

Committee Name and Date of Committee Meeting

Cabinet – 15 June 2020

Report Title

Rotherham's All Age Autism Strategy and Implementation Plan 2020 -2023

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

Yes

Strategic Director Approving Submission of the Report

Anne Marie Lubanski, Strategic Director of Adult Care, Housing and Public Health

Report Author(s)

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Ward(s) Affected

Borough-Wide

Report Summary

The purpose of this paper is to present the Rotherham's All Age Autism Strategy and Implementation Plan 2020 -2023 for comment and approval.

The strategy is grounded in the vision and passion expressed in the Council Plan and in the Rotherham's Integrated Health and Social Care Place Plan - based on the values of ensuring collaboration and co-production. The strategy supports and progresses the outcomes outlined in Integrated Health and Social Care Place Plan and the Councils Housing Strategy.

The strategy uses a 'whole life approach' which is used in the Rotherham Health and Wellbeing Strategy. The strategy is based on a clear co-produced vision and identifies key activity focused on 5 areas. These are:

1. Starting Well: All Rotherham's autistic children and young people are healthy and safe from harm
2. Developing Well: All Rotherham's autistic children and young people start school ready to learn for life

3. Moving on well to independence: Rotherham's autistic children and young people are provided with the same opportunities to thrive going into adulthood.
4. Living well: Autistic adults living in Rotherham will get the right support when needed
5. Ageing well: Autistic adults living in Rotherham will be better supported as they grow old

The new All Age Autism Strategy and Implementation Plan provides an overarching framework for the Council, NHS Rotherham Clinical Commissioning Group (CCG) and partners. It identifies priority areas based on the national requirements and local findings.

It is proposed that both the Strategy and the accompanying Implementation Plan will be delivered over a period of three years, from 2020 to 2023. The Plan will work on the principle of a strength-based approach; this means the Strategy should encourage people to recognise their strengths to support choice and control.

The Strategy will build on work being carried out in Rotherham and South Yorkshire by individuals, groups and communities, as well as the Council and partners to improve the lives of people with autism.

Recommendations

1. That the content of the report be noted.
2. That approval be given to the proposed Rotherham All Age Autism Strategy and Implementation Plan.
3. That the intention to review the Plan in 2022 noted.

List of Appendices Included

- Appendix 1 Equalities Initial Screening (part A) and full Assessment (part B)
- Appendix 2 Rotherham's All Age Autism Strategy and Implementation Plan 2020 - 2023

Background Papers

N/A

Consideration by any other Council Committee, Scrutiny or Advisory Panel

Overview and Scrutiny Management Board – 10 June 2020

Council Approval Required

No

Exempt from the Press and Public

No

Rotherham's All Age Autism Strategy and Implementation Plan 2020 -2023

1. Background

- 1.1 Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism can live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over – or under – sensitivity to sounds, touch, tastes, smells, light or colours.
- 1.2 Autism is a disability and is recognised by the Equality Act 2010; it is estimated that around 50% of those with autism also have a learning disability and 71% of those with autism may experience mental health problems.
- 1.3 Both as a society and a community, we can all do some simple things to improve the lives of people with autism. For example: businesses and amenities making small changes (such as reducing noise, distractions and putting in place clear signage) so that their services can be enjoyed by those on the spectrum, and people with autism and that their families are well supported.
- 1.4 A note on terminology: research has 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 to adults who identify themselves in this way.

National policy and priorities:

- 1.5 The National Autism Strategy, 'Fulfilling and Rewarding Lives', was originally published by the government in March 2010 as a result of the Autism Act 2009 and applies to adults in England. The National Autism Strategy set out a vision for all public services in England to respond appropriately to the needs of people with autism. This was followed by statutory guidance for local authorities and NHS organisations in December 2010. The Autism Act 2009 required that local authorities and local health bodies work together to improve on supporting the needs of adults with autism.
- 1.6 The Autism Act 2009 remains the only disability specific piece of legislation in England. It places clear legal responsibilities on local authorities, NHS bodies (including Clinical Commissioning Groups) and NHS Foundation Trusts. Local authorities are required to treat the statutory guidance that accompanies the Act 'as though it were guidance issued under section 7 of the Local Authority Social Services Act 19706 (LASS Act).
- 1.7 Both the National Strategy (2009) and the statutory guidance (2010) have been revised and refreshed as there has been concern about the progress of transformation. "Think Autism" in 2014 refreshed the national strategy and affirmed the importance of five areas for action:
 - To improve the lives of adults with autism;
 - Increase awareness and understanding of autism;

- Develop clear, consistent pathways for the diagnosis of autism;
- Improve access for adults with autism to services and support;
- Help adults with autism into work; and enable local partners to develop relevant services.

In particular, “Think Autism” had a new focus on:

- building communities that are more aware of and accessible to the needs of people with autism;
- promoting innovative local ideas, services or projects that can help people in their communities; and
- Ensuring advice and information about services is clear and accessible for people.

This was followed by a refresh of the Statutory Guidance in March 2015 (see 1.8 below).

It is expected (subject to the impact of COVID-19), that both the national strategy and Statutory Guidance will be further updated in 2020/21

1.8 The 2015 Statutory Guidance is organised into nine areas and contains ‘must’ and ‘should’ statements. Where the guidance says local authorities, NHS bodies and Foundation Trusts, “must” refers to ‘legal duties imposed upon these bodies by the Autism Act 2009 or other Acts of Parliament e.g. the Care Act 2014, and the Children and Families Act 2014 (or secondary legislation made under such Acts).’ The Council and its health partners are responsible for providing leadership and to secure the implementation of all aspects of the Act. The nine areas are:

1. Training of staff who provide services to adults with autism;
2. Identification and diagnosis of autism in adults, leading to assessment of need for relevant services;
3. Planning in relation to the provision of services for people with autism as they move from being children to adults;
4. Local planning and leadership in relation to the provision of services for adults with autism;
5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015;
6. Reasonable Adjustments and Equality – this is a theme that is relevant to all our functions and which we plan to monitor through Equality Impact Assessment (EIA);
7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity.
8. Employment for adults with autism
9. Working with the criminal justice system.

2. Key Issues

2.1 Autistic people in Rotherham and their families have identified that the autism strategy and the implementation plan will take a ‘whole life approach’ - as developed by Rotherham’s Health and Wellbeing Strategy. The Rotherham Autism strategy identifies 5 areas to improve the health and wellbeing of autistic people in Rotherham. The areas are:

1. Starting Well: All Rotherham's autistic children and young people are healthy and safe from harm
2. Developing Well: All Rotherham's autistic children and young people start school ready to learn for life
3. Moving on well to independence: Rotherham's autistic children and young people are provided with the same opportunities to thrive going into adulthood.
4. Living well: Autistic adults living in Rotherham will get the right support when needed
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Ensuring that autistic children, young people and adults have timely diagnosis and have access to post diagnostic support if needed.

- 2.2 Rotherham has higher recorded rates of autistic children in primary, secondary and special educational schools – with figures for secondary schools more than double the national average.

	Rotherham	National
Primary	8.5%	6.7%
Secondary	18.2%	8.8%
Special	30.4%	26.9%

The reasons about these differences remain unclear. Activity is being commissioned by Rotherham CCG to better understand these differences.

- 2.3 There is a neurological diagnostic pathway for autistic children and young people delivered by the Rotherham, Doncaster and South Humber foundation Trust (RDaSH). Joint work between Rotherham CCG and RDaSH estimates that the current pathway can respond to approximately 25 children per month. The average number of new referrals per month is 47.
- 2.4 There has been a high level of requests for diagnosis for autism in children. This has also been reported nationally. We aim to reduce waiting times as Autistic children; young people and their families have reported waiting much too long to receive a diagnosis.
- 2.5 A joint action plan between Rotherham CCG and RDaSH has been developed to reduce the diagnosis waiting list over time. This work will ensure that the current pathway is effective and efficient. A pilot commenced in February 2020; to increase capacity by commissioning a second provider (Healios) to work in partnership with RDaSH to offer a diagnostic pathway via an online platform. Such solutions are also encouraged in relation to addressing demand for diagnosis during the COVID-19 crises.
- 2.6 In addition to seeking to balance demand and the capacity to respond, work is required to understand the level of demand in Rotherham and to explore if there might be ways to reduce this. Other areas have seen a reduction in the number

of referrals by introducing a comprehensive behaviour pathway with schools; ensuring that early intervention is embedded and understood across the system.

For Rotherham adult population (18+) the number of adults with autism is estimated to be 2017. There are currently only 117 adults with autism known to social care services within Rotherham at this time.

- 2.7 The table below shows the projected prevalence rates of autism (Projecting Adult Needs and Service Information- POPPI and Projecting Older People Population Information System -PANSI) in Rotherham and in neighbouring authorities.

Age	Rotherham's diagnosis numbers (age)	Rotherham - predicted	Doncaster - predicted	Barnsley - predicted	Sheffield - predicted
18-24	542 (19-24)	207	240	193	833
25-34	327 (25 -40)	322	414	307	863
35-44		294	374	280	685
45-54	109 (41-55)	385	426	364	737
55-64	29* (56+)	330	387	310	589
<i>Total aged 18-64</i>		<i>1538</i>	<i>1,840</i>	<i>1,455</i>	<i>3,706</i>
65 -74	*See above	280	312	259	474
75+	*See above	199	224	178	388
<i>Total over 65</i>		<i>479</i>	<i>536</i>	<i>437</i>	<i>862</i>
Grand Total	1007	2017	2376	1892	4568

The table above shows that the number of people aged 18 – 24 diagnosed with autism in Rotherham is higher than the predicted numbers, although this equalises in the 25 - 40 age range.

Figures regarding levels of diagnosis were requested but they were not available. The paucity of data for adults with autism is reflected across Councils and health care systems across England with a current overreliance on estimated prevalence rather than facts.

- 2.8 Provision of the diagnostic assessment of adults for autism is currently commissioned from Sheffield Health and Social Care (SHSC) at the Sheffield Adult Autism and Neurodevelopment Service (SAANS) meaning that people with autism registered with a Rotherham GP currently travel to Sheffield for a diagnostic assessment. The specialist service undertakes a detailed assessment over a period of 3 – 4 hours with input from the person with autism and their carers.
- 2.9 Current average waiting time to access diagnosis services is 28 weeks. This is too long as the expected waiting time is no longer than 18 weeks. The implementation plan seeks to reduce waiting times to ensure people are waiting than 18 weeks.

2.10 Rotherham CCG is developing an all age neurological pathway across children's and adults services with RDaSH supported by an investment of £800k from the CCG.

2.11 There is no post diagnostic support offer for adults in Rotherham now, we intend to address this. This means that autistic adults may struggle to get the level of support to access health, welfare and work support they need following a diagnosis. Rotherham CCG are investing £80k per annum to create a personalised, asset-based post diagnostic service. The post diagnostic support service will provide advice and support if a person's needs require a Care Act Assessment (CAA).

Supporting autistic young people and adults to access Rotherham's job market.

2.12 During the development of the Autism Strategy autistic young people and adults said they wanted greater opportunities to work and to be included in their communities. The strategy and implementation plan will create these opportunities by:

- Using initiatives such as the European Social Funding (ESF) Pathways Programme. Pathways to Progression - supports 15 to 19 year-olds not in education employment or training (NEET) to engage in learning or employment and Pathways to Success supports adults.
- Linking with Job Centre Plus work coaches.
- Ensuring better local post-19 education provision – as offered by Rotherham Opportunities College.
- Creating supported internships through Project Search. Project Search is a service to support young people in the preparing for adulthood cohort. The scheme offers specialist advice and support and has been very successful in developing employment opportunities in Doncaster.

Ensuring that the Criminal Justice System in Rotherham is accessible and can meet the needs of autistic people.

2.13 Autistic people can come into contact with the Police and criminal justice system both as victims and perpetrators of crime. Rotherham partners are working closely with South Yorkshire Police and the South Yorkshire Police and Crime Commissioner to:

- Develop the Autism Alert Card. This will ensure the needs of autistic people are known by the police and criminal justice system. This was previously a significant gap and was launched in September 2019.
- Provide autism awareness training sessions for all South Yorkshire Police officers
- Raise awareness of hate crime by training sessions (dealing with hate crime, being radicalised, controlling and cohesive behaviour, being groomed or abused in other ways.)

2.14 The strategy and implementation plan will improve:

- Access to mental health support (including suicide prevention) as rates of recorded mental health issues (stress, anxiety and depression) are lower for autistic people than expected, when compared to national trends
- Housing options.
- Promote awareness and understanding of autism in Rotherham in NHS, Council and Police services and the general public.

3. **Options considered and recommended proposal**

3.1 In developing the Autism Strategy and Implementation Plan the following options were considered:

- Create separate strategies for autistic children and adults – this would reflect what most other local authorities have done and complies with the Autism Act.
- Develop the strategy first, followed by the development of an implementation plan.

3.2 The Rotherham Autism Partnership Board stated it wished Rotherham to develop:

- An All age Strategy – working across children, young people and adults
- a clear implementation plan with a clear programme of work to ensure that the strategy was delivered.
- Whole life approaches.

This is the preferred option that has framed the development of the strategy.

4. **Consultation on proposal**

4.1 A core principle which underpins the development of the Strategy and implementation plan is that: autistic people and their families and carers are at the centre of everything we do.

4.2 To develop the strategy, workshops have been held with representatives from a wide range of professionals, 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. This information then led to the development of the areas for focus as well as the actions for improvement.

4.3 People with autism said they required housing which is suitable for people with autism; it would be able to support people with autism who have a range of sensory issues. The Autism Partnership heard from people who had a negative experience from the Criminal Justice System; they told us many professionals still do not understand autism.

4.4 The Autism Partnership Board was set up to advise on all aspects of implementation associated with national and local autism policy - Fulfilling and Rewarding Lives (2010) and Think Autism (2014) 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 delivery plan are implemented.

5. **Timetable and Accountability for Implementing this Decision**

- 5.1 Rotherham's All age Autism Strategy and implementation plan will last for 3 years until 2023. The Strategy has a implementation plan which ensures that under the 5 key areas identified in 2.1 are delivered. The impact of COVID-19 may have an impact on delivery times and this will be evaluated as the Council and partners move into 'recovery'.
- 5.2 The successful delivery of the Strategy is for all Rotherham Place partners. In terms of governance, the responsibility for the strategy will sit under Rotherham's 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 Autism Strategy will be subject to separate future decisions within the overall context of the Council's budget.
- 6.2 There are no known procurement implications that apply to the implementation of this strategy as it stands. For any additional and currently unplanned commissioning arrangements, that may arise over the next 3 years as a result of implementing this strategy, will be subject to compliance with the Councils Financial and Procurement Procedure Rules and Public Contract Regulations.

7. **Legal Advice and Implications**

- 7.1 The *Statutory guidance for Local Authorities and NHS organisations to support Implementation of the Adult Autism 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."

8. **Human Resources Advice and Implications**

- 8.1 No implications identified at this stage.

9. **Implications for Children and Young People and Vulnerable Adults**

- 9.1 Both the strategy and implementation plan are 'all age' in scope. The implications both for Children, Young People and Vulnerable Adults are set out in the report.

10. **Equalities and Human Rights Advice and Implications**

- 10.1 Both Parts A and B have been completed. The Equalities Analysis Action Plan (see PART B – Equality Analysis Form in appendix 1) has concluded that the following actions need to be addressed:
- Data: Autism is captured in Council Children and Adult Care systems and is linked to some Protected Characteristics (Age, Gender and BAME status). There remain gaps in relation to sexual orientation and marital status.

Further work is also required to ensure that autism is accurately captured. This will be done as part of the refresh of Rotherham's Joint Strategic Needs Assessment (JSNA). There is a need to explore that all systems in the Rotherham Place – (For example: the NHS, leisure and libraries etc) capture autism as a Protected Characteristic. Target July 2021

- Ongoing engagement with autistic people, their families, Unpaid Carers and place partners principally through Rotherham's Autism Partnership Board. This will last for the duration of the strategy and beyond.
- The implementation plan addresses the priorities highlighted in engagements and the 2018 Autism Self-Assessment Framework. It is proposed (and if accepted) that updates on progress will be provided to both Rotherham's SEND Strategic board and Health and Wellbeing Board every 6 months.

11. Implications for Ward Priorities:

11.1 The Rotherham Autism Strategy and Implementation plan supports the three key outcomes which are set out in '*Thriving Neighbourhoods*', *our neighbourhood strategy for 2018/2025*:

- Neighbourhoods are safe and welcoming with good community spirit
- Residents are happy, healthy and love where they live
- Residents use their skills and assets to contribute to the outcomes that matter to them.

11.2 Both the strategy and implementation plan are Rotherham wide in scope. There are opportunities to address the needs of autistic people working with local Councillors and Neighbourhood services.

11.3 In reviewing the ward plans for Rotherham, both the strategy and implementation plan supports the following priorities within one or more of the Ward Plans:

- Support local voluntary and community organisations that provide activities and services for older people and young people and families.
- Supporting initiatives which will look at the health and wellbeing in the individual wards. The strategy discusses how positive mental health will be promoted.
- Ensuring a co-ordinated response to crime and anti-social behaviour – the development of the autism alert cards will ensure that the police and criminal justice services know that they are supporting autistic people.
- Decreasing loneliness and social isolation – the post diagnostic service will work with the voluntary sector to develop opportunities.

12. Implications for Partners

12.1 The Rotherham autism strategy has implications for all place partners. The principle partners identified are:

- NHS Rotherham CCG – this is set out in the report, strategy and will be approved via CCG governance.
- RDaSH: RDaSH are partners on the Rotherham Autism Partnership Board and have been instrumental in the development of the strategy and the implementation plan.

- Criminal Justice Partners: For example - South Yorkshire Police – this is set out in the strategy and implementation plan.
- Third Sector: Voluntary Action Rotherham (VAR), Rotherham Speak Up, Rotherham National Autistic Society and Rotherham Parents Carers Forum have been principle partners in developing both the strategy and implementation plan.

13. Risks and Mitigation

13.1 The following risks have been identified:

- Legal compliance with Autism Act (2009) and Statutory Guidance: the adoption of both the strategy and the implementation plan will close this risk and it anticipates national movements towards all age strategies.
- Support for the strategy and implementation plan from 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.
- financial implications: the development of an all age neurological diagnostic pathway and post diagnostic support has been accounted in Rotherham CCG spending.

14. Accountable Officers

Anne Marie Lubanski, Strategic Director of Adult Care, Housing and Public Health

Nathan Atkinson, Assistant Director – Strategic Commissioning

Approvals obtained on behalf of Statutory Officers:-

	Named Officer	Date
Chief Executive	Sharon Kemp	01/06/20
Strategic Director of Finance & Customer Services (S.151 Officer)	Judith Badger	27/05/20
Head of Legal Services (Monitoring Officer)	Bal Nahal	27/05/20

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