

Committee Name and Date of Committee Meeting

Cabinet – 12 February 2024

Report Title

Rotherham All Age Autism Strategy 2024 - 2027

Is this a Key Decision and has it been included on the Forward Plan?

Yes

Strategic Director Approving Submission of the Report

Ian Spicer, Strategic Director of Adult Care, Housing and Public Health

Report Author(s)

Garry Parvin

Joint Head of Learning Disability, Autism and Transition Commissioning,
Strategic Commissioning, Adult Care, Housing and Public Health

Email: garry.parvin@rotherham.gov.uk

Mobile: 07887 057491

Ward(s) Affected

Borough-Wide

Report Summary

The purpose of this report is to seek approval of the Rotherham All Age Autism Strategy 2024 – 2027, attached at Appendix 1.

The Strategy builds on the progress made in the delivery of the Rotherham All Age Autism Strategy 2020 - 23 and sets the strategic direction and priorities for the next three years. This has been informed by the co-production work undertaken with people with lived experience, attached at Appendix 2.

The report provides an overview of factors which have shaped the development of the Strategy. These are:

1. National policy developments.
2. Changes in Rotherham's autistic population.
3. The importance of co-production - the inclusion of the autistic voice from all communities.

The vision for the Strategy remains unchanged from the 2020 -23 Strategy to ensure consistency of approach and strategic direction. Measures have been included to

demonstrate the impact being made and this is based on the co-production report about what is important to people with lived experience from the autistic population.

The Strategy outlines Rotherham's four cornerstones and this is used to structure the strategy and priorities. The Strategy looks at key areas and connects to Rotherham's SEND Strategy and Learning Disability Strategy. The key areas are:

- Preparing for Adulthood.
- Independence and Choice.
- Education and Employment.
- Health and Care.

Lived experience, as reported by autistic children, young people and adults is captured in these key areas. The Strategy also identifies existing work programmes which are taking place to address these areas of development, as it is clear that significant progress is being made and will be further built upon over the next three years.

The following changes have been made to the Strategy, to ensure it remains reflective of the needs of autistic people within Rotherham:

1. The restructuring of the priorities to the Rotherham Four Cornerstones:
Rotherham developed the Four Cornerstones, which 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 Four Cornerstones are : Welcome and Care, Value and Include, Communicate, and Work in Partnership. This will ensure a golden thread between Children and Young Peoples Services and Adult Services, as well as Housing.
2. The plan is to co-produce a detailed action plan to address the priorities in 2024. The rationale is to ensure that autistic children, young people and adults with families and professionals, work together on the strategic priorities important to them and can demonstrate delivery and impact.

Recommendations

That Cabinet:-

1. Approve the refreshed Rotherham All Age Autism Strategy 2024 – 2027 and acknowledge the commitment to develop a co-produced action plan.
2. Agree to receive a further report in 18 months on delivery against the All Age Autism Strategy 2024 - 2027 and that the plan is to co-produce a detailed action plan in 2024

List of Appendices Included

Appendix 1: Rotherham All Age Autism Strategy 2024 – 2027.

Appendix 2: Rotherham All Age Autism Strategy Engagement Findings Summary -

Appendix 3: PART A - Initial Equality Screening Assessment

Appendix 4: PART B – Equality Analysis Form

Appendix 5: Carbon Impact Assessment

Background Papers

- Rotherham’s All Age Autism Strategy and Implementation Plan 2020 -2023:
<https://www.rotherham.gov.uk/health-social-care/rotherham%E2%80%99s-age-autism-strategy-2020-2023/8>
- Autism Strategy and Pathway: Update to Health Select Commission:
<https://moderngov.rotherham.gov.uk/documents/s135804/Autism%20Strategy%20and%20Pathway%20Update.pdf>

Consideration by any other Council Committee, Scrutiny or Advisory Panel

No committees, scrutiny or advisory have requested to consider.

Council Approval Required

No

Exempt from the Press and Public

No

Rotherham All Age Autism Strategy 2024-2027

1. Background

- 1.1 The purpose of this report is to seek approval of the Rotherham All Age Autism Strategy 2024-2027, attached at Appendix 1.
- 1.2 The Strategy builds on the progress made in the delivery of the Rotherham All Age Autism Strategy 2020-2023 and sets the strategic direction and priorities for the next three years. This has been informed by the co-production work undertaken with people with lived experience, attached at Appendix 2.
- 1.3 The Council approved its first All Age Autism Strategy 2020-2023.
- 1.4 The 2020-2023 Strategy and implementation plan were built around 5 priorities across the life course. These 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 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.
- 1.5 Progress across these priorities has been made and this was reported to the Health Select Committee on 7 April 2022. In summary:
 - 1.5.1 **Starting Well and Developing Well: Creation of mental health support platforms and Inclusion of autistic voices in Rotherham cultural initiatives:**
 - Completion of investment and pathway work to develop new mental health support platforms, namely KOOTH and QWELL.
 - This was made through NHS Rotherham CCG investment.
 - These platforms are designed to be accessible for autistic children, young people, and adults.
 - Involvement of the voices of autistic children and young people in shaping the Children's Capital of Culture in 2025.
 - This initiative aims to ensure that the perspectives and needs of autistic individuals are considered in cultural events and activities.

1.5.2 **Starting Well, Developing Well, Moving on Well to Independence, Living Well and Aging Well: Development of all age diagnostic pathways:**

- Investment in pathway development to establish all-age diagnostic pathways, led by Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH) and the Rotherham Adult Autism Diagnostic Service.

1.5.3 **Moving on Well, Living Well and Aging Well: Establishment of a post diagnostic Neurodiversity Support Service:**

- Creation of the Rotherham Adult Neurodiversity Support Service (RANSS), provided by the Rotherham Parent Carers Forum.
- This was made through NHS Rotherham CCG investment.
- This service focuses on providing support specifically tailored to the needs of neurodivergent adults in the Rotherham area. It expanded to provide support to adults who were diagnosed prior to the creation of the Rotherham pathway and supports adults who are waiting to be diagnosed.

1.5.4 **Moving on Well, Living Well and Aging Well: Growing a new employment offer:**

- Creation of employment opportunities for autistic young people and adults through Rotherham Opportunities College (ROC).
- This was made possible with investment from CYPS.
- The involvement of Working Win in providing employment opportunities promoting a multi-faceted approach to supporting autistic individuals in the workforce.

1.5.5 These initiatives cover a wide range of areas, including mental health support, diagnostic services, cultural inclusion, and employment opportunities, demonstrating a broad approach to addressing the needs of autistic individuals in the community.

1.5.6 A progress report was presented to the Health Select Committee on 7 April 2022, with detailed information available in the background papers linked to the report.

1.6 Despite progress, challenges have been encountered in fully implementing the 2020 - 23 strategy, and the impact of COVID-19 added complexities to the situation. Namely:

1.6.1 **Increased demand to access diagnosis pathways (CYP and Adults):**

- Plans have been developed to address this challenge, including the creation of additional capacity.

- Early offer pathways have been developed to provide support to children, young people, schools, and their families while waiting for a diagnosis.
- Additional investment has been allocated to expand capacity for adult diagnosis, with a specific focus on utilising online diagnostic providers to improve accessibility.

1.6.2 **Ensuring Inclusion of all voices in the strategy:**

- In April 2022, the Health Select Committee highlighted that certain groups of the population were not fully included. This was addressed in the action plan delivery and has been reviewed in the Strategy refresh.

2. Key Issues

2.1 This section of the report considers factors which have informed the Strategy. These are:

- National policy developments.
- Changes in Rotherham’s autistic population.
- The importance of co-production - the inclusion of the autistic voice from all communities.

2.2 National Policy Developments

2.2.1 In July 2021, the Government released its new National Autism Strategy (NAS), setting out the steps it plans to take to improve provision for autistic people across England.

2.2.2 The NAS is structured around 6 priority areas. Over the next 5 years, under the headlines of these 6 priority areas, the Government has committed to:

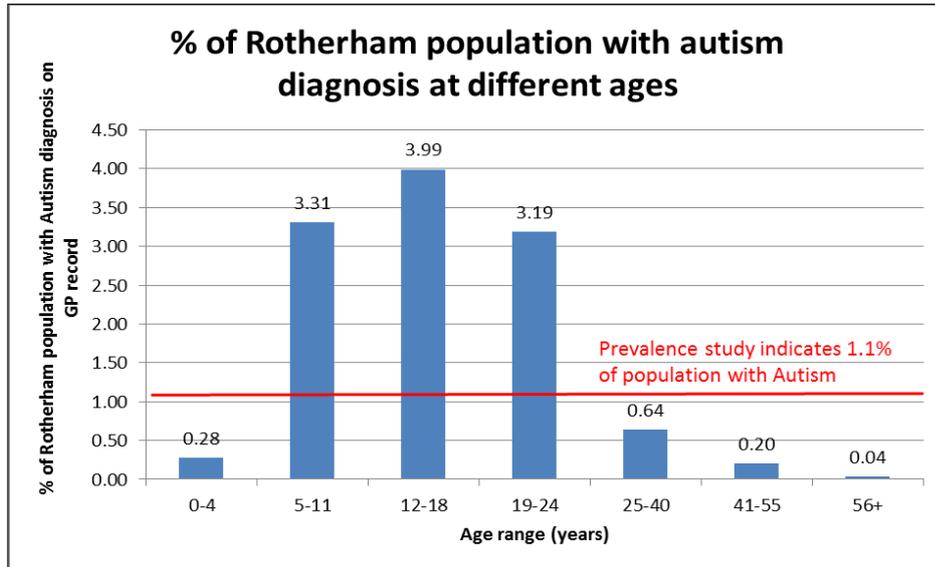
- a. Improving understanding and acceptance of autism within society.
- b. Improving autistic children and young people’s access to education and supporting positive transitions into adulthood.
- c. Supporting more autistic people into employment.
- d. Tackling health and care inequalities for autistic people.
- e. Building the right support in the community and supporting people in inpatient care.
- f. Improving support within the criminal and youth justice systems.

2.2.3 The importance of tackling health inequalities is highlighted with the recent publication of the Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR - see background papers). In terms of the deaths reported to LeDeR for autistic people, the most frequent cause of death was suicide, misadventure, or accidental death.

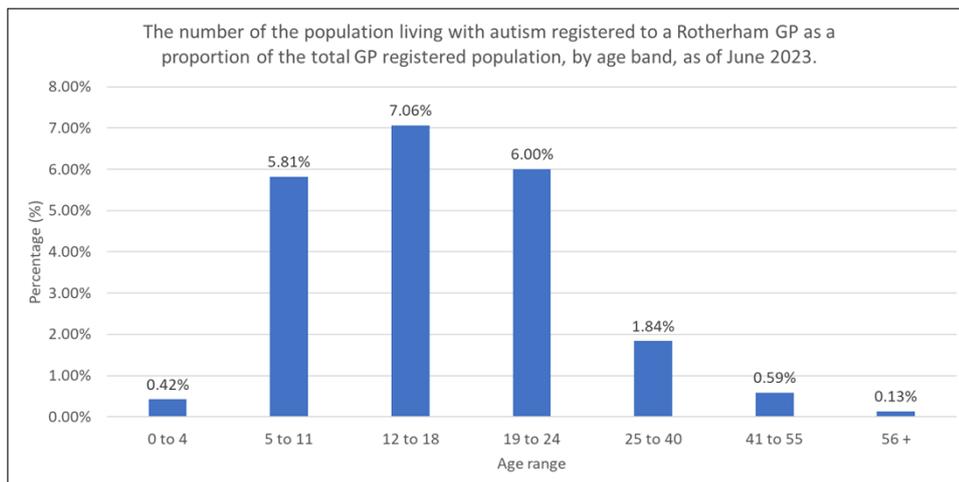
2.3 Changes in Rotherham's autistic population

The Strategy has been refreshed using the latest population data and intelligence. This data has in the main, been derived from GP databases within the NHS.

The table below was included in the All Age Autism Strategy 2020-2023, and shows the prevalence of autism by age:



2.3.1 The table below is included in the All Age Autism Strategy 2024 – 2027 and shows the prevalence of autism by age.

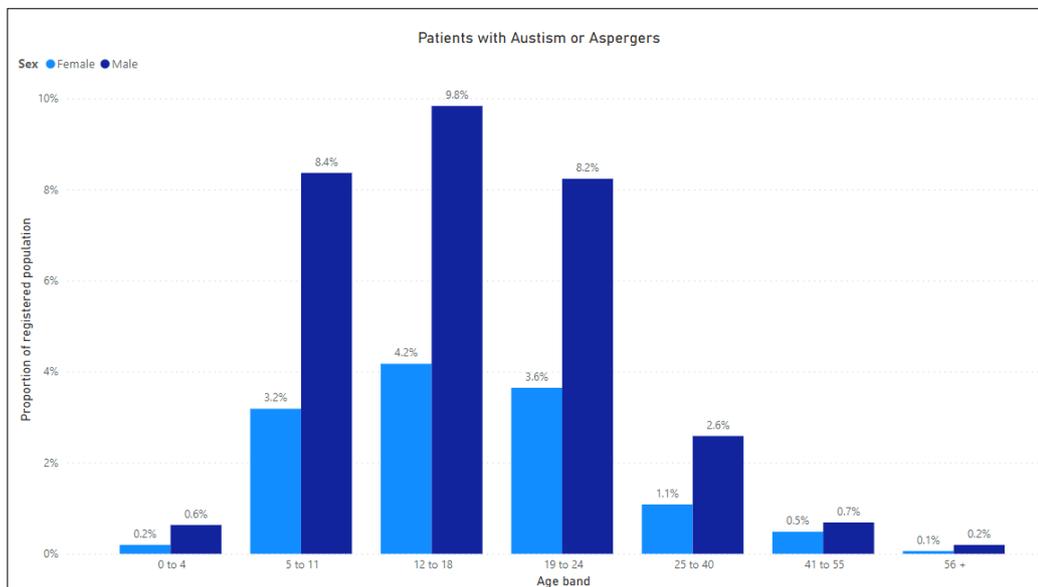


2.3.2 The tables above show an increase in the prevalence of autism across all age groups in Rotherham.

2.3.3 In reviewing Rotherham's GP records, it is evident 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 that local rates of diagnosis are higher than the national average and that there may be some adults who have not been diagnosed. The reasons why

local rates are higher is complex, related to shifts in diagnostic criteria, increased awareness of autism and improved diagnostic pathways.

2.3.4 The table below shows the prevalence of autism by sex and age. The data shows that, although there are more males currently diagnosed, the numbers of females with a diagnosis has increased.



2.3.5 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 camouflaging¹ difficulties in the female population, alongside under-reporting, and hence under-diagnosis, of traits in girls.

2.3.6 In relation to Council held Adult Social Care data, the Council has 167 autistic people listed as receiving a service. Most (81%) have an additional learning disability. This clearly shows a connection with Rotherham's Learning Disability Strategy. 19% of autistic people accessing support of Adult Social Care had either mental health or physical disabilities.

2.3.7 The Council is seeing more autistic young people being supported by Adult Social Care. This identifies the importance of the Preparing for Adulthood pathway and the need for an all-age strategy, priorities and strategic approach.

2.3.8 In terms of gender, Adult Social Care supports more autistic men than autistic women which is consistent with NHS reported data.

¹ 'masking' or 'camouflaging' Women with autism "camouflage"—hiding symptoms or behaviours seen by others as problematic—more than men with autism or people without autism. Autistic camouflaging has been shown to be linked to a heightened risk of depression, anxiety, and suicidality in women with autism.

2.4 **The importance of co-production - the inclusion of Rotherham's autistic voice from all communities**

2.4.1 To ensure that the voice of autistic children, young people and adults was captured and used to shape the strategy, a public consultation was undertaken by Rotherham Parents Forum Ltd from 24th July to 10th October 2023. 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. This questionnaire was promoted by the Council as well as the co-production partner.
- Four in-person focus groups were held.
- A range of engagement events and contacts took place to make people aware of the consultation and how they could take part.

2.4.2 A total of 175 people provided their views and experiences (149 questionnaires and 26 people attended a focus group), of whom approximately 79% identified 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.

2.4.3 A summary report regarding the co-production is attached as appendix 2 to this report, and a summary is included as an appendix to the strategy. The level of involvement of people with lived experience in shaping the development of the strategy was extensive and will ensure the future strategic direction is reflective of the needs and aspirations of autistic people in Rotherham.

2.5 **Overview of the Strategy**

2.5.1 Rotherham's All Age Autism Strategy 2024 - 2027 is built on the principles of co-production. It retains the 2020 - 23 vision:

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.

2.5.2 The Strategy outlines the Rotherham four cornerstones, and these are used to structure the strategy and its priorities. The strategy looks at key areas and connects to Rotherham's SEND Strategy and the Learning Disability Strategy. The four key areas are:

2.5.3 **Preparing for Adulthood:** Rotherham has been working since the Joint SEND inspection to improve its offer for autistic young people moving into adulthood. Developing a robust transition pathway will ensure that young people receive the right support, at the right time, from the appropriate support service. The young person's voice is at the centre of planning for

their future in Rotherham. This pathway will consider how work and / or college can play a role.

- 2.5.4 **Independence and choice:** There remains a lack of awareness and understanding of autism. Some autistic people feel ashamed to disclose that they are autistic because of societal attitudes.

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.

- 2.5.5 **Education and Employment:** South Yorkshire Integrated Care System (SYICS) and the South Yorkshire Mayoral Authority (SYMCA) are developing an employment pathway that will support identifying people's skills and matching them with employers, as well as providing ongoing support to maintain their employment.

- 2.5.6 **Health and Care:** 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.

- 2.5.7 The importance of good health and addressing health inequalities is seen in the LeDeR 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.

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

- 2.5.9 The experience as reported by autistic children, young people and adults is captured in these areas. The Strategy also identifies existing work programmes that are being implemented to address these areas of development.

- 2.5.10 The following key changes are made to Rotherham's All Age Autism Strategy 2024 -2027:

- 2.5.11 The restructuring of the Rotherham priorities to the Rotherham Four Cornerstones – Welcome and Care, Value and Include, Communicate, and Work in Partnership. This will ensure a golden thread between Children and Young Peoples Services and Adult Services, as well as Housing.

- 2.3.12 The plan is to co-produce a detailed action plan to address the priorities in 2024 and 2025. The rationale is to ensure that autistic children, young people, adults with families, and professionals work together on the

strategic priorities important to them and can demonstrate delivery and impact.

3. Options considered and recommended proposal

3.1 The following options were considered:

3.1.1 Not to update Rotherham's All Age Autism Strategy 2020 – 23. This is not recommended because the strategy needs to remain current and reflective of local need as well as regional and national strategic direction.

3.1.2 To develop the strategy implementation plan without co-production. This is not recommended as the importance of co-production lies at the heart of the Council's vision and principles.

3.1.3 Adopt the refreshed Rotherham All Age Autism Strategy 2024 - 2027 with the commitment to develop a co-produced action plan. **This is recommended to ensure Rotherham has a clear strategic direction and is able to fulfil the Statutory Autism Guidance.**

4. Consultation on proposal

4.1 The report (2.4) gives a summary of the co-production which informed the development of the All Age Autism Strategy 2024-2027. The Co-production report attached at appendix 2 also provides details of this engagement.

4.2 The Co-production which has underpinned the strategy, included workshops with representatives from a wide range of professionals, autistic people (including young people) with autism, parents, families, carers and local businesses. The workshops gathered rich information and ideas for key priorities for people with autism in Rotherham.

4.3 Discussions have been held with the following Rotherham Place groups and partnerships to consider and comment on the strategy:

- Social, emotional and mental health (**SEMH**) Needs Group.
- Rotherham Mental Health, Learning Disability and Neurodiversity Group.
- Preparing For Adulthood Group.

4.4 The Autism Partnership Board was set up to advise on all aspects of implementation associated with national and local autism policy and is made up of people with autism, carers, representatives of community and voluntary groups and professionals from the statutory sectors and will have a lead role in ensuring both the strategy and the development of the delivery plan are implemented.

5. Timetable and Accountability for Implementing this Decision

- 5.1 Rotherham's All Age Autism Strategy covers the period 2024 - 2027. An action plan will be co-produced to ensure the priorities are delivered and the outcomes and impact can be demonstrated.
- 5.2 The successful delivery of the Strategy is for all Rotherham place partners, with oversight for the strategy sitting under the leadership of the Rotherham Health and Wellbeing Board.

6. Financial and Procurement Advice and Implications

- 6.1 There are no direct financial implications from the proposals in the report. Any additional resources required to support the strategy will be subject to separate future decisions within the overall context of the Council's budget.
- 6.2 The LGA is working with the government to identify any new financial burdens that may result in meeting the Oliver McGowan Mandatory Training on Learning Disability and Autism.
- 6.3 There are no known procurement implications that apply to the implementation of this Strategy. Where there is procurement activity required to support the strategy, this will be subject to compliance with the Councils Financial and Procurement Procedure Rules and Public Contract Regulations 2015 (as amended).

7. Legal Advice and Implications

- 7.1 The Statutory guidance for Local Authorities and NHS organisations to support Implementation of the strategy, as set out in section 3 of the Autism Act 2009, is to be treated as though it were guidance issued under section 7 of the Local Authority Social Services Act 1970 (LASS Act). This means that the Council must "follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course."
- 7.2 The Health and Care Act 2022 introduced a statutory obligation to ensure the social care workforce access the Oliver McGowan Mandatory Training on Learning Disability and Autism.
- 7.3 The Council will need to ensure that commissioners, providers (both in-house and commissioned), quality monitoring staff, safeguarding leads and workforce leads are aware of this new requirement, and the regulation updated by CQC: Regulation 18 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 and are using both the relevant core capability frameworks to underpin all workforce development.

8. Human Resources Advice and Implications

- 8.1 The implementation of the Statutory Training programme (as set out in the Health and Care Act 2022) - Oliver McGowan Mandatory Training on Learning Disability and Autism which aims to ensure the health and social care workforce have the right skills and knowledge to provide safe, compassionate and informed care to autistic people and people with a learning disability will require staff to be released to undertake Level 1 or Level 2 training. The impact is currently being assessed.

9. Implications for Children and Young People and Vulnerable Adults

- 9.1 The All Age Autism Strategy 2024-2027 takes a life course approach for Children, Young People and Vulnerable Adults as set out in the report and will positively address the needs of autistic people throughout all stages of their life.

10. Equalities and Human Rights Advice and Implications

- 10.1 Part A and part B have been completed. The Equalities Analysis Action Plan (see Part B – Equality Analysis Form in appendix 3) has concluded that the following actions need to be addressed:
- Data: There remains the need to explore that all systems in the Rotherham Place – (For example: the NHS, leisure and libraries etc.) capture autism as a Protected Characteristic. Further data emerging from Learning Disability and Autism mortality review (LeDeR) will be incorporated into the suite of data to inform the strategy and its delivery.
 - Development of a co-produced action plan.
 - Cabinet receive a further report on delivery against the strategy and action plan before the end of the current strategy term in 2027.

11. Implications for CO2 Emissions and Climate Change

- 11.1 There are no direct or indirect climate change implications as a result of this report.

12. Implications for Partners

- 12.1 The Strategy has implications for all place partners. The principal partners identified are:
- 12.2 NHS South Yorkshire ICB – this is set out in the report and the strategy will be approved by Rotherham Place SYICB governance.
- 12.3 RDaSH: are partners on the Rotherham Autism Partnership Board and have been instrumental in the development of the strategy. RDaSH have given a strong commitment to meeting the needs of Rotherham's neurodivergent

communities (including autistic people) in the Clinical and Organisational Strategy 2023-2028.

- 12.4 Criminal Justice Partners: For example - South Yorkshire Police.
- 12.5 Voluntary and Community Sector: Voluntary Action Rotherham (VAR), Rotherham Speak Up, Rotherham National Autistic Society and Rotherham Parents Carers Forum have been fully engaged in the development of the strategy and will be central to the action plan development and delivery.

13. Risks and Mitigation

- 13.1 The following risks have been identified:
- 13.2 Legal compliance with the Autism Act (2009), Statutory Guidance and meeting the obligations under the Health and Care Act 2022: the adoption of both the strategy and the development of the action plan will close this risk and it aligns with the current national strategy.
- 13.3 Co-production lies at the heart of this strategy and will underpin the development of the action plan. This approach is very much welcomed by autistic people, their families and unpaid carers: as the equality impact assessment highlights there has been an ongoing dialogue with these groups, and this will continue as set out in the report.
- 13.4 Financial implications: the development of an all age neurological diagnostic pathway and post diagnostic support has been accounted in SY ICB spending plans.

14. Accountable Officers

Ian Spicer, Strategic Director of Adult Care, Housing and Public Health

Approvals obtained on behalf of Statutory Officers: -

	Named Officer	Date
Chief Executive	Sharon Kemp	29/01/24
Strategic Director of Finance & Customer Services (S.151 Officer)	Judith Badger	23/01/24
Assistant Director, Legal Services (Monitoring Officer)	Phil Horsfield	23/01/24

Report Author: Garry Parvin, Joint Head of Learning Disability, Autism and Transition Commissioning, Strategic Commissioning, Adult Care, Housing and Public Health Email: garry.parvin@rotherham.gov.uk

This report is published on the Council's [website](#).