

Summary Sheet

Council Meeting:

Cabinet and Commissioners' Decision Making Meeting – 10 October 2016

Title Development of the Rotherham Autism Strategy

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 Adult Care & Housing

Ian Thomas – Strategic Director, Children and Young People's Services

Report Author(s)

Samantha Leonard – Strategic Commissioning Officer

Nathan Atkinson – Assistant Director, Strategic Commissioning Adult Care & Housing

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Ward(s) Affected

All

Summary

This paper seeks approval to implement a strategic approach to the commissioning and delivery of services for people with Autism within Rotherham. The approach seeks to develop a set of strategic commissioning intentions that promote independence, choice and control for people with Autism. The strategy will strengthen Rotherham's statutory commitments and the approach positively adds to the direction of the Adult Care Development Programme and the Children and Young People's Special Educational Needs and Disabilities (SEND) agenda.

The proposed programme of work outlined in the approach is based on guidance from:

- The Autism Act 2009
- Fulfilling and Rewarding Lives 2010
- Think Autism 2014
- Legislative requirements set out within the Care Act
- Children and Families Act 2014
- Good practice in other parts of the country
- A need to modernise and deploy resources as effectively as possible.

The strategic approach outlines a number of actions that will support people to be more independent and provide a wider choice of services to support children and adults with Autism to fulfil their potential.

Recommendations

1. That the strategic direction outlined in this report for people with Autism and their carers through the development of an All Age Autism Strategy be approved as a joint strategy for the Council and the Rotherham Clinical Commissioning Group.
2. That the Autism Partnership Board be established to oversee implementation plans that will be developed following the strategy.
3. That consultation take place with children and adults with Autism, their carers and those young people, who may use adult services in the future to co-produce, fit for purpose and sustainable opportunities for people with Autism in Rotherham.
4. That approval be given to the action plan to strengthen statutory compliance.

List of Appendices Included

Appendix A – Rotherham Autism Strategy Draft Action Plan

Background Papers

- The Autism Act 2009 <http://www.legislation.gov.uk/ukpga/2009/15/contents>
- Fulfilling and Rewarding Lives 2010
<https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england>
- Think Autism 2014 <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>
- Lincolnshire All Age Autism Strategy
<https://www.lincolnshire.gov.uk/residents/adult-social-care/strategies/all-ages-autism-strategy/a-strategy-for-lincolnshire/114447.article>
- North Yorkshire Autism Strategy
<http://www.nypartnerships.org.uk/index.aspx?articleid=22697>

Consideration by any other Council Committee, Scrutiny or Advisory Panel

No

Council Approval Required

Yes

Exempt from the Press and Public

No

Title: Development of the Autism Strategy

1. Recommendations

- 1.1 That the strategic direction outlined in this report for people with Autism and their carers through the development of an All Age Autism Strategy be approved as a joint strategy for the Council and the Rotherham Clinical Commissioning Group.
- 1.2 That the Autism Partnership Board be established to oversee implementation plans that will be developed following the strategy.
- 1.3 That consultation take place with children and adults with Autism, their carers and those young people, who may use adult services in the future to co-produce, fit for purpose and sustainable opportunities for people with Autism in Rotherham.
- 1.4 That approval be given to the action plan to strengthen statutory compliance

2. Background

- 2.1 For the purpose of this document the term “Autism” will be used throughout, however it is recognised that there are a number of terms that different groups and individuals prefer to use.
- 2.2 The National Autistic Society describes autism as:

“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.”
- 2.3 There are around 700,000 people in the UK living with Autism - that's more than 1 in 100¹. If you include their families, Autism touches the lives of 2.8 million people every day.
- 2.4 There are 7124 Rotherham children (16% of children) in schools who are identified as being in some form of need for additional help to learn, also known as special educational needs (SEN), from the overall school population of 44,515. 866 children from the 7124 cohort (12.2%) are recorded as having an Autistic Spectrum Condition (or Disorder) as their primary need, of whom 714 are boys and 152 are girls (source: 2016 Rotherham School Census). It is recognised that girls tend to be underrepresented in SEN diagnostics and therefore present in greater numbers in adulthood. Of these, 321 children have an Education, Health and Care Plan (EHCP) or Statement of SEN following a statutory assessment of their needs. There are approximately 1843 children and young people with a diagnosis of Autism Spectrum Condition (ASC) (March 2016, source: RCCG).
- 2.5 Most children with Autism have their needs met by universal services such as mainstream schools, and targeted services such as Inclusion Support Services or Autism Communication Team (in Education), Occupational or Speech Therapy (in health). Of the 866 children for whom Autism is their

primary need, 702 children attend maintained nurseries, or primary and secondary schools, with 164 attending special schools.

- 2.6 In terms of education provision, in Rotherham there are two Autism Resource Centres (for primary age learners at Milton Special School and for secondary age learners at Swinton Academy).
- 2.7 There are 27 children placed in out of authority provision who have their primary need identified as Autism. Part of the SEND sufficiency group agenda is to explore ways to address this and bring children back into services based in Rotherham.
- 2.8 There is a graduated response to meeting autism need within mainstream and special schools which includes three levels of targeted service beyond a school or setting's own response; Learning Support Service teachers (LSS), Autism Communication Team Inclusion Support Staff (ACT) and Educational Psychologist Service (EPS).
- 2.9 There is no national or local register or exact count kept. Any information about the possible number of people with Autism in the community is therefore based on epidemiological surveys (i.e. studies of distinct and identifiable populations).
- 2.10 The latest prevalence studies of Autism indicate that 1.1% of the population in the UK may have Autism. This number comes from a range of studies in children and adults. In adults, the numbers were estimated based on household surveys, but the researchers found similar figures to what had previously been found in children. The prevalence rate is based on two relatively recent studies, one of children and the other of adults. The prevalence study of children, (Baird G. et al., 2006) looked at a population in the South Thames area. The study of adults was published in two parts, Brugha et al (2009), and The NHS Information Centre, Community and Mental Health Team, Brugha et al (2012). This is the only known prevalence study to have been done of an adult population.

3. Policy and Statutory Drivers

- 3.1 The Autism Act 2009 was the first ever disability-specific law in England.

The Act did two key things:

- the first was to put a duty on the Government to produce a strategy for adults with Autism, which was published in March 2010.
- the second was a duty on the Government to produce statutory guidance for Councils and health bodies on implementing the adult Autism strategy by the end of 2010. This guidance was published in December 2010.

- 3.2 The first ever strategy for adults with Autism in England - entitled *Fulfilling and Rewarding Lives* was published in 2010. The adult Autism strategy was the Government's plan to make sure that adults with Autism get the help that they need e.g. to get a job or help at home. The strategy also informs Councils and health services as to how they can help people with autism.

- 3.3 In 2013, the Government asked for feedback from adults with Autism, parents, carers and professionals about how well the 2010 strategy had been implemented so far by Councils and health services. The new strategy - *Think*

Autism was published in April 2014, building upon the content of the previous one.

- 3.4 There are three new key proposals in the *Think Autism* strategy. These are in addition to the existing duties of the 2010 strategy, and are expected to make a big difference to the lives, services and support for adults with Autism over the next five years.

The three proposals are:

- Autism Aware Communities - *Think Autism* community awareness projects will be established in local communities and there will be pledges/awards for local organisations to work towards.
- Autism Innovation Fund – this provided funding in 2014/15 for projects that promote innovative local services and projects, particularly for lower-level preventative support. The fund is now closed.
- Better data collection and more joined up advice and information services - including a new way of social care staff recording someone's condition as Autism, and a commitment to make it easier for people with Autism to find information online about how their local authorities are performing.

- 3.5 The Government published further statutory guidance in March 2015. The guidance was to ensure that Council's and health bodies have implemented the Adult Autism strategy, with clarification of the actions that should be taken to meet the needs of people with Autism living in their area. Namely Council's and the NHS should:

- provide Autism awareness training for all staff
- provide specialist Autism training for key staff, such as GPs and community care assessors
- not refuse a community care assessment for adults with Autism based solely on IQ
- appoint an Autism champion in each locality¹
- develop a clear pathway to diagnosis and assessment for adults with Autism
- commission services based on adequate population data.

- 3.6 The 2015 guidance includes a lot more information than the 2010 version. In fact, there are five new chapters on:

¹ An Autism Champion is someone who has an in depth knowledge and understanding of Autism. An Autism Champion would help to develop local expertise. That knowledge can be used to train people and to cascade training to their colleagues and improve practice in supporting people with Autism.

- Preventative support and safeguarding
 - Reasonable adjustments and equality
 - Supporting people with autism and complex needs
 - Employment
 - Criminal justice
- 3.7 Some of the duties have been strengthened to things that local authorities and health bodies "must" do. This is because new duties have been brought in by other laws (particularly the Care Act). The new guidance gives more information about how these new duties can lead to improvements for people with autism. This is particularly true of duties around training, which have been improved to give much clearer guidance on which professionals should have what levels of training
- 3.8 There is not a statutory duty that requires Children and Young People's Services to develop an Autism Strategy, however, the Children and Families Act (2014) and SEND Code of Practice (2015) have led to significant changes in the approach to provision for children and young people with Special Educational Needs (SEN) and/or Disability. In particular:
- to meet need through Education, Health and Care Plans (EHCs) and a single registered stage of SEN Support.
 - the statutory requirement for Local Authorities to publish a Local Offer of relevant SEND services and support, including publication of how the views of young people and their parents have been acted upon.
 - a clear directive for agencies and services to be led by the views of children, young people and their families in the delivery and monitoring of provision that supports SEND.
 - a move to provision from birth to 25 to aid transition to adult services and to improve outcomes in adulthood.
 - a joint approach to commissioning of services across involved areas including education, health and social care.
 - a potential for the provision of personal budgets to enable young people and families to purchase some services directly.

4. Key Issues

- 4.1 Key Issues in relation to Adult service provision:
- 4.1.1 During the last few years strategic commissioning activity has been limited across adult care services and as a consequence this has impacted on the range and type of services available to people with Autism and their carers.
- 4.1.2 The current service offer is narrow and traditional, which has impeded the effective implementation of the personalisation agenda across the Borough.
- 4.1.3 The current offer inadvertently encourages people to be dependent and is reliant on a residential rather than independent living approach. There will be a need to strengthen planning around transitions from Children's services to Adult Care in the future and to work closely with individuals and their families to support them to be resilient, independent and fully integrated members of their communities.

4.2 Key Issues in relation to Children and Young Peoples service provision:

- 4.2.1 In 2012, the Health Commission undertook a scrutiny review of Autism Spectrum Disorder in Rotherham. The review made a number of recommendations in its published report, which is available at http://www.rotherham.gov.uk/download/downloads/id/1821/autistic_spectrum.pdf.
- 4.2.2 There have been many developments since the scrutiny review. Education, Health and Care Plans (EHCP) are now in place, with all statements of SEN to be converted to the new EHCPs by April 2018. The Parent and Child Charter was launched in June 2016. A new post Autism diagnosis family support service has been established, and is being delivered by Rotherham Parents' Forum Ltd as part of the Autism Pathway.
- 4.2.3 Transitions support remains underdeveloped. However, through the SEND reforms, data and understandings of the profile of need are much improved. There is not detailed information about Autism included in the JSNA and this requires further consideration and input.
- 4.2.4 Sufficiency planning for Autism has identified a number of gaps in current arrangements for meeting the needs of children and young people with Autism in Rotherham, as follows:
- Information and advice at all life stages
 - Clear pathways
 - Strategic planning
 - Clearer key worker approach for individual cases;
 - Reassurance/ accountability;
 - Length of time for diagnosis;
 - Better support and education for parents;
 - Clear expectations for every school
 - Key stage 3-4 speech and language resources
 - Pre and post diagnosis support for parents;
 - Sensory integration therapy support;
 - Restrictive CAMHS thresholds
 - Joint EHC placement panel
 - Insufficient provision currently at the highest end of need
- 4.2.5 An integrated SEND 'hub', hosting services for disabled children and their families across education, health and social care is being established and will be in place by December. This will bring services together on one site, to aid cross disciplinary working, reduce duplication and improve access and experience for families.
- 4.2.6 A transitions review is being undertaken, which will make recommendations for the development of improved and more integrated approaches to supporting young people across life stages from 0-25, including preparation for adulthood.

4.2.7 Whilst there are a number of strategic developments in relation to Children and Young People with Autism, there is not an Autism specific strategy for Rotherham.

5. Required Activity

- 5.1 Further work will need to be undertaken to support adults currently receiving services to progress towards independence where appropriate. This strategic approach is based on a commitment to put people with Autism and their carers in control of important areas of their lives including service and support arrangements. This approach seeks to ensure that services enable people with Autism to take up the opportunities on offer to any other person living in Rotherham. This is about people using their rights, making choices, leading independent lives and being included in society.
- 5.2 It is proposed that a direction of travel is established that enables people to transform their lives from one where they either live in and use specialist services or live in the community but are not part of it, into living as part of the community, mainly using services open to everyone with some specialist services. This approach may require some of the services open to everyone to change to make it easier for people with Autism and their carers to use them. The amount of specialist services that only people with Autism and their carers will use will be kept to a required minimum. People's needs will be met in the least restrictive settings possible, based on strengths based assessment.
- 5.3 Following discussion between Children and Young Peoples Services, Adult Care and Housing and Rotherham Clinical Commissioning Group, it is proposed that an all-age Autism Strategy be developed for Rotherham. This approach is seen as good practice, as we need to strategically consider the needs of people with Autism across the whole age continuum. The SEND 0-25 years agenda is also a key driver in taking this approach and work has begun in this area in the SEND/Inclusion Department of Education and Skills.
- 5.4 In order to deliver the vision outlined above, urgent action needs to be taken in a number of areas:
- Development of an All Age Autism Strategy with robust implementation plan.
 - Development of an Autism Partnership Board Chaired by the Autism Lead for Rotherham – Anne Marie Lubanski, Strategic Director, Adult Care & Housing. We will seek a person with Autism from Rotherham to act as Co Chair. The Board would comprise of:
 - people with autism
 - carers
 - adult care
 - children & young people's services
 - health
 - education
 - work and skills

- criminal justice system
- voluntary sector
- service providers
- There has been limited consultation with adults with Autism in Rotherham regarding their hopes and aspirations for the future. Speak up for Autism has been established and seeks to ensure people with Autism are involved in decisions about their future. A grant of £5,000 will be awarded to support the group to develop and provide expertise for consultation on strategy. The grant will fund the group to increase membership, organise consultations regarding strategy development and provide peer support for people with Autism.
- The connection between services for Children and Adults with Autism needs to be strengthened to ensure continuity in meeting needs.
- Ensuring everyone with Autism to have more control over all aspects of their life.
- Ensuring everyone with Autism to reach their potential – with the right support at the right time.
- Ensuring a joint approach to commissioning services across health and social care is introduced within children's and adult services to reduce duplication, confusion and cross-agency issues.

- 5.5 The issues outlined above will require a significant programme of work over next three years, with the immediate focus on ensuring that robust systems and processes are in place to meet statutory duties. They require partners across the Council and more widely across Rotherham to work closely together to make the most of Rotherham's resources and to deliver the activity outlined in the Action Plan (See Appendix A). It will require a programme management approach to ensure each key area is properly managed and that identified outcomes are delivered.
- 5.6 It is likely that a significant programme of decommissioning and re-commissioning of adult service provision will be required – all current and prospective providers of service in Rotherham to be engaged through an effective consultation and communication process.

6. Best Practice from other areas

- 6.1 There is a range of best practice from neighbouring authorities who have recently developed All Age Autism strategies including Lincolnshire and North Yorkshire which can provide us with valuable learning and ideas for implementation including promoting innovation and meaningful co production.
- 6.2 The Lincolnshire All Age Strategy 2015-2018 is based on the principles of *Fulfilling and Rewarding Lives* and extending it to cover all ages 'All adults with Autism are able to live fulfilling and rewarding lives within a society that accepts and understand them. They can get a diagnosis and access support if

they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them to make the most of their talents'.

- 6.3 Lincolnshire have developed a vision to build on the capacity and understanding of the community to deliver the best possible experience for people living with Autism and to enable them to fulfil their potential as citizens. The vision takes into account common life events and the life journey from birth to old age.

The vision is underpinned by a set of strategic principles;



- 6.4 Achievements to date have focused on improving awareness of Autism including facilitating training across social care and health, organising a number of across health services events and also improvements in diagnostic pathways.
- 6.5 A three month consultation period enabled all stakeholders including people with Autism and their carers to give feedback on the strategy and initial implementation plan. Transition from children's to adults social care was one area which was highlighted by stakeholders as a particular area for development and one of the reasons for developing an all age strategy. A Head of Commissioning with responsibility for Autism has been appointed to oversee the implementation plan working alongside the Autism Partnership to ensure plans are kept on track.
- 6.6 The Autism strategy in North Yorkshire has been developed with a partnership approach across health and social care, whilst also engaging with the voluntary and community sector to ensure the strategy is adopted by all partners. There is an ambition for North Yorkshire to become an Autism friendly place. The partnership hopes by working together they can empower people with Autism and their families to live their lives to their full potential.

Joint priorities have been identified;

- Support for people with autism and their families
- Assessment and diagnosis
- Raising awareness and training
- Information and signposting
- Employment and education
- Supporting people with autism during key life changes
- Working together

- 6.7 During the consultation to create the strategy, people with Autism, their families and organisations working with them told partner agencies in North Yorkshire what was important to them. They said they wanted greater awareness of Autism among professionals they might work with and better access to assessment and diagnostic services near their homes. They also wanted better local information to help them to increase their wellbeing.
- 6.8 There have been a number of achievements, including the establishment of joint strategic groups consisting of senior managers from the NHS and North Yorkshire County Council (NYCC). The joint strategic groups are driving the work around the development of the Autism strategy and the associated actions within it. These groups work alongside a virtual reference group which is for people with Autism and their families.

7. Recommended Proposals and Action Plan

- 7.1 It is recommended that a strategy is developed with a robust implementation plan following consultation with all stakeholders.
- 7.2 An Autism Partnership Board will need to be established to oversee the further development of the draft Action Plan in Appendix A
- 7.3 The co-production activity will develop further options to meet the assessed needs of people with Autism who are eligible for services.
- 7.4 It is necessary to ensure a clear communication strategy outlines how and when the Council intends to communicate its intentions when co-production is relevant and where consultation is necessary.

8. Consultation

- 8.1 Consultation must be undertaken so that the Council complies with its duty to act fairly. There are four main principles to be followed to ensure that consultation is lawful. The consultation must:
- be undertaken at a time when the proposals are still at a formative stage
 - include sufficient reasons for particular proposals to allow those consulted to give informed consideration and an intelligent response;
 - give adequate time for consultees to formulate a viewpoint; and be conscientiously taken into account when the ultimate decision is made.

- 8.2 Adult Care and Housing will work closely with Speakup for Autism, a local advocacy organisation to support this activity.
- 8.3 An initial engagement event across all age Health and Social Care was held on 3rd August regarding the development of a strategy. This meeting confirmed the need for an All Age Strategy across health and social care.
- 8.4 There is a well-established Children and Young People's Autism Stakeholder Group that has taken forward a number of recent developments and were actively involved in the previous scrutiny review. This group will play an active role in developing the Autism Strategy from a children and young people's perspective.
- 8.5 A gap analysis event is being planned and will take place in autumn. This will look to identify current pathways across childrens and adults, health and social care.
- 8.6 Consultation events to develop the strategy will take place in autumn involving all Stakeholders. Key stakeholders will be people with Autism and their families, the Council's Children's and Adults Care services, Rotherham Clinical Commissioning Group (CCG), Rotherham Doncaster and South Humber NHS Foundation Trust RDASH, The Rotherham NHS Foundation Trust, providers of support for people with Autism, Community and voluntary sector.

9. Timetable and Accountability for Implementing this Decision

- 9.1 If this report is approved, work will commence immediately to further develop an Autism strategy and formally set up an Autism Partnership Board to further develop the Action Plan and oversee implementation.
- 9.2 The programme of work will span the Adult Care and Housing Directorate, Children and Young People's Directorate and more widely the Council and key partners. A significant proportion of this work will be managed through the Adult Social Care Development Programme and through improved commissioning partnerships with Rotherham CCG. Ownership of the work programme will rest with the Strategic Director of Adults Care and Housing.
- 9.3 The communication strategy will be shared and a clear project timeline put in place.

10. Financial and Procurement Implications

- 10.1 In developing the Council's Autism Strategy it is likely that there will be a financial need for additional investment in service provision which will facilitate and help realise service efficiencies being derived from:
 - longer term planning and effective commissioning for young people prior to transition;
 - development of flexible models of care that promote independence;
 - less reliance on traditional residential care provision; and
 - more in borough solutions mitigating use of out of area placements.

- 10.2 Any financial and procurement implications will be fully outlined within the draft Autism Strategy and will be taken through the relevant governance processes for consideration in due course.

11. Legal Implications

- 11.1 Section 7 of the Local Authority Social Services Act 1970 requires local authorities, in exercising their social services functions, to act under the general guidance of the Secretary of State (“Section 7 Guidance”). Case law has established that complying with this requirement involves more than simply taking account of the guidance. Rather, local authorities 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”
- 11.2 A local authority which failed to comply with the Secretary of State’s guidance without a compelling reason for doing so would be acting unlawfully and could find itself subject to judicial review or default action by the Secretary of State. The Autism Act 2009 provides for the guidance issued under that Act, referred to at paragraphs 3.5 to 3.7 of this report, to be treated as section 7 guidance, so that local authorities will be under the same duty to act under that guidance as they would be in the case of any other section 7 guidance.

12. Human Resources Implications

- 12.1 None

13. Implications for Children and Young People and Vulnerable Adults

- 13.1 These proposals will have a positive impact on children, young people and adults with Autism and their families.

14. Equalities and Human Rights Implications

- 14.1 We need to work with people with Autism and their families to co-produce an Equality Impact Assessment.

15. Implications for Partners and Other Directorates

- 15.1 Key partners and stakeholders will be engaged with as part of the consultation process.

16. Risks and Mitigation

- 16.1 The current offer is limited and more work is required to fully meet the Council’s statutory duties.
- 16.2 The Action plan is a mitigation and this will be regularly monitored

16.3 Young people coming through transition currently have limited choice and therefore commissioning plans will need to be developed to create new service offers.

17. Accountable Officer(s)

Approvals Obtained from:-

Strategic Director of Finance and Corporate Services:
Named Officer: Mark Scarrott, Finance Manager

Assistant Director of Legal Services: Dermot Pearson

Head of Procurement (if appropriate):-

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