

ROTHERHAM'S ALL AGE AUTISM STRATEGY

2024 -2027



www.rotherham.gov.uk

FOREWORD

Rotherham's All Age Autism Strategy refresh shows the progress Rotherham has made since its first strategy launched during the height of the COVID pandemic in 2020. The feedback from Rotherham's autistic people was that there is still more to do.

Our first strategy set out a vision for all autistic people living and working in Rotherham to have the same opportunities as anyone else to live rewarding and fulfilling lives, whatever their age. This remains Rotherham's vision.

Our ambition remains that we want Rotherham to become an autism-friendly borough, in which autistic people can reach their full potential at all stages of their lives. We have again developed a strategy for the next three years which includes all ages - children, young people and adults with autism - and the needs of families and carers.

I would like to thank all the people, communities, and organisations who have assisted in the refresh.

In Rotherham, we are committed to improving the lives of autistic people. We will continue working with families, local autism groups, and partner agencies to ensure that this Strategy and the future implementation plan are a success.



Cllr. David Roche

Cabinet Member for Adult
Social Care and Health



PROGRESS (AND CHALLENGES) SINCE 2020

Rotherham's first All Age Strategy was launched at the height of the COVID-19 pandemic in June 2020. The strategy was built on 5 priorities, which were:

- Starting Well: All of Rotherham's autistic children and young people are healthy and safe from harm.
- Developing Well: All of Rotherham's autistic children and young people start school ready to learn for life.
- Moving on well to independence: Rotherham's autistic children and young people are provided with the same opportunities to thrive going into adulthood.
- Living well: Autistic adults living in Rotherham will get the right support when needed.
- Ageing well: Autistic adults living in Rotherham will be better supported as they grow old.

Despite the huge challenges which the NHS and social care were under, Rotherham as a place has committed to:

- Staff training to ensure that Rotherham's most vulnerable autistic children are being seen and supported elsewhere in the system. Work is commencing to develop Rotherham's public health plan, to ensure that autistic young people can access activities or programs which promote health. An example of this can be seen with KOOTH and QWELL: KOOTH is a digital mental health counselling service for young people aged 11 – 25 jointly commissioned by Rotherham MBC and the then Rotherham CCG, which went live in October 2021, and QWELL is a digital mental health counselling service which offers support to adults.

- Ensure autistic children and young people shape and participate when Rotherham will be the world's first Children's Capital of Culture in 2025, which will involve 365 days of arts and culture devised, developed, and delivered in partnership with children and young people from across the borough and beyond. As the Children's Capital of Culture, Rotherham will develop large-scale, high-profile commissions and partnerships between local arts organisations, venues and national partners.

There will be exhibitions, events, performances, festivals, artworks, murals and more, all curated and created with children and young people from a range of backgrounds. A key aim of this work is to empower children and young people, not only to participate in culture, but to create it in their own image and on their own terms. Rotherham's autistic children and young people, as well as participating, will play an important part in shaping this important event. At the launch event, autistic children and young people shared what autism means to them in the Truth to Power Café.

- Create all age pathways. All Age Pathways acknowledge that there are differences between being an autistic child/young person or adult. We are working to ensure that there is greater coordination as the young person becomes an adult.
- Work to develop an employment offer for autistic young people, which has seen the creation of the Rotherham Opportunities College Project Search Supported Internship model and pilot linkup to Gulliver's Theme Park. Rotherham is working with partners to progress and develop supported internships.
- Launch RotherHive, which included a series of accessible self-help leaflets covering a range of topics, from alcohol problems to stress.

- Create a Rotherham Safe Space, which supports anyone experiencing a mental health crisis in Rotherham and the surrounding areas. This provides a safe place during the weekend evenings, designed to offer support for people in crisis and to prevent avoidable attendances at A&E. People who identify as autistic have been benefiting from this service.
- RDaSH have created a new all age autism diagnostic pathway which has been welcomed.
- Significant and ongoing investment was made to create an innovative post-diagnostic offer in the form of Rotherham Adult Neurodiversity Support Service (RANSS) hosted by Rotherham Parents Carers Forum. This has expanded to include people who self-identify as autistic and autistic people who were diagnosed in the past but were not offered support following diagnosis. Autistic people value this support and have said:

I'll be able to say to anyone in my situation if they've been referred that they've been referred to a wonderful service.

Its helped me identify areas I struggled with and helped me identify ways of managing them.

There were (and remain) challenges:

- There are high numbers of autistic children, young people and adults asking to be diagnosed, and this has created waiting lists. There are pathways to: ensure that children and young people are supported while waiting to be diagnosed. Adults can access the Rotherham Adult Neurodiversity Support Service. Work is occurring at an ICB level to consider how to reduce the waits for diagnosis.
- Autistic people want (and need) to be 'seen', included and valued in their communities and society as a whole.
- Rotherham is always striving for real and meaningful coproduction in developing plans, and autistic people need to be included in plans to shape services from the start. This was picked up in the coproduction for this strategy, and will be a core theme in developing the action plan for its delivery.

Small (but big) kindness

Autistic people value the small, thoughtful acts or gestures that positively impact others in their 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 the co-production, from the views and experiences shared with Rotherham Parent Carers Forum, it was obvious just how important these small kindnesses were. Many people's positive and negative experiences were often also based on the person/staff member that they had encountered, and were not solely about the service. Small kindness evidently had a lasting impact and were greatly valued by autistic people.

CONTEXT

Autism Act and Statutory Guidance:

The National Autism Strategy, *'Fulfilling and Rewarding Lives'*², was originally published by the Government in March 2010 as a result of the Autism Act 2009 and applies to adults in England. This was followed by statutory guidance for local authorities and NHS organisations in December 2010. The Autism Act 2009 required that local authorities and health bodies work together to better support the needs of adults with autism.

Revised Statutory Guidance

The Department of Health published statutory guidance to support the updated Strategy in December 2014, following a public consultation exercise. The revised statutory guidance covers nine areas:

- Training of staff who provide services to adults with autism;
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services;
- Planning concerning the provision of services for people with autism as they move from being children to adults;
- Local planning and leadership concerning the provision of services for adults with autism;
- Preventative support and safeguarding in line with the Care Act 2014 from April 2015;
- Reasonable Adjustments and Equality – This is a theme that is relevant to all our functions and which we plan to monitor through Equality Impact Assessments;

- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity;
- Employment for adults with autism;
- Working with the criminal justice system.

The national strategy for autistic children, young people and adults: 2021 to 2026

In 2021, the Government published a new National Strategy. The strategy set out a vision for what the Government wants autistic people and their families' lives to be like in 2026 across six priority areas, and the steps that national and local government, the NHS, and others will take towards this.

For children and young people, the Special Educational needs and Disability (SEND) Code of Practice (2015), continues to place duties on local authorities, NHS organisations, and schools in respect of autistic children and young people.

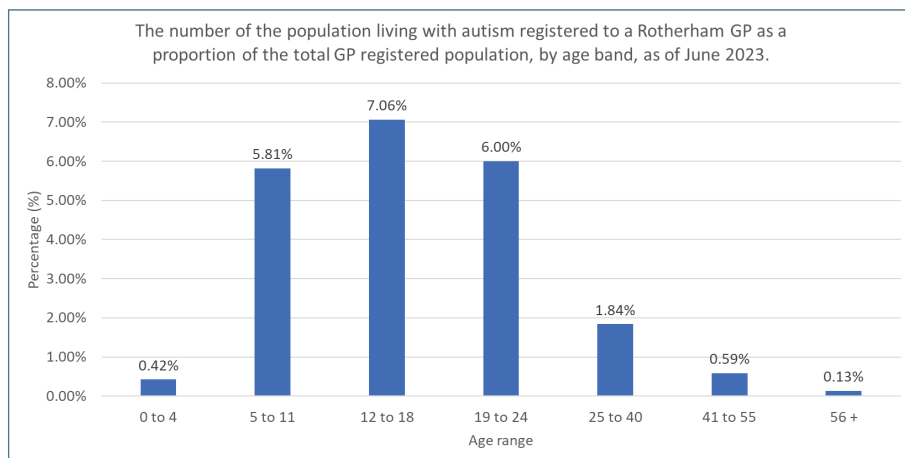
Rotherham's refreshed strategy connects and fits with the national strategy for autistic children, young people and adults: 2021 to 2026.

To learn more: The national strategy for autistic children, young people and adults: 2021 to 2026 (publishing.service.gov.uk)

This strategy has been designed to complement wider strategic plans for Rotherham, including our Adult Social Care Strategy, Learning Disability strategy and SEND vision, as well as wider place-based plans such as The Health and Wellbeing Strategy and the Rotherham Health and Care Plan.

² Department of Health. Fulfilling and rewarding lives: the strategy for adults with autism in England. London : s.n., 2010.

The Local Picture:



In the UK, the estimated prevalence of autism in adults is around 1.1%. Applied to the Rotherham GP registered population, this would be approximately 2,300 people³.

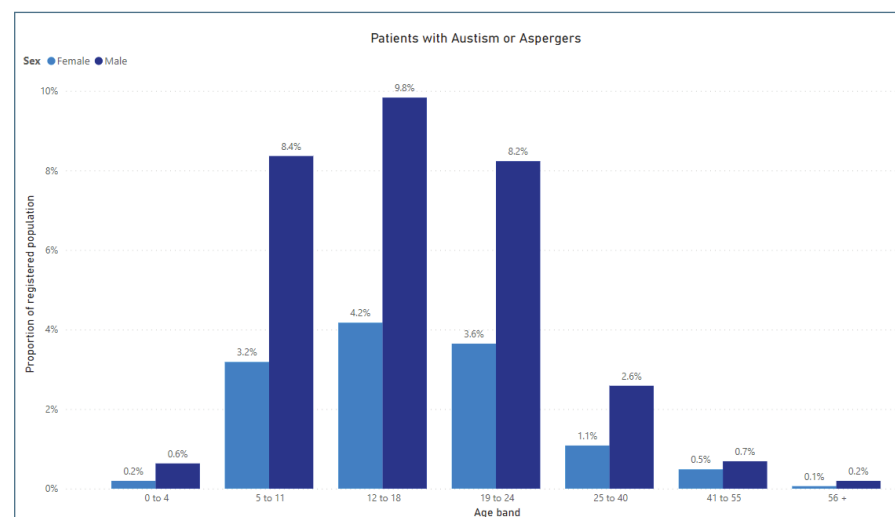
Rotherham Council's children's service has recorded 1894 children/young people who are autistic as at the end of September 2023; out of this cohort, 902 children have an Education, Health and Care Plan (EHCP).

In reviewing Rotherham's GP records, we have found out that there are 5,504 Rotherham registered patients diagnosed with autism or Asperger's syndrome. 4,036 of these are aged under 25 years old which may indicate our local rates of diagnosis are higher than the national average and that there may be some adults that have not been diagnosed.

³ National Collaborating Centre for Mental Health, 2012; SIGN, 2016; Buckley, 2017; National Collaborating Centre for Women's and Children's Health, 2017; BMJ, 2018; National Autistic Society, 2018a

Numbers of people diagnosed with autism as split by age and sex.

The number of females diagnosed varies across studies, but there is consistently a higher proportion of males to females (mostly ranging from 3:1 to 5:1). The gender split is thought to be as a result of camouflaging difficulties in the female population alongside under-reporting, and hence under-diagnosis, of traits in girls⁴.



For more information about autism can be found in Rotherham's Joint Strategic Needs Assessment: https://www.rotherham.gov.uk/jsna/downloads/file/140/rotherham_context_-_autism

⁴ Prevalence | Background information | Autism in adults | CKS | NICE

REFRESHING AND UPDATING OUR STRATEGY

Co-production lies at the heart of our vision. Refresh Rotherham's All Age Autism Strategy (2020 -2023) - a public consultation was undertaken by Rotherham Parents Forum Ltd from 24th July 2023 - 10th October 2023. (More detail about the consultation and the coproduction workshops can be found in appendix 2).

Feedback on the previous Strategy 2020 – 2023

- While progress was noted in terms of improving care and support for autistic people, the overwhelming response from autistic people was that there is still more to do.
- Autistic people 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 strategy is not available in a range of formats and languages.
- Parts of it on the website are incomplete.
- The implementation plan was 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, and people could only find them via an internet search.

Rotherham has listened to these comments and will make the following changes:

- The priorities for the refreshed all age strategy will be based on the 4 cornerstones
welcome and care
value and include
communicate
work in partnership
- Communication and understanding is a clear theme for autistic people of all ages which will be developed as a priority.

The Rotherham Autism Partnership Board plays a crucial role in overseeing the Strategy.

A Note on Terminology

Autism is considered to be a disability under the Equality Act 2010. It is not an illness or a mental health problem.

The research found that all groups like the terms 'on the autism spectrum' and 'Asperger syndrome'. Autistic adults prefer the identity-first terms 'autistic' and 'Aspie', whereas families didn't like 'Aspie'. Practitioners also like the term 'autism spectrum disorder (ASD) or conditions (ASC)'. To reflect the findings of this research, the Strategy will use the term 'autistic' – particularly when talking about children and adults who identify themselves in this way.

This approach aligns to the national strategy.

OUR VISION AND VALUES

In speaking to autistic people, Rotherham still needs to work towards making the borough an autism-friendly place to live. Rotherham supports and celebrates its neurodiversity.

We want Rotherham to be a place where:

- You can get a timely diagnosis with support, meet professionals with a good understanding of autism, find services, organisations and employers that make reasonable adjustments when required, and where people can feel safe, have aspirations and fulfil your potential, be independent, and become a full member of the local community.

This means having:

- Access to education and employment opportunities and your own home.
- Access to the right information, at the right time, to make informed choices.

We will know this because autistic people in Rotherham will tell us that they:

- Feel welcomed and included.
 - Are listened to and have a voice.
- and
- That young people and their families / carers who are preparing for adulthood know what to expect.

Rotherham's *Refreshed All Age Autism Strategy 2024 -2027* sets out a vision for all autistic people to have the same opportunities as anyone else to live rewarding and fulfilling lives, whatever their age.

This vision remains the same, and it is shared by all public, voluntary, and independent organisations that have worked together to develop the Strategy.

Rotherham has developed the Four Cornerstones, which we believe are essential for ensuring that the autistic community (children, young people, adults, parents and carers) and the neurodivergent community in Rotherham have an equal voice.

The Cornerstones build trust by making the commitment to welcome and care, value and include, communicate and work in partnership. The cornerstones are:

WELCOME AND CARE

VALUE AND INCLUDE

COMMUNICATE

WORK IN PARTNERSHIP

Developing and nurturing each of these to build

TRUST

To Learn more: The-Four-Cornerstones-Approach-to-Co-production.pdf (genuinepartnerships.co.uk)

Preparing for Adulthood (PFA):

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.

Rotherham has been working since the Joint SEND inspection to improve its offer for autistic young people moving into adulthood. It has implemented the National Training and Development Team for Inclusion PFA minimum standards¹, but more work is still required.

Developing a robust Transitions pathway will ensure that young people receive the right support at the right time from the appropriate support service. We will ensure that the young person's voice is at the centre of planning for their future. This pathway will consider how work and / or college can play a role - see below.

Independence and Choice

Social interactions and accessing local services can be challenging due to the lack of awareness and understanding of autism. Some autistic people feel ashamed to disclose that they are autistic because of societal attitudes.

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.

There will be an emphasis on developing services that promote independence and equip people with practical life skills, which will support them to maintain their own homes, secure employment, and maximise independent living as much as possible. People will be at the centre of planning and designing the services that they receive.

Community groups, and not just autism specific groups, are seen as sources of support and play a positive role in the lives of autistic people.

Education and Employment Skills

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.

Autistic children and young people still experience misconceptions about autism, based on outdated and negative information which hinders appropriate support being available.

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.

¹ PFA Minimum Standards - NDTi

South Yorkshire Integrated Care System (SYICS) is developing a employment pathway that will support identifying people's skills and matching them with employers, as well as providing ongoing support to maintain their employment.

To Learn more: Employment Opportunities For Autistic Adults | Employment Is For Everyone

Joined up working between services will allow workers and people to identify what their aspirations are at an earlier stage, and then work collaboratively with each other to achieve these.

Health and Care

... 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.

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

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

Autistic children, young people and adults have described the issues they face in terms of accessing health. The importance of accessible mental health services was frequently mentioned.

The importance of good health and addressing health inequalities is seen in the LeDeR5 reports which show that health inequalities have an enormous impact on the health outcomes for autistic people. The highest cause of death for autistic people (taken from the 2022 LeDeR report) was suicide, misadventure or accidental death.

We will work with people, health colleagues, partners, and other organisations to improve health accessibility and ensure that information is available in accessible formats. We will work with partners to ensure that people can access health screening and appointments in an inviting and welcoming environment.

People said that there was 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.

Rotherham is working with South Yorkshire ICB to implement the Oliver McGowan Mandatory Training.

The Autism strategy is set within the context of the Adult Social Care Strategy, with the following themes for delivering adult social care :

- Wellbeing and Independence: enabling people to live their best life.
- Informed Choices: having the right information at the right time.
- Connected to People: support to maintain relationships with people that matter the most to them.
- My Support, My Way: focused on strengths, abilities, and cultural needs of the person.

OUR PRIORITIES 2024 -2027

In 2024/25 a series of coproduction workshops will be held to **create a detailed action plan for Rotherham**. This will include autistic children, young people and adults with their families, carers and with professionals.

Four Cornerstones	Autistic People (children, young people and adults) said	Areas for Development	Priorities	Timeframe
<p>Welcome and Care</p>	<p><i>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></p>	<p>Lack of understanding of autism in education, health and care services.</p> <p>Lack of Cultural and Religious Understanding.</p>	<p>Support young people with care and support needs to prepare for adulthood.</p> <ul style="list-style-type: none"> ● Implement a new transitions assessment process with partners and create an end-to-end Transitions pathway. ● Ensure the voice of the person is heard, listened to, and respected. ● Improve employment opportunities for people with care and support needs. ● Explore if the NHS Autism in School Programme can be expanded into Rotherham Schools. 	<p>2025 onwards.</p>

Four Cornerstones	Autistic People (children, young people and adults) said	Areas for Development	Priorities	Timeframe
<p>Value and Include</p>	<p><i>... they (NHS) 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.</i></p>	<p>Individuals shared challenges with navigating the NHS system and care system, including delayed diagnoses, referral issues, service criteria and lack of post-diagnostic support.</p> <p>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.</p> <p>Improve waiting Assessment and diagnosis times.</p>	<p>Tackling health and care inequalities for autistic people and Provide more opportunities for care and support closer to home.</p> <ul style="list-style-type: none"> ● We will roll out the Oliver McGowan training for all frontline NHS and social care staff. ● South Yorkshire ICB with NHS providers to build assessment capacity and work to reduce waits for children, young people and adults. ● To review mental health pathways to ensure that the needs of autistic people are captured. ● Creating a 'safe space' to prevent admissions into mental health hospital provision. ● Providing more opportunities for real choice in employment through supported internships. ● Develop options around Transport. ● Create more options to support building independence and life skills. 	<p>2024 onwards.</p>

Four Cornerstones	Autistic People (children, young people and adults) said	Areas for Development	Priorities	Timeframe
Communicate	<p><i>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.</i></p>	Clear Accessible Information.	<p>Provide accessible information and advice to support making informed choices</p> <ul style="list-style-type: none"> ● Ensure information including this strategy is accessible. ● Redesign children and adult social care web pages to be accessible – Rotherham Local Offer ● Ensure links from adult social care incorporate the My Front Door (MFD) website and local offer (LO). 	2025 onwards.

Four Cornerstones	Autistic People (children, young people and adults) said	Areas for Development	Priorities	Timeframe
Work in Partnership	<i>Everything is a fight, and navigating systems that are intent on not supporting due to their lack of funds is incredibly stressful and traumatic.</i>	Support more people to enjoy a positive experience of working or volunteering. Housing: Limited Housing Options.	<p>Provide needs lead support.</p> <ul style="list-style-type: none"> ● Improved collaboration between Adult, Childrens, Health and Education services. ● Invest in new assistive technologies (AT) and digital solutions supported by an AT strategy. ● Develop Rotherham’s supported accommodation strategy. 	2025 onwards.
Foundation Co-production				
Outcomes	<p>Improving understanding and acceptance of autism within society.</p> <p>Tackling health and care inequalities for autistic people.</p> <p>Making sure autistic people get the right health and social care help in their communities.</p> <p>Improving autistic children and young people’s access to education, and supporting positive transitions into adulthood.</p> <p>More autistic people will enjoy the benefits of work and employment.</p>			

YOU SAID...

I am glad I was diagnosed as autistic. 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.

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

Being autistic makes adulthood 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.

GLOSSARY OF TERMS USED IN THIS STRATEGY

Term	Expanded Version	Meaning (if applicable)
ADASS	Association of Directors of Adult Social Services	ADASS is the association of directors of adult social services in England. We are a charity and the association aims to further the interests of people in need of social care by promoting high standards of social care services and influencing the development of social care legislation and policy.
ASC	Autistic Spectrum Conditions	Autism spectrum Condition (ASC) is the name for a range of similar conditions, including Asperger syndrome, that affect a person’s social interaction, communication, interests and behaviour.
CAMHS	Child And Adolescent Mental Health Services	CAMHS is used as a term for all services that work with children and young people who have difficulties with their emotional or behavioural wellbeing.
EIA	Equality Impact Assessments	An equality impact assessment is a process designed to ensure that a policy, project or scheme does not discriminate against any disadvantaged or vulnerable people – this includes autistic people.
Rotherham HWB	Rotherham Health and Wellbeing Board	Rotherham HWB is the single strategic forum to ensure coordinated commissioning and delivery across the NHS, social care, public health and other services directly related to health and wellbeing. The HWB also sets the strategic direction for the Integrated Health and Social Care Partnership Place Boward, which was set up to drive integration and deliver transformation across health and social care. The HWB has a comprehensive outcomes framework and receives quarterly performance reports on the place plan to assure progress. Partners provide constructive challenge and are keen to collaborate across organisational boundaries for the benefit of people in Rotherham.

Term	Expanded Version	Meaning (if applicable)
Rotherham's Integrated Health and Social Care Place Plan		This plan aligns to the new Rotherham Health and Wellbeing Strategy. The plan is intended to work as a catalyst to deliver sustainable, effective and efficient health and care support and community services with significant improvements underpinned by collaborative working through the development of the Rotherham Integrated Care Partnership (ICP). Partners are fully committed to working together to make decisions on a best for Rotherham basis to achieve the transformations set out in this plan.
Life Course Approach		A life course approach to health is based on the understanding that multiple factors, which include biological, social, psychological, geographic, and economic, shape health over the life course. This approach aims to increase the effectiveness of interventions throughout a person's life, focusing on a healthy start to life then targeting the needs of people at critical periods throughout their lifetime such as adolescence, moving into work, pregnancy, retirement, bereavement and end of life.
NAS	National Autistic Society	The NAS Rotherham Branch launched in October 2008 and is run on a voluntary basis by people affected by autism spectrum conditions (ASCs). See: http://rotherham.webeden.co.uk/
Neurodevelopmental Pathway		Neurodevelopmental pathway is a specialist service responsible for the assessment of neurodevelopmental conditions such as Autism Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD).
NICE	National Institute for Health and Care Excellence	The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care
Pathways to Progression		Supporting 15 to 19 year-olds not in education employment or training (NEET) to engage in learning or employment.

Term	Expanded Version	Meaning (if applicable)
Pathways to Success		A needs-led community-based programme which focuses on supporting adults with health issues from marginalised communities, not mandated for the Work Programme or inactive in the labour market to develop basic skills and move towards or into employment.
The South Yorkshire Mayoral Combined Authority		<p>Led by South Yorkshire’s Mayor, Oliver Coppard, the combined authority brings together local authorities of Barnsley, Doncaster, Rotherham and Sheffield.</p> <p>The aim is to create a stronger, greener, fairer South Yorkshire, to unlock the potential of our communities, our businesses and our places so they can thrive.</p> <p>Our vision is for an economy which works for everyone, with inclusive and sustainable growth, building on our strengths in innovation and advanced manufacturing.</p>
South Yorkshire Integrated Care Board		<p>South Yorkshire Integrated Care Board works with our partners in the four Places (Barnsley, Doncaster, Rotherham and Sheffield) to understand and meet the local health and care of people in each of these areas.</p> <p>Integrated Care Boards (ICBs) are a part of the health and social care system in England, established as part of the government’s efforts to integrate health and care services. Integrated Care Systems (ICSs) bring together health and care organisations,</p>
RDASH	Rotherham Doncaster and South Humber NHS Foundation Trust	Specialises in delivering the following: Adult and Older Adults Inpatient and Community Mental Health; Children and Adolescent Mental Health; Learning Disabilities; Substance Misuse; Psychological Therapies, Forensic and Community Services.
Rotherham Business Growth Board’s employment and skills sub-group		Is a sub group of the Rotherham Business Growth Board which oversees the Rotherham Employment and Skills Strategy.

APPENDIX 2: CO-PRODUCTION OF THE REFRESH OF ROTHERHAM'S AUTISM STRATEGY 2024-2027

The refresh of Rotherham's All Age Autism Strategy required coproduction. To undertake this, Rotherham Parent Carers Forum (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. www.genuinepartnerships.co.uk

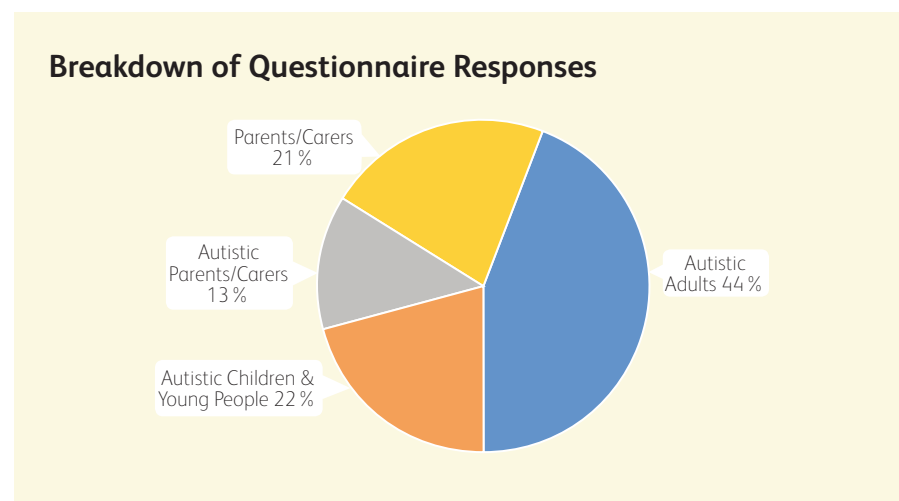
A public consultation was undertaken by Rotherham Parents Forum Ltd from 24th July 2023 - 10th October 2023. In developing the consultation, we were mindful of the specific needs of autistic people and their parents and carers. The following methods were used:

- 1 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.
- 2 Four in-person focus groups also took place.
- 3 A range of engagement events and contacts took place to make people aware of the consultation and how they could take part.

A total of 175 people provided their views and experiences, of whom approx. 79% identify as autistic. No formal autism diagnosis was required, so this figure 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 charts below.

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



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 who 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 maintain anonymity.

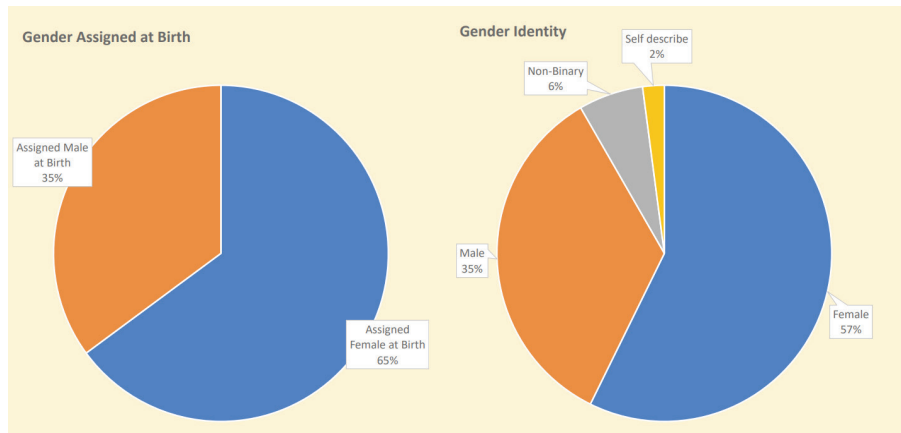
Groups who were consulted:

- Social prescribing
- Nayi Zingadi
- Speak Up
- Live Inclusive

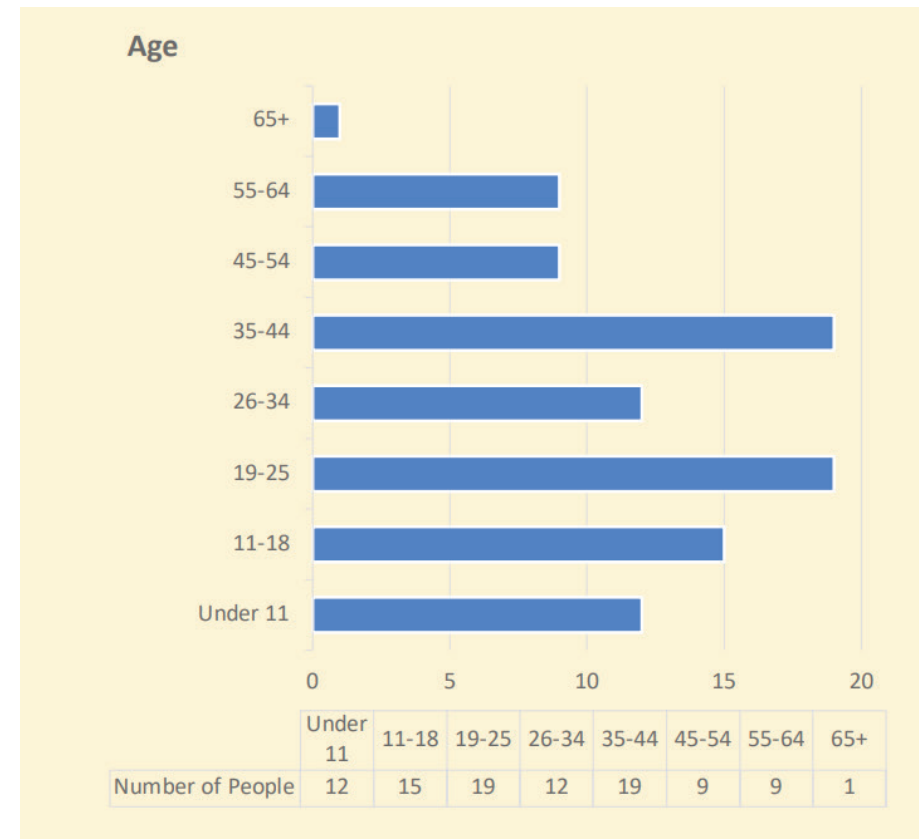
- Age UK
- CYP consortium
- Rotherham United community sport trust
- NAS Rotherham
- Active independence
- Rotherfed
- REMA
- Clifton learning partnership
- BAME Send group
- YAWS – you asked we said
- Autism East Midlands
- Carers Forum
- PFG
- Touch stone
- S62 project
- Kooth/Qwell
- RPCF & RANSS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

The people who responded to the consultation had the following characteristics:

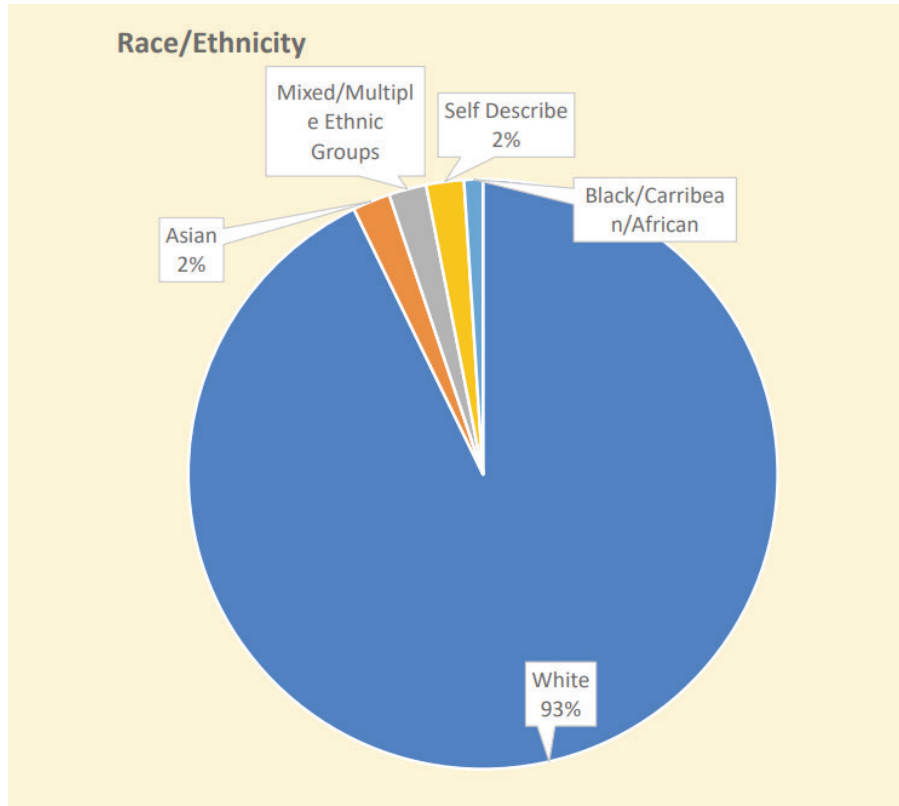
Gender/Gender Identity:



Age of people who responded:



The race/ethnic background of people who responded:



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.

