

Rotherham Adult Neurodiversity
Support Service

Rotherham All Age Autism Strategy Engagement Findings: Summary

October 2023

Full Version is available on request

DIAGNOSIS
ASSESSMENT
GP LIST
SUPPORT SERVICES
WAITING LIKE WAIT
AUTISTIC
REFERRED
MONTHS KNOW
PEOPLE WORK
ACCESS
EDUCATION
FEEEL ASKED STOP CAN
FORMAL SCHOOL SOCIAL WANT
DOCTORS LOT FEMALES MANY JOB
OFFERED COMPUTER ALSO
POST MUCH
YEAR SPENT OLD JUST DIAGNOSED
HEALTH HELPFUL GET TIME
WAITING LIKE WAIT SERVICE YEARS ONLINE REALLY
RANSS WENT DIAGNOSTIC
DR FEEL FROM LATE
DECLINED COUNSELLING TOOK TOLD KEEP DUE MONTHS KNOW INFORMATION RECEIVED PRIVATE
RANSS CAMHS LONG ONE HELP PEOPLE WORK REFERRAL GIVEN
PHONE REFER ACCESS INITIALLY EDUCATION
MOVING ACCESSING



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.

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:

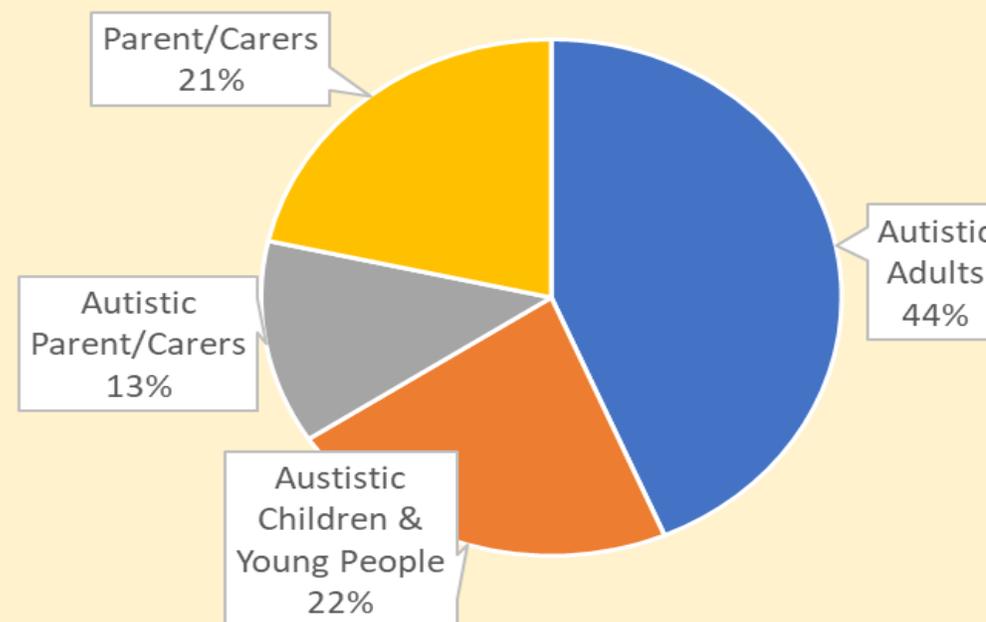
- A Microsoft forms document containing a range of open and closed questions was developed and published online. Text to talk videos reading the long pieces of text were provided as an option. Alternative methods could also be requested.
- 4 in-person focus groups also took place.
- A range of engagement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

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

Breakdown Of Questionnaire Responses



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.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Clear Accessible Information	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Social workers need comprehensive training to better understand autism and the specific needs of autistic people.
Separate Autism Services	<ul style="list-style-type: none"> • Separate services for autistic people from those for people with learning disabilities to better cater to the unique needs of each group.
Inclusive Services	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Continuous communication between individuals and social care, providing timely responses to enquiries and referrals.
Accessibility for Seeking Help	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Ensure that autistic people have access to advocates or support to help navigate the assessment process and provide guidance.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Create Autism-Friendly Sessions (Pools, Gyms etc)	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Offer sessions at various times during the day and week to provide flexibility for diverse schedules.
Support	<ul style="list-style-type: none"> • Offer the option of having an autism trained person to support and facilitate engagement in physical exercise.
Accessible Information and Awareness	<ul style="list-style-type: none"> • Improve communication and information dissemination to ensure that autistic people are aware of available support and resources for physical exercise.

Improvements Autistic Adults, Children and Young People Recommended. Health

Key Themes	Summary
Frequent Health Checks	<ul style="list-style-type: none"> • Offer frequent health checks to enable improved identification and monitoring of health conditions.
Extended/Flexible Appointment Times	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Autism training for staff to ensure they understand and cater to the specific needs of autistic patients.
Home Visits	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> Allow for online appointment booking as phone calls are difficult/inaccessible for many autistic people.
Sensory-Friendly Environments	<ul style="list-style-type: none"> Create comfortable, quiet, and sensory-friendly healthcare settings that reduce sensory overload and anxiety.
Follow-up Communication	<ul style="list-style-type: none"> Follow up telephone calls and appointments with emails or text messages to help autistic individuals remember and understand the verbal information provided.
Patient Information	<ul style="list-style-type: none"> Ensure that autistic people are informed about the support available to them before each appointment and that any required support is readily available.

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Use of Short and Quick Communication Tools	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none">• For patients to be made aware of what reasonable adjustments can be put in place and to be asked what they need.
Sensory-Friendly Environment	<ul style="list-style-type: none">• 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.

Improvements Autistic Adults, Children and Young People Recommended: Mental Health and emotional wellbeing

Key Themes	Summary
Provide Holistic Support	<ul style="list-style-type: none"> • Provide support that considers the whole person, taking into consideration their specific circumstances, communication styles and needs.
Autism Training	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none">• 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

Improvements Autistic Adults, Children and Young People Recommended:

Key Themes	Summary
Community Awareness and Engagement	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Autism training for public facing staff.
Support Services	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Clear and Accessible Information	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none">• To help staff be more aware and understanding of the challenges faced by autistic people.
Affordable Public Transport	<ul style="list-style-type: none">• Improve the affordability of public transport, making it easier to access essential services and resources within the community.

Criminal Justice

Improvements Autistic Adults, Children and Young People Recommended

Key Themes	Summary
Autism Training	<ul style="list-style-type: none"> • Training for staff on how to effectively communicate with and understand autistic people.
Support Person/Advocate	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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.

Improvements Parents and Unpaid Carers Recommended

Key Themes	Summary
More Empathy and Support	<ul style="list-style-type: none"> Practitioners and support services to show more empathy and provide practical assistance rather than just expressing sympathy.
Transparent Communication	<ul style="list-style-type: none"> Improved communication and transparency in the system, ensuring that parents and carers are informed about their options and rights.
Increased Awareness and Understanding	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Increase the availability of support groups to include evening and weekends.
Increase Availability of Childcare Options	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Encourage employers to implement work-life balance initiatives to support parents/carers.
Mental Health and Well-Being Support	<ul style="list-style-type: none"> Provide a range of resources and support for the mental health and well-being of parents/carers.
Reduce Barriers for Social Care Support	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> A need for comprehensive support for parents/carers after diagnosis.
Improved Educational Support	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> • Services should be available based on needs and not diagnosis.
Using Technology	<ul style="list-style-type: none"> • 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 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