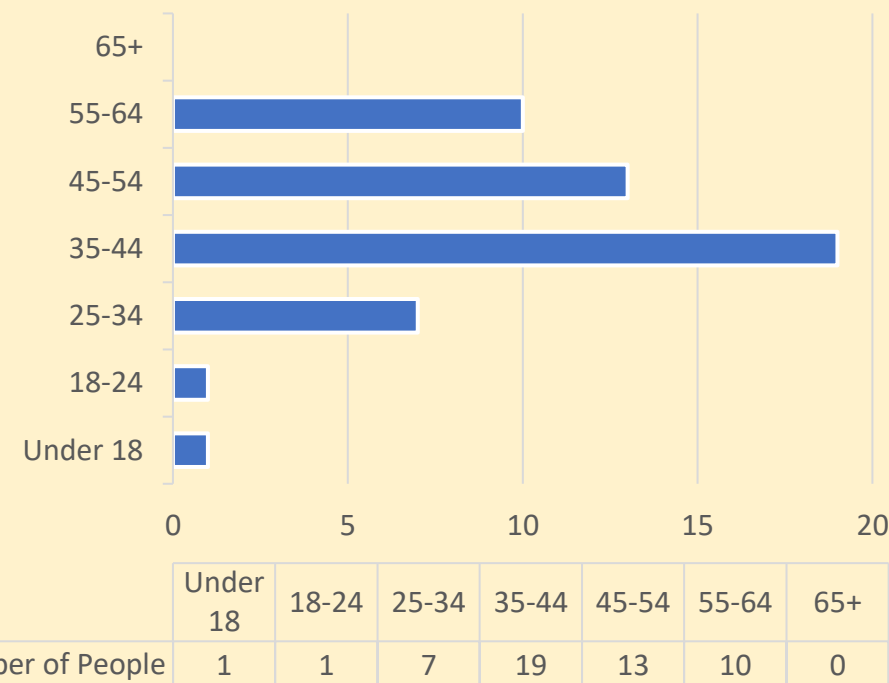
Parents and Unpaid Carers

We asked parents/carers if they would like to share their experiences with us. 51 people chose to answer this section of the questionnaire.

Race/Ethnicity



Age



Parents and Unpaid Carers

Parents/carers told us that:

- 92% cared for their child
- 43% cared for more than 1 person
- 92% provided care for 35 hours and over each week
- 37.5% identified as autistic or were questioning
- 98% said that they can or may feel isolated or lonely because of their caring responsibilities
- 54% continued to provide care when they felt at breaking point
- 48% are worried about the cost of living and 22% said that they are in debt as a result of caring
- 96% said it affected socialising
- 92% said it affected their ability to look after their well-being
- 86.5% said it affected personal relationships
- 81.5% said it affected employment
- 56% said that it affected access to healthcare
- 44% said it affected their education
- 31.5% said it affected housing

Information, Advice and Support

We asked parents/carers where they get information and advice from:

- 60% said the internet
- 55% said social media
- 44% said family or friends
- 33.5% said other carers
- 31.5% said local carers organisations
- 29% said GPs or health practitioners
- 25% said an autism specific charity
- 18.5% said national carers organisations
- 14.5% said they were unsure where get information from
- 10.5% the local authority
- 6% said social care

Information, Advice and Support

We asked whether people had accessed a carers assessment. 46% said that they were unsure what a carers assessment is and 22% told us that they had accessed a carers assessment.

Of the people that had accessed a carers assessment, only 27% found it useful.

We also asked whether parents/carers felt that practitioners listened to their views about the needs of the person they care for. 42% of non-autistic parents/carers said no in comparison to 82.5% of autistic (or questioning) parents/carers.

We asked if people had tried to take a break from their caring responsibilities in the last year. This could be as little as one hour. They told us:

- 44% said yes and that replacement care was provided by family and friends
- 26% said that they had not tried to take a break as it was too difficult
- 14% said that they worried about asking for help
- 4% said yes and that replacement care was provided by social care

Employment

We asked parent/carers if they wanted to share their views and experiences of working whilst also juggling caring responsibilities. They told us;

- 42% are employed part-time
- 22% are employed full-time
- 10% are self-employed part-time
- 30% had reduced their working hours due to their caring responsibilities
- 28% said that they felt tired at work due to their caring responsibilities
- 20% said they feel anxious about caring whilst at work
- 22% said that they were unable to work due to caring responsibilities

However, 30% felt that work gave them a break from their caring responsibilities and 20% said that they had developed skills as a result of caring which were beneficial in their workplace.

We also asked about the impact of caring on retirement plans. 61% said that caring had negatively impacted their ability to save for retirement and 39% said that they had not thought about retirement.

What Parents and Unpaid Carers Told Us

Key Themes	Summary
Feeling Unheard	Some parents and carers express frustration at not feeling heard by practitioners. Practitioners with lived experience are seen as more likely to listen.
Lack of Understanding	Practitioners can lack understanding about autism and masking causing misunderstandings.
Lack of Tailored Services	Services are often not tailored to the specific needs of the person they care for, creating barriers to access and effective support.
Blame	- Some parents and carers report being/feeling blamed for their child's difficulties - Some parents report being accused of fabricating their child's difficulties

What Parents and Unpaid Carers Told Us

Key Themes	Summary
Post Diagnostic Support	Parents and carers feel left to find support on their own.
Carers Assessments	- Many carers are unaware of the existence of carers assessments or the services they provide. - Some people had to challenge the system to receive a carers assessment. - The criteria and process is unclear. - Social care assessments primarily focus on the needs of the person they care for, neglecting any support required for the carer. - Barriers and rules put in place preventing accessing an assessment that are local policies.
Challenges during School Holidays	Parents face significant difficulties during school holidays due to lack of appropriate care options. This also impacts on peoples ability to work.

What Parents and Unpaid Carers Told Us

Key Themes	Summary
Time-Consuming and Complex Processes	Obtaining support is complex and time-consuming due to processes such as EHCP assessments, social care assessments and long waiting lists.
Support Group Availability	Many support groups take place during the day, making it challenging for working parents and carers to participate.
Impact on the Family	Caring can have a significant impact on the entire family, which is generally not taken into account by practitioners and services.
Concerns for the Future	Parents and carers are concerned about how the people they care for will navigate all the complex systems and receive the care they need when they are no longer here to support them.
Unpredictability	What service people receive is reliant on the knowledge and understanding of the practitioner. Reported experiences are a mixture of positive and negative.

Having the carers assessment wrapped up in the Childs needs assessment for parent carers does not consider the carers and them as an individual, I found the process even more isolating, challenging and disheartening. I was made to feel I didn't matter as an individual and I just had to get on with it.

Because I work around my children at school I miss out on all the support groups as they all happen during the day leading to isolation. I cant afford to take unpaid time off to attend any support groups because we would then struggle financially... because we work we are forgotten.

Feel like we are just left by all services, no help, no one to ask questions

The services that are meant to support me and the people that I care for generally make my caring role more difficult. There seems to be an approach of how they can do as little as possible to help. I worry how the people I care for could navigate this dreadful system when I'm no longer here.

Improvements Parents and Unpaid Carers Recommended

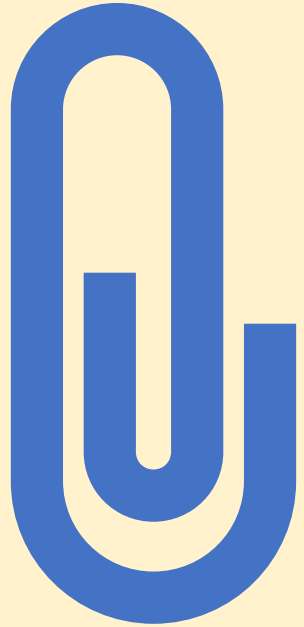
Key Themes	Summary
More Empathy and Support	Practitioners and support services to show more empathy and provide practical assistance rather than just expressing sympathy.
Transparent Communication	Improved communication and transparency in the system, ensuring that parents and carers are informed about their options and rights.
Increased Awareness and Understanding	- Autism training for practitioners - Training for practitioners to understand the challenges of being a carer. - Training for employers to help them better understand about the needs of carers.
Evening and Weekend Support Groups	Increase the availability of support groups to include evening and weekends.
Increase Availability of Childcare Options	Improve the availability and accessibility of childcare options, especially during school holidays and after school.

Improvements Parents and Unpaid Carers Recommended

Key Themes	Summary
Workplace Awareness Initiatives	Encourage employers to implement work-life balance initiatives to support parents/carers.
Mental Health and Well-Being Support	Provide a range of resources and support for the mental health and well-being of parents/carers.
Reduce Barriers for Social Care Support	- For the criteria to be clear and lawful. - To ensure that parents/carers needs are considered during social care assessments - For information to be clear about what should happen and how social care can help. - For social care support to be person centred and not based on what is available.
Post Diagnostic Support	A need for comprehensive support for parents/carers after diagnosis.
Improved Educational Support	Adapting school environments and autism training for school staff and pupils to improve support and understanding.

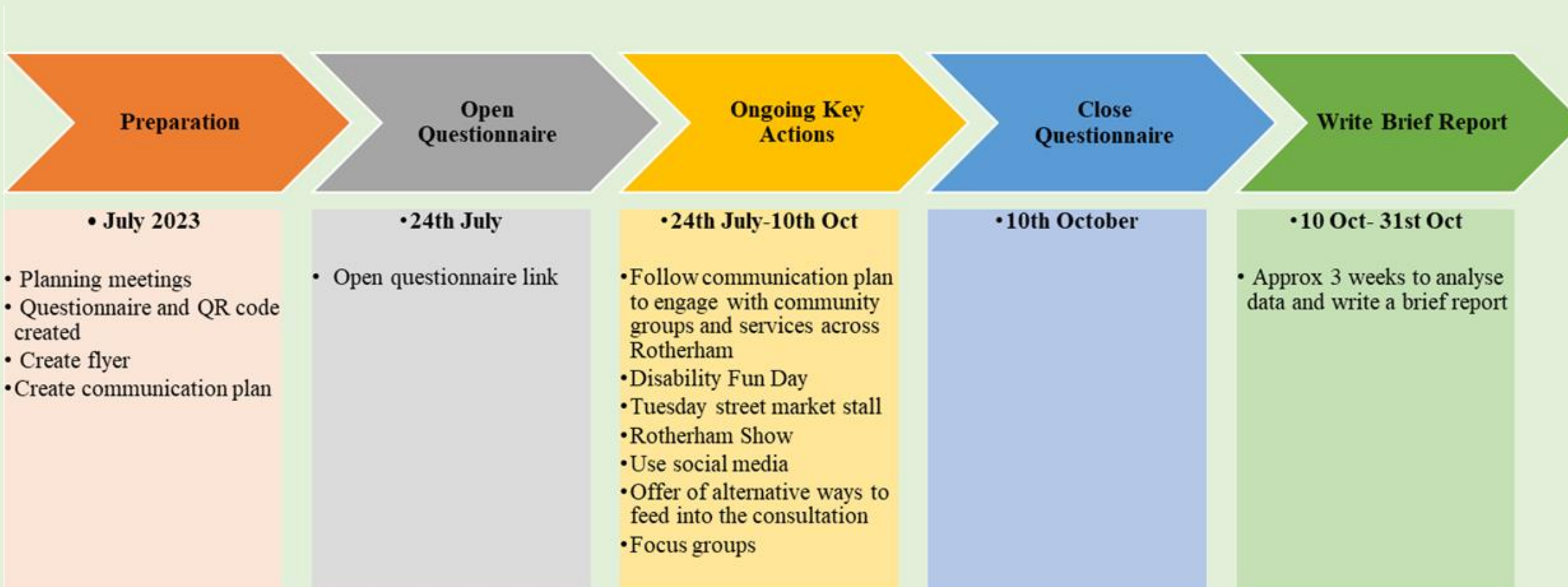
Improvements Parents and Unpaid Carers Recommended

Key Themes	Summary
Equal Access to Services	Services should be available based on needs and not diagnosis.
Using Technology	- On-line support groups - On-line access to book and access appointments for the parent/carer and the person they care for - Online access to the health records of the person they care for. - Being identified as a carer on their health records and on the records of the person they care for. - Information sharing so as to remove the burden of having to repeat the same information across different services.



Appendix

Appendix 1 Consultation Timeline



Appendix 2 Questionnaire Design Rationale

Many people face barriers in receiving an autism diagnosis for a variety of reasons, such as issues around the knowledge of diagnosticians and the availability of diagnostic services. Underdiagnosis is believed to be prevalent across a wide range of marginalised groups (McDonald, 2020; Wigham et al., 2022). Furthermore, some people choose to self-identify and little is known about this group (McDonald, 2020). Research indicates that self-identification is generally accurate and is now recognising how important it is to include this group of people in research, particularly around the diagnostic processes. Therefore, taking this in to account alongside the length of local waiting lists, it was decided to include self-identifying autistic people within our target audience.

It is vital to keep the target audience in mind when designing questionnaires as it shapes the terminology, the research process and the design which in turn influences the level of responses and the validity of the data (Cottrell, 2014).

Hosting questionnaires increases accessibility for many by offering flexibility as to when and where it is completed, providing time to process information and providing anonymity. It also removes the necessity to interact with the researcher face-to-face therefore, including people who would be unable to access a face-to-face discussion with a stranger (Braun et al., 2021).

This is vitally important considering the high levels of social anxiety experienced within the autistic community (Benevides et al., 2020; Spain, Sin, Linder, McMahon, and Happé, 2018). Therefore, according to Beardson's (2019) golden equation of autism + environment = outcome, self-administration should increase accessibility and facilitate completion of the questionnaire. Consequently, an online questionnaire could provide data that is more open and honest and avoids placing additional stress on the participants. It also facilitates a wider geographic reach that is unique within qualitative research (Braun et al., 2021) which, combined with anonymity, may encourage underrepresented groups (Braun et al., 2021; Crane, Sesterka, and Den Houting, 2021; Hayfield and Křížová, 2021).

It is important to include demographic questions about ethnicity, gender and age as autistic minority groups exist just as they do in society (Simmonds, 2021). Obscuring the intersection of other identities with autism can create privilege for one dominant identity (Ropers-Huilman and Winters, 2014). White cisgender males currently dominate autism research (Crane et al., 2021; Simmonds, 2021) so it is vital that we know which communities we are engaging with. Furthermore, the wording and format of demographic questions is important. Although these questions can feel intrusive, explaining the rationale for asking the questions can help reduce concerns (Braun et al., 2021). Therefore, before asking the demographic questions in the questionnaire, we explained why we are collecting demographic data.

Fixed options are used alongside the ability to choose an open ended option to provide an element of control for participants to define themselves (Braun et al., 2021). The terminology used was decided based on government research for terminology used in the 2021 census and the views from ethnic minorities and the LGBTQ+ community.

Good topic-based qualitative questions are generally open questions and endeavour not to make assumptions about what the participant may think or feel (Braun et al., 2021). However, open-ended questions can be difficult for autistic people (National Autistic Society, 2020) with many also experiencing language difficulties which can cause difficulties with completing questionnaires (Nicolaidis et al., 2020). Given that a questionnaire's success is reliant on its completion, it is important participants are not caused undue stress. By ensuring questions are unambiguous, use appropriate language, are as succinct as possible (Denscombe, 2017) and use concrete language, many of the difficulties can be avoided (Nicolaidis et al., 2020). To further help with this and any visual processing difficulties we used specific colours for the questionnaire and have included text to speech videos in the instructional text sections.

Alexithymia is a term used to describe difficulties with recognising and expressing internal and external emotions and bodily sensations (Kinnaird, Stewart, and Tchanturia, 2019). Approximately 63% of autistic people experience high levels of alexithymia as opposed to 5% of non-autistic people (Kinnaird et al., 2019) with an increasing amount of research suggesting that alexithymia as opposed to autism, is the cause of emotion processing differences identified in some autistic people (Fletcher-Watson and Bird, 2020; Kinnaird et al., 2019; Santiesteban et al., 2021).

Therefore, when wording the topic-based questions, it was important to take this into account. Asking closed questions followed by the option to explain can be beneficial even if responses are brief, as the overall data can still provide depth (Braun et al., 2021). Therefore closed questions are used alongside open questions to facilitate a way for participants who are not able to use written language to describe their experiences to be involved.

Questionnaire length is also important as it can cause fatigue and/or disengagement if it is too long (Braun et al., 2021). Although the use of closed questions has resulted in a lengthy questionnaire, it has also provided the ability for the subsequent questions to be filtered, ensuring that the participant is only asked questions that are relevant. Combined with the ability to skip sections/questions this helps to keep the time required to complete the questionnaire under the control of the participant.

Appendix 3 Stakeholders and Engagement

Voluntary and community services

- Social prescribing
- Nayi Zingadi
- Speak Up
- Live Inclusive
- Age UK
- CYP consortium
- RU community sport trust
- NAS Rotherham
- Active independence
- Rotherfed
- REMA
- Clifton learning partnership
- BAME Send group
- YAWS – you asked we said
- Autism East Midlands
- Carers Forum
- PFG
- Touch stone
- S62 project
- Kooth /Qwell
- RPCF &RANSS targeted mailout and texts
- RPCF&RANSS social media
- Rainbow Project
- Touchstone

Engagement Events

Approx. 300 people were engaged with at the following events:

SEND Connect coffee evening
Jump Inc.
Disability Fun Day
Rotherham Street Market
Rotherham Show

Statutory services

- Adult Social Care
- Educational Psychology
- Sendco Network and SEND Lead
- RDaSH – LDA MH collaborative
- With Me In Mind
- Camhs
- Children's Disability Team
- Inclusion/Exclusions Lead
- Autism Senior Navigators
- Special School Heads
- Rotherham Local Offer
- Early Help
- RMBC Comms/press
- TRFT – Autism/LD Service
- Public Health
- Adult ADHD Clinic
- RAADS
- Employment Forum (CYPS)
- Swallownest Court
- Ferham Clinic
- Designated Social Care Officer
- Designated Clinical Officer