

Committee Name and Date of Committee Meeting

Health Select Commission – 07 April 2022

Report Title

Autism Strategy and Pathway Update

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

No

Strategic Director Approving Submission of the Report

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Ward(s) Affected

Borough-Wide

Report Summary

This report updates the Health Select Commission on:

- Progress on delivering Rotherham's All Age Autism Strategy and Implementation Plan 2020 -2023.
- Waiting Times for Diagnosis across Rotherham's All Age Neurodevelopmental Pathway.
- Rotherham's post-diagnostic offer.
- Review of Rotherham's Autism Strategy considering the publication of the National Autism Plan

The report looks ahead to reviewing options for Rotherham's Autism Strategy after 2023.

Recommendations

The Health Select Commission is asked to:

- Note the content and comment on the update and the intended actions to address issues raised.

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: <http://modgov-p-db/documents/s130888/Autism%20Strategy%20and%20Pathway%20Update.pdf>
- Children's Neuro-developmental Pathway - Rotherham Health Select Commission (Thursday 10th December 2020) <http://modgov-p-db/documents/s128895/Health%20Select%20Neurodevelopmental%20Update%20Dec%202020.pdf>
- Ofsted/ Care Quality Commission SEND Local Area Inspection – Written Statement of Action inclusive of an update on SEND Sufficiency Phase 3, Improving Lives Select Commission – 08 March 2022: <http://modgov-p-db/documents/s135062/Report.pdf>
- Rotherham Safeguarding Children Partnership – Annual Report 2020 – 2021, Improving Lives Select Commission – 08 March 2022: <http://modgov-p-db/documents/s135078/ILSC%20Report%20RSCP%20Annual%20Report%2020%20-%202021.pdf>
- National Development Team for inclusion Preparing for Adulthood Minimum Standards (see <https://www.preparingforadulthood.org.uk/SiteAssets/Downloads/miap3csp637789722528041215.pdf>).
- Working Win scheme: South Yorkshire Mayoral Combined Authority (see: [Working Win - South Yorkshire MCA \(southyorkshire-ca.gov.uk\)](http://www.southyorkshire-ca.gov.uk))
- Rotherham Works newsletter article: <https://content.govdelivery.com/accounts/UKRMBC/bulletins/2e40ec7>
- *National Strategy for autistic children, young people, and adults: 2021 to 2026* (see https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf)
- RotherHive series of accessible self-help leaflets which cover a range of topics from alcohol problems to stress. Copies of the guides can be found at: <http://www.selfhelpguides.nrw.nhs.uk/rotherhamccg/>
- Voluntary Action Rotherham has produced a list of useful resources for autistic people living in Rotherham. This can be found: <https://www.varotherham.org.uk/news/a-really-helpful-list-of-autism-resources/>
- Rotherham SEND resource kit (see: <https://sendcorotherham.co.uk/>)

Council Approval Required

No

Exempt from the Press and Public

No

Autism Strategy and Pathway Update

1. Background

- 1.1 The purpose of this paper is to update the Health Select Commission on the progress being made on Rotherham's All Age Autism Strategy and Implementation Plan 2020 -2023, which was approved in June 2020.
- 1.2 The strategy was grounded in the vision and passion expressed in the Council Plan and Rotherham's Integrated Health and Social Care Place Plan - based on the values of ensuring collaboration and co-production.
- 1.3 The strategy supported the outcomes outlined in the Integrated Health and Social Care Place Plan and the Council's Housing Strategy.
- 1.4 The Health Select Commission has received regular progress updates on Rotherham's All Age Autism Strategy and Implementation Plan 2020 - 2023.

2 Key Issues

2.1 This section updates the Health Select Commission on:

- Progress on delivering Rotherham's All-Age Strategy.
- Waiting Times for Diagnosis across Rotherham's All Age Neurodevelopmental Pathway.
- Rotherham's post-diagnostic offer for all ages.
- Review of Rotherham's Autism Strategy considering the publication of the National Autism Plan

2.2 **Update on Rotherham's All-Age Autism Strategy:**

Rotherham Council approved its 3-year all-age strategy in June 2020. The Strategy was published online (see: Rotherham's All Age Autism Strategy 2020 - 2023 – Rotherham Metropolitan Borough Council) and in easy word / read versions. Rotherham adopted 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 activities 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.

2.2.1 COVID-19 has made an impact on the delivery timeline (as published in 2020) and this was reported to the Health Select Committee in 2020 and 2021. Despite the pandemic, progress has been made.

- 2.2.2 Starting Well:
Most of the objectives have been completed or are on target to be completed (please see **appendix 1**). Work is still required to ensure 'visibility' of the pathways to autistic children, young people, and their families. This is being addressed through the Local Offer work being completed as part of the Written Statement of Action (WSOA) to support the Ofsted SEND inspection outcome response (see background papers for context and detail). During the COVID-19 lockdowns in 2020 and 2021, the trailblazer offered remote consultations and interventions in schools.
- 2.2.3 Developing Well:
Work is continuing to ensure that Rotherham's most vulnerable autistic children are being seen and supported elsewhere in the system – (see update provided to Improving Lives Select commission in background papers). Work is commencing to developing Rotherham's public health plan to ensure that autistic young people can access activities or programs which promote health. An example of this can be seen with KOOOTH. KOOOTH is a digital mental health counselling service for young people aged 11 – 25 jointly commissioned by Rotherham MBC and Rotherham CCG and went live in October 2021.
- 2.2.4 Kooth.com is an award-winning and innovative online counselling and support service that is now available to all young people and young adults across Rotherham aged 11-25. It is a safe, confidential, and anonymous way for young people and young adults to access emotional wellbeing and early intervention mental health support. Offering personalised support with short waiting lists and no thresholds.
- 2.2.5 Rotherham will be the world's first Children's Capital of Culture in 2025. 365 days of arts and culture, devised, developed and delivered in partnership with children and young people from across the borough and beyond. Large-scale, high profile commissions and partnerships between local arts organisations, venues and national partners. It will have Exhibitions, events, performances, festivals, artworks, murals and more, all curated and created with a range of children and young people from a range of backgrounds. A key aim is Empowering children and young people to not only participate in culture but to create it in their own image on their own terms. Rotherham's autistic children and young people as well as participating, will play an important part in shaping this important event. In the launch event, autistic children and young shared what autism means to them in the Truth to Power Café.
- 2.2.6 Moving on well to independence:
The workstreams have been embedded into the Preparing for Adulthood workstream of the Written Statement of Action. This work is overseen by the Preparing for Adulthood Board and the SEND Board. A new framework based on the National Development Team for inclusion minimum standards has been drafted (see background papers for link). NTDi are commissioned by Department for Education to support areas in

developing their preparing for adulthood offers if flagged as an area for development following an OFSTED/ CQC inspection.

- 2.2.7 A key success has been the expansion of the Rotherham Parents Carers Forum post-diagnostic offer to build support for autistic young people moving into adulthood. This offer will include peer support, counselling and activities designed to allow the autistic young person to explore what becoming adult means to them.
- 2.2.8 Employment support in Rotherham can be accessed through the government's Access to work scheme which "provides practical advice and support to disabled people and their employers to help them overcome work-related obstacles resulting from disability. This can include assessments and costs to cover reasonable adjustments under the Equality Act 2010. Autism Plus offer support for adults to enter into employment, apprenticeships and volunteering. They can also work with employers to offer training and advice. A similar offer is also available through the autism Centre based in Sheffield.
- 2.2.9 There is local support on offer through the Working Win scheme supported by the South Yorkshire Mayoral Combined Authority (see background papers for link) that supports people to find, stay and thrive in employment.
- 2.2.10 In terms of promoting employment for autistic young people has success has been the creation of the Rotherham Opportunities College Project Search Supported Internship model and pilot linkup to Gullivers Theme Park. Students graduated from the 2021 cohort. 2022 cohort is underway, with recruitment taking place for the 2023 cohort. Staff support young people are trained and experienced. Employer Engagement Event planned June 2022 in partnership with Integrated Care Services (Employment is for Everyone) and Gullivers, to showcase good practice.
- 2.2.11 Rotherham Invest Development Office (RIDO), part of the Council is leading by example by offering a Supported Internship to a young person from Landmarks Opportunities College. See Rotherham Works newsletter article (link in background papers)
- 2.2.12 Living well:
Work here has focused on the creation of all age pathways. All Age Pathways acknowledges that there are differences between being an autistic child / young person or adult but works to ensure that there is greater coordination as the young person becomes an adult. Work is ongoing to raise awareness of autism in the criminal justice system and will connect to the investment and timelines put forward in the *National Strategy for autistic children, young people, and adults: 2021 to 2026* (see link in background papers)
- 2.2.13 The launch of RotherHive also included a series of accessible self-help leaflets which cover a range of topics from alcohol problems to stress. A link to the guides can be found in the background papers.

- 2.2.14 RDASH have been completing a Mental Health and Autism audit by April 2022. The aim of this project was to identify how many Autistic adults were accessing their secondary mental health services, gather peoples experiences of using their services and asking staff working in those services about any training needs they have. It is hoped that outcomes from the audit will help shape further transformation discussions and service developments.
- 2.2.15 With end of year funding RDASH have also been trialling specialist Autism weekly drop in supervision sessions for staff working in secondary mental health services this started in January 2022 and will end in March 2022. Staff have really valued this space to reflect and develop their clinical skills to improve health outcomes for Autistic adults accessing their services.
- 2.2.16 Aging Well:
Work is ongoing to develop Rotherham's older people offer to include the needs of autistic people. This includes Rotherham's voluntary sector being supported to access autism awareness training. Voluntary Action Rotherham has produced a list of useful resources for autistic people living in Rotherham (a link can be found in background papers). Age UK and Rotherham libraries are working to challenge mental and physical deconditioning due to COVID-19, which has impacted disproportionately on older people. The project will also work to be accessible to autistic older people
- 2.2.17 Research suggests that 10% of Autistic individuals will go on to develop dementia. In January 2022, RDASH conducted an audit identifying how many autistic people were accessing secondary care mental health services found that only one person had an official diagnosis of Autism although this number is very low, it is acknowledged that autism awareness and assessments were not available back in people's working-age lives. However, now due to more awareness and developments into autism clinical assessment tools, more adults than ever are receiving an Autism diagnosis, and adults will age and transition into older people's services. There need to equip our older adult services with further autism awareness training and awareness, this work has already started in RDASH.

2.3 **Waiting times for Diagnosis:**

2.3.1 Children and Young People element of the All-Age Neurodevelopmental Pathway:

2.3.2 Investment:

Since 2020, Rotherham CCG has invested approx. £500k / annum to address issues pertaining to access for diagnosis. In 2022 Rotherham CCG has worked with RDASH to develop a mobilisation plan to address the waiting list sustainably over the next three years. This is being monitored monthly and is currently on track to ensure a maximum waiting time of 18 weeks by 2025

- 2.3.3 Pathway Update:
In November 2021 94% of the children on the waiting list had waited longer than 18 weeks. This had already reduced to 86% at the beginning of February 2022. 35% of these children wait less than a year. 64% of children wait less than 2 years. 2% of children have waited longer than 3 and a half years.
- 2.3.4 Rotherham CCG is aware of the waiting times for the CAMHS neuro-developmental pathway, which provides diagnosis for Autism Spectrum Disorder and Attention, Deficit, and Hyperactivity Disorder.
- 2.3.5 Since October 2018 it is has been apparent that the diagnostic capacity was not sufficient to meet demand. Identifying sufficient capacity to meet demands for Autism diagnosis is a national issue due to increasing awareness, demand, and a challenging workforce position.
- 2.3.6 The creation of the Rotherham SEND resource kit (see background papers for link) was to provide easy access to consistent, high-quality information, practical ideas, and resources for school staff in Rotherham who are supporting children with special educational needs and disabilities (SEND). This enables a proactive response rather than waiting for the formal diagnostic system before providing support and appropriate interventions.
- 2.3.7 Stakeholders from education, early help, social care and health, and the voluntary and community sector have worked closely with the RDaSH CAMHS service to understand the demand and capacity issues across the system.
- 2.3.8 As reported in January 2020 and March 2021, the pathway has been designed to ensure that the needs of children who present with neuro-developmental differences are met, regardless of whether they have a diagnosis of autism. This is now embedded and currently can deliver 40 – 50 assessments a month.
- 2.3.9 Rotherham CCG commissioned 220 Children and Young People (CYP) Autism Assessments from Healios during 2021/22. Since the partnership with Healios was established in late 2019 a total of 509 CYP Assessments have been undertaken through the CCG's contract with Healios. Over and above this RDaSH has also established a trust-wide subcontract with Healios that has enabled a further cohort of CYP to be assessed.
- 2.3.10 A whole system training based on the licensed Autism Education Trust model (further exploration underway with ADHD Foundation) is in place. This is supported by a structured and consistent resource pack to support the workforce in schools is in place.

2.3.11 A rolling program of evidence-based training modules that parents can access to support for challenging issues (regardless of whether their child has a diagnosis)

2.3.12 South Yorkshire ICS Keyworker Pilot:

2.3.13 The South Yorkshire Transforming Care Partnership successfully submitted an Expression of Interest, which was pulled together with all key stakeholders including CCG's, LA's, NHS Trusts, VCR's, PCF's and individuals with LD and Autism to become one of the pilot sites for the development of the CYP keyworker pilot. The pilot aims to support young people, their families, and professionals to prevent/reduce admissions into hospital

2.3.14 Rotherham now has two keyworkers embedded into Rotherham's CAMHs service and the CYP Rotherham Council service. The key workers are working across health, education, and care services to ensure that autistic children, young people, and their families are better supported to prevent crises.

2.3.15 Adult element of the All Age Neurodevelopmental Pathway:

2.3.16 Investment:

Rotherham CCG invested approx. £400k during 2021/22 into the adult element (diagnostic -RDaSH and post-diagnostic elements -RANSS) of Rotherham's All Age Neurodevelopmental Pathway. These investments will increase to £458k in 2022/23. This is being supported by additional investment from the South Yorkshire ICS to support the expansion of Rotherham's post-diagnostic offer – **see 2.4.14.**

2.3.17 Pathway Update:

The adult element of the All Age Neurodevelopmental Pathway has seen sustained demand for adult diagnosis (14 referrals per week), the reasons for this demand are complex. The outcome is that there has been an increase in the waiting times that adults wait before diagnosis commences (currently 9.5 mths). RDaSH has commissioned a digital provider to create a similar offer seen in the CYP side of the All Age Neurodevelopmental Pathway. 40 people have accepted this offer, and this will reduce the wait by 8 weeks.

2.4 **All-Age Post Diagnostic Pathway:**

2.4.1 Autistica - UK's national autism research charity published a Plan in November 2021. The plan outlined the importance of post-diagnostic support following a diagnosis of autism. It highlighted that too many autistic people feel abandoned after diagnosis with zero effective support and the need that personalised support to be offered from day one to ensure autistic people and their families receive the help they need when they need it. Rotherham as part of its post-diagnostic pathway has taken great strides to meet this ambition.

2.4.2 Post Diagnostic Support Children and Young People:

2.4.3 Rotherham Parent Carer Forum Parent peer support, also commonly called family peer support or family support services, offers hope, guidance, advocacy, and camaraderie for parents and caregivers of children and youth receiving services from mental health, and related service systems.

2.4.4 Parent support providers deliver peer support through face-to-face support groups, phone calls, or individual meetings. They bring expertise based on their own experience parenting children or youth with social, emotional, behavioural, or additional needs and challenges, as well as specialised training, to support other parents and caregivers.

2.4.5 Rotherham Autism Information and Advice Service: Offer training in a range of areas that are designed to increase knowledge, build confidence, and increase resilience through practical strategies, guided learning, and shared experiences.

2.4.6 Training is for parents and carers of young people 0 - 25 who are on the neuro pathway or have an autism diagnosis. The child or young person will also need to be registered with a Rotherham GP Practice. This year an additional investment of £140k (2021/22 and 2022/23) is being made from South Yorkshire ICS monies allocated from NHSE/I investment.

2.4.7 This will expand the pathway to include young people who are in Rotherham's Preparing for Adulthood cohort. This is being done as a 2 year pilot (2021 -23). The pilot will extend the remit of the RANSS service to this group of young people: what the RANSS service does see - 2.4.5 and 2.4.11 and 2.4.12

2.4.8 Post Diagnostic Support – Adults:

There are two elements to the adult post-diagnostic support pathway. The first is specialist support. This is provided by RDaSH through its Rotherham Adult Autism Diagnostic Service (RAADS). This part of the service is led by occupational therapists and is person-centred and goals are collaboratively identified with the service user. The most frequently provided areas of support in the first 12 months of the Service were sensory processing, employment and reasonable adjustments, relationships, executive functioning difficulties, learning support at College or University and promoting positive self-esteem and identity adjustment. The service has received the following comments from people who have highlighting the impact this service has had in people's lives:

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

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

“Its helped me make sense of how my senses can affect me and its given me some ways to calm down around how when I’m overstimulated”

- 2.4.10 September 2020 saw the launch of the Rotherham Adult Neurodiversity Support Service (RANSS):
- 2.4.11 The Service provides a wider offer of support for people with a historic (over 12 months ago) diagnosis, currently in or awaiting an assessment or self-questioning. The wider offer is accessible via a self-referral and consists of:
- Meet-ups (virtual or face-to-face)
 - Signposting
 - Access to other training opportunities
- 2.4.12 The Service also provides a personalised post-diagnostic support offer for people who have recently received an Autism ADHD diagnosis which can include all or some of the following:
- Group workshops
 - Peer support and/or counselling coming to terms of coming terms of with that persons diagnosis.
- 2.4.13 There is no waiting list for this element of the pathway. There is strong partnership ethos between the RDaSH and Rotherham Parent Carers Forum (RPCF) to ensure that once people have been diagnosed and don’t require additional clinical post-diagnostic support can access support earlier.
- 2.4.14 Additional funding from NHSE and South Yorkshire ICS has been received (£70k) to expand the Rotherham Adult Neurodiversity Support Service (RANSS) to ensure that autistic adults without a learning disability have been historically diagnosed can benefit from this service.
- 2.4.15 RPCF /RANSS have representatives both on northern regional workstreams and at a national level with NHS England and partners on behalf of Yorkshire and Humber parent carer forums.
- 2.4.16 This active involvement locally, regionally and nationally ensures the lived experience of the Rotherham autistic community who they reach, CYP and their families and newly diagnosed adults is included in shaping policy and informing provision developments alongside national partners.
- 2.4.17 The value that this service brings to autistic residents in Rotherham can be seen in the case studies included in **Appendix 2**. These case studies show the diversity of the issues that RANSS supports autistic people with. The case studies also highlight the importance of diagnosis and enabling autistic people to be less isolated and connected to their community, live their lives, and challenge any loneliness.

2.5 **Review of Rotherham’s Autism Strategy considering the publication of the National Autism Plan**

2.5.1 In July 2021, the Government released its new strategy setting out the steps it plans to take to improve provision for autistic people¹ across England.

2.5.2 The Autism Act (2009) states that this guidance “is to be treated as if it were general guidance of the Secretary of State under section 7 of the Local Authority Social Services Act 1970 (c. 42)”.

2.5.3 The vision set out in the strategy was:

‘We want to create a society that truly understands and includes autistic people in all aspects of life; one in which autistic people of all ages, backgrounds and across the country have equal opportunities to play a full part in their communities and to have better access to the services they need throughout their lives. This is our vision to make life fundamentally better for autistic people, their families, and carers by 2026, and we are determined to make it happen.’

2.5.4 The strategy builds on and replaces the preceding adult autism strategy; Think Autism, which was published in April 2014.

2.5.5 The new strategy 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

2.5.6 Rotherham’s Autism Strategy is largely coterminous with the National Strategy in that:

- Rotherham’s strategy is ‘all age’ in approach – reflecting Rotherham’s current Autism Partnership Board.
- Rotherham’s strategy adopts the ‘identity first’ language.
- A focus on delivery and action.

2.5.7 There are differences between Rotherham’s local plan and the National Autism Plan. The gaps that Rotherham and South Yorkshire partners need to consider are:

¹ 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 adopted to use the term 'autistic' – particularly when talking about children and to adults who identify themselves in this way.

- The areas of reform for public transport. Next steps: The Rotherham Autism Partnership Board are currently approaching South Yorkshire Passenger Executive and Sheffield City Region is proposed to consider how the National Strategy will be adopted about Rotherham's public transport network.
- STOMP² / STAMP³. The focus of reducing the use of antipsychotics has been on children, young people, and adults with a learning disability and/or autism. Next Steps: The expansion of STOMP/ STAMP for autistic children and adults needs to be considered in the local place. Local discussions are currently progressing with RDaSH about developing a local plan to support the delivery of STOMP/ STAMP.

2.5.8 Proposed national investments being made by the Government in the 2021/22 Implementation Plan

The National Plan appears to make significant financial investments to support the delivery of the National Autism Strategy. The focus of much of the investment proposed will be committed in NHS, CYP- education, and Criminal Justice. There is one element of funding cited in the annual plan for 2021/22 that is available directly to Adult Social Care and that is the commitment to:

- 2.5.10 'Providing £21 million funding to local authorities as part of the £62 million Community Discharge Grant for the second year, to accelerate discharges.'
- 2.5.11 This will be done as part of the Transforming care program.
- 2.5.12 Other 'pots' may be available by bidding through Expressions of Interest.
- 2.5.13 In discussion with planning partners (Rotherham CCG, South Yorkshire TCP, etc.) it remains unclear if:
 - There is (in fact) any 'new' investment.
 - Any new investments will be announced in the National Budget announcements.

3. Next Steps

- 3.1 Rotherham's All Age Autism Strategy is due to end in 2023. There is a need to review the strategy and its impact. Rotherham's Autism Partnership Board will be asked to review Rotherham's strategy and make recommendations to the Council and partners.

4. Recommendations

- 4.1 The Health Select Commission is asked to:

² stopping over medication of people with a learning disability, autism or both with psychotropic medicine

³ stop the overuse of psychotropic medications for children and young people with a learning disability, autism or both

- Note the content and comment on this update and the intended actions to address issues raised.

APPENDIX 1: PROGRESS UPDATE ON KEY WORK PROGRAMS TO DELIVER ROTHERHAM'S AUTISM STRATEGY - MARCH 2022

Please note delivery dates have been revised due to the impact of the COVID-19 pandemic on work programmes:

Objective	Key focus of work	Lead	Completed:	To do
Objective 1: All Rotherham's autistic children and young people are healthy and safe from harm:	Improve the children's pre support, diagnosis and post diagnosis support pathway:	Helen Sweaton	<ul style="list-style-type: none"> • Pathway document created • All practitioners understand and adhere to pathways protocols 	<ul style="list-style-type: none"> • Timely diagnosis: Ongoing- to reach agreed national wait times by 2025 • Young people and families understand pathways and is visible – now aligned to work to overall Rotherham's Local Offer website by 30th April 2024
	Implement a new sensory support offer for children and young people Rotherham		New sensory support offer completed in 2020 / 21	<ul style="list-style-type: none"> • Work is ongoing to ensure visibility and will be aligned to the work programme to overall Rotherham's local offer by 30th April 2024
Objective 2: Rotherham's autistic children and young people start school	Assure ourselves that the most vulnerable children are being seen and supported	Helen Sweaton	<p>New developments which include autistic children and young people , include:</p> <ul style="list-style-type: none"> • contextual safeguarding in the identification, assessment and response to criminal exploitation and adolescent neglect. 	<ul style="list-style-type: none"> • Work is continuing to ensure that Rotherham's most vulnerable autistic children are being seen and supported elsewhere in the system – (see http://modgov-p-db/documents/s135078/ILSC%20Report%20RSCP%20Annual%20Report%202020%20-%202021.pdf. Commenced and Ongoing

ready to learn for life	elsewhere in the system		<ul style="list-style-type: none"> Review of the Multi-agency Safeguarding Arrangements and safeguarding business plan Ensuring the voices and lived experiences of children and young people, families and workforce are represented across the activities undertaken by the RSCP. 	
	Addressing Health Inequalities	Alex Hawley / Ruth Fletcher	<ul style="list-style-type: none"> Launch of KOOTH: a digital mental health counselling service for young people aged 11 – 25 jointly commissioned by Rotherham MBC and Rotherham CCG and went live in October 2021 	<ul style="list-style-type: none"> Work is commencing to develop Rotherham's public health plan to ensure activities or programs which promote health are accessible to autistic children and young people. To complete by April 2023
Outcome 3: Rotherham's autistic children and young people are provided with the same opportunities to thrive going into adulthood	Ensure that advanced planning and coordination of care occurs for autistic young people moving into adult social care	Garry Parvin and Helen Fisher	<ul style="list-style-type: none"> A priority for Rotherham's Preparing for Adulthood Board 	<ul style="list-style-type: none"> Good transition framework has been drafted based on the NTDi minimum standards (see: https://www.preparingforadulthood.org.uk/Site/Assets/Downloads/miap3csp637789722528041215.pdf) . This is due to be launched by June 2023.
	Raising awareness of	William Shaw	<ul style="list-style-type: none"> NTDi has reviewed the Local Offer from a 	<ul style="list-style-type: none"> To review, check existing information, give suggestions about how the site can be more

	the options and offers available to autistic young people as they move into adulthood		Preparing for Adulthood perspective and made recommendations for improvement: see new site: https://www.rotherhamsen.dlocaloffer.org.uk/ and see: https://www.rotherhamsen.dlocaloffer.org.uk/site-search/results/?q=autism	accessible, and provide updates on new information. The local offer subgroup are asking people to complete the attached template for updates, changes, and feedback and then send it to SendLocalOffer@rotherham.gov.uk . To complete by 30th April 2024
Outcome 4: Autistic Adults living in Rotherham will get the right support when needed	Improve the diagnosis and post-diagnosis support pathway for autistic adults living in Rotherham	Garry Parvin	<ul style="list-style-type: none"> Rotherham CCG invested approx. £400k during 2021/22 into the adult element (diagnostic - RDaSH and post-diagnostic elements - RANSS) of Rotherham's All Age Neurodevelopmental Pathway. These investments will increase to £458k in 2022/23. 	<ul style="list-style-type: none"> Deliver the expansion to extend the Rotherham Adult Neurodiversity Support Service (RANSS) offer to ensure that autistic adults without a learning disability have been historically diagnosed can benefit from this service. To commence in April 2022
	Raising awareness of autism in the public	Garry Parvin/ SYP service	<ul style="list-style-type: none"> Rotherham Council offers in-person and online training offer. SYP has autism awareness training to police officers. 	<ul style="list-style-type: none"> To support the planned national autism awareness campaign: no date has been issued by the National Government.
	Improving health and	Public Health / Ruth	<ul style="list-style-type: none"> Ensure that autistic adults are participating in the 5 ways to wellbeing 	<ul style="list-style-type: none"> To raise awareness of the risk of suicide for autistic people through 'Being the One'. 31st November 2022

	wellbeing for autistic adults	Fletcher – mental health	campaign – accessible information and promotion. Accessible leaflets have been created and available http://www.selfhelpguides.ntw.nhs.uk/rotherhamccg/ through the RotherHive website.	
Outcome 5: Autistic Adults living in Rotherham will be better supported as they grow old.	The Council and partners will ensure that the needs of autistic people are included in strategies and plans (health and wellbeing) to meet the needs of older people in Rotherham.	Garry Parvin	<ul style="list-style-type: none"> Voluntary Action Rotherham has produced a list of useful resources for autistic people living in Rotherham. This can be found: https://www.varotherham.org.uk/news/a-really-helpful-list-of-autism-resources/ 	<ul style="list-style-type: none"> Age UK and Rotherham libraries are working to challenge mental and physical deconditioning due to COVID-19, which has impacted disproportionately on older people. The project will also work to be accessible to autistic older people (see https://www.rotherham.gov.uk/libraries/online-library/3).

Appendix 2: Case Studies from Autistic residents who use the Rotherham Adult Neurodiversity Support Service (RANSS):

The case studies are anonymised and the names used are not the real resident's name

Case Study 1 - Melissa

Melissa (not her real name) is a university student who went for an assessment for autism after it was suggested to her by another mental health service. After doing some research, the traits of autism in women resonated with her and she hoped it might help her to understand her brain better. The whole process of referral to diagnosis took two months for Melissa and although it felt like it answered some questions the diagnosis was still a shock, and she wasn't sure what it would mean for her going forward. "I felt heard, confused, relieved, stressed and angry all at the same time. My own brain started making sense to me and it felt validating almost as if I was finally told someone believed me about my struggles, however, I also felt almost a bit betrayed that no one noticed and didn't try and help me with this sooner."

Melissa was referred to RANSS for post-diagnostic support and opted for one-to-one peer sessions. She was apprehensive about these sessions and didn't know if they would help her. "Even though I was heavily reluctant to seek the peer-to-peer support it was definitely the best thing I could possibly have done. I was helped with the confusion of a new diagnosis, understanding myself more, feeling more comfortable with my diagnosis almost like I could practice getting used to accepting my diagnosis so I could feel more comfortable if it was brought up elsewhere."

Melissa worked with her peer support worker on areas such as sensory sensitivities, executive functioning, education, and more broadly about what ASD is and how it affects her. Having someone that understood what she was struggling with helped her to realise that she was not "broken" and that this label could be helpful to learn more about looking after her needs. "I felt less alien, I found it easier to accept that I am autistic and get rid of ingrained stereotypes which is hard when you're applying them to yourself. It helped me get a better understanding and it helped me get rid of the stress and confusion of a whole new diagnosis that came as a shock. I felt comforted and felt less alone with it."

Since accessing peer support with RANSS, Melissa has found it easier to access the support she needs within the university and with other medical needs. She can communicate these needs easier now she has a better understanding of herself, she is feeling much more comfortable within herself and has a better understanding of ASD as a whole.

When asked about how she feels about her diagnosis now she said, “I feel like now I’m not embarrassed about it which sounds silly why would I be embarrassed by it, but it was something never particularly talked about and very much so portrayed in a negative way and I just feel more explained?? like things make sense and I’m happy with it and have made my peace with it.”

Case Study 2 – James

James (not his real name) is in his early 50’s and moved to Rotherham in 2020 with his wife. James worked in the Information Technology field for many years, but he left his last role around two and a half years ago, after experiencing difficulties with his employer. He applied for several other positions but had what he described as some ‘horrific’ job interviews. Moving to a new area, being unable to find work and well as the impact of the Covid 19 pandemic led to James feeling isolated and depressed.

James spoke to his wife, and his GP to get help with the mental health difficulties he was experiencing. After reflecting on it for some time, he decided that employment was not something to prioritise at that point. Initially, depression was the focus of his discussions with the GP, however, his wife (who works in the health service) had raised the idea that James may be autistic. James mentioned this to his GP, and he was asked to fill in an autism screening tool. As James identified with everything on the questionnaire and scored quite highly, he agreed to a referral to the Rotherham Adult Autism Diagnostic Service. During an appointment, James’ GP had mentioned ‘RANSS’ to him, and James looked up the website for RANSS and read about the wellbeing walks. He decided to give them a try whilst he was waiting for his assessment to start and said “I was really glad I did, as contact with you guys has been a real help through the diagnostic process”.

James also felt that “talking to others attending the walks has been helpful”. He has formed a friendship with another autistic adult who comes along to the walks, and they sometimes visit the café afterward to have a coffee together. This friend has also introduced James to the local leisure centre, and he has started to go swimming regularly. James now talks to some of the other ‘regulars’ who also go to the swimming pool and he said this has been helpful as he is very new to the area.

James said the diagnostic process seemed to happen quite quickly, and he got a diagnosis within a couple of months of starting the assessment process. He had an online appointment, followed by a face-to-face appointment at the clinic. James said “my autism diagnosis explains a lot of what I am about, and some of the things that I think or do. I understand myself a bit better”

“Attending activities and workshops with other neurodiverse adults has made me realise we all have a lot of common experiences”. For example, at a wellbeing walk, someone started a conversation about sensory differences. James said he had not thought about some of the problems he has with wearing certain fabrics until he heard others talking about their individual sensory differences.

James has signed up to volunteer with RANSS and is going to help with the website and social media. He said it gives him “an opportunity to help improve the service, and to give something back”.

“It’s still fairly early on, so I am still accessing help. I hope to move back into work in the future, and volunteering is a step towards that. Who knows what the future holds”

Case Study 3 – Jennifer

Jennifer (not her real name) is a young woman who has recently received a diagnosis of ASD. Jennifer had always felt “different” and came across some research on ASD in women. She continued to read the information on it and felt it could answer some questions she had about herself so sought an assessment. “I just knew in myself that there was something different about me and how I navigated the world.” It took eight months from referral to diagnosis.

Getting the diagnosis was a confusing time for Jennifer, although she had done her research and it made sense to her that she would get a diagnosis, it still came as a shock. “Getting a diagnosis was a mixture of emotions for me as I wasn't necessarily seeking the diagnosis at first it was a bit of a shock, I felt angry at the people in my life for not realising it earlier and that I had to figure it out myself. After I had the chance to come to terms with the diagnosis it definitely explained a lot for me, with how I have always felt out of place and how things have always been more challenging to me. It was validating and helped me realise that I wasn't being difficult or challenging, I was just experiencing things differently to others.”

Jennifer was referred to RANSS for post-diagnostic support straight after her diagnosis and opted for peer support, counselling, and our Autism & Me course. She found the course helpful in understanding what ASD means for her, “This course helped me understand myself and autism so much more than I previously did. Things like sensory issues, special interests and stimming were all new to me and this course helped me learn about them in more detail.”

Counselling sessions were helpful for Jennifer in understanding her diagnosis and coming to terms with it, it wasn't something that she had realised she needed. “Having weekly sessions has been a huge help in giving me a wider understanding of myself and has helped me realise things about myself that I didn't know could be linked to being autistic.”

Along with counselling, Jennifer accessed peer support which helped her to process the diagnosis, “this gave me someone to talk to about whatever I wanted to talk about which helped me when I was feeling overwhelmed and didn't want to speak to my family, as I find it easier to speak to someone out of my inner circle.”

Now she feels more comfortable with her diagnosis she has been attending the wider offer support groups. These groups allow people to meet others with a diagnosis in a social setting to chat, play games and do crafts, “I was in a place where I felt accepted. There was no pressure to speak or take part in things, but the environment was welcoming, and I felt really comfortable taking part. Also hearing from other people and their experiences also helped me learn that everyone has different backgrounds.”

Jennifer is still accessing support from RANSS with her peer support worker, she has been able to help her family understand more about her diagnosis through what she has worked on throughout her support so far. “The support from RANSS has overall been really helpful to me. I learned things about myself that have taught me to be more patient with myself and that I don't have to live up to the social norms that everyone else lives by. It has helped not just me but also my family as my mum and my sister have been able to retrieve information from things like the autism and my course, by being sent the slides after each session they were able to also read them and learn more even though they didn't take part in the actual course.”

Jennifer is still coming to terms with her diagnosis and learning to understand her limits and boundaries more, she is working on understanding her triggers for meltdowns and shutdowns so she can look after her needs better. When asked if things have changed since accessing support from RANSS, Jennifer told us that it “has helped change my mindset towards me and how I go about doing different things. I know that pushing myself in certain situations can lead to me to a meltdown, causing me to be out of commission for a few days. Before receiving the support from RANSS I wasn't aware of things like the term meltdown and how they affected me, so now knowing this has helped me a lot in knowing when I can and cannot push myself.”

Case Study 4 – Jane

Jane (not her real name) is in her 50s and retired from her job a few years ago. Before her autism diagnosis, Jane was feeling quite low and depressed. She described feeling isolated and had experienced difficulties in her relationships with some family members. Jane had a relative who was autistic, and she noticed some similarities which made her question whether she was autistic too.

After her diagnostic assessment, Jane was referred to RANSS for post-diagnostic support. Jane first attended the Autism & Me 4-week online group workshop. Before the workshop started Jane felt very anxious about attending, but by the end of the first session, she said she felt comfortable with the peer supporters and the other newly diagnosed adults who were attending. After the group workshop ended, Jane began attending the RANSS social activities. These include a weekly ‘wellbeing walk’ in a local park, and a weekly ‘meet up’ session where attendees can meet other neurodiverse adults in a relaxed environment. Jane said “I really enjoy coming on a Friday, I can chat freely or just sit and listen and not feel that I have to say anything. I don't have any close friends so it's good to come away from home and talk to other people”.

After attending the activities for several weeks Jane asked about volunteering opportunities and is now regularly volunteering at the RANSS activity sessions. Jane is really enjoying her volunteering role and is a valued member of the RANSS team. She has a skill in welcoming and including people into the group, particularly those who are new. Jane said that she can empathise with what other new attendees feel, as “I remember what I felt like the first time I attended.”

Jane said that over recent months her mood has lifted a lot, and she feels happy. Her relationships with family members have also improved. Jane said that she wishes she had been diagnosed with autism years ago, as it would have helped her earlier in her life.

Case study 5 – Thomas (a man with a historic diagnosis)

I am only relatively young still - 32 - but have been diagnosed with ASD for well over a decade now. After a huge relapse where I ended up in hospital (primarily due to my OCD), I have been looking to rebuild a healthy weekly schedule. I have had some help with doing this and was basically pointed in the direction of RANSS by somebody who has been helping support me from RDASH. The weekly walk quickly became a regular enjoyable fixture for me and has proved a key foundation in helping me gain the confidence and momentum to move forwards. I must mention that the staff are genuinely a very empathetic, supportive and friendly bunch! Also, a big bonus in particular to come from the walks for me was making a very close friend! We always spend a couple of hours together in the cafe afterwards, are in very regular contact, have been swimming together and have other plans to do things too! So from my own experiences I would, and in fact do, highly recommend the walking group and service as a whole to people it would be appropriate for!