

# NHS Rotherham Clinical Commissioning Governing Body

Operational Executive – 19 June 2020

Strategic Clinical Executive – 24 June 2020

GP Members Committee (GPMC) – Date

Clinical Commissioning Group Governing Body - 5 August 2020

## Proposal to Re-design the Neurodevelopmental Diagnostic and Support Pathway for Children and Young People

Lead Executive:	Ian Atkinson, Deputy Chief Officer
Lead Officer:	Jenny Lingrell, Joint Assistant Director – Commissioning, Performance and Inclusion  Rebecca McAlister, Senior Contract Manager – Mental Health and Learning Disabilities
Lead GP:	Dr Jason Page

### Purpose:

To provide Governing Body with an update on the Neurodevelopmental Diagnosis and Support Pathway for Children and Young People and seek approval for the outlined proposals. The report includes:

- 1) An updated position statement on the current waiting list and the impact of the pilot to offer an online pathway via Healios;
- 2) A proposal to **re-design the pathway to reduce demand and ensure that the needs of children who present with neuro-developmental difference are met, regardless of whether they have a diagnosis of autism;**
- 3) Details of the required activity and proposed investment to deliver the new pathway and reduce waiting times for neurodevelopmental diagnosis

### Background:

The CCG commissions RDaSH to provide an ASD/ADHD diagnosis service for children & young people (C&YP), aged 5 years and above, in Rotherham. Children under the age of 5 years are diagnosed by the Child Development Centre (TRFT).

Since October 2018 it has been apparent that there is a significant waiting list that continues to grow. In **October 2018** it was reported that there were **591** children waiting for a diagnosis of either Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD). At the end of **June 2019** it was estimated that the number of children waiting had increased to approximately **800**, and, **at the time of writing this report the number of children waiting is 1295**. It has been highlighted to Chief Executives at a Rotherham Place level that this is an unacceptable position, and a commitment was made by the CCG to invest £250,000 non-

recurrently in 2020/21 and £250,000 recurrently commencing in 2020/21 to address this.

It is important to note that identifying sufficient capacity to meet demands for Autism diagnosis is a national issue due to increasing awareness, demand and a challenging workforce position. In response to this national trend, the NHS Long Term Plan proposed that ASD/ADHD waiting times would be monitored through the Mental Health Standardised Dataset (MHSDS); this will give a clearer national comparison of referrals and waiting times.

In September 2019 Governing Body approved a proposal to pilot an alternative digitally enabled Autism assessment with an organisation called Healios. 120 Autism assessments were commissioned from Healios as part of a wider action plan to reduce long waiting times within the RDaSH CAMHS Neurodevelopment Pathway.

Rotherham CCG has also worked closely with the RDaSH CAMHS service to understand the demand and capacity issues across the system. Stakeholders from education, early help and social care and health and the voluntary and community sector have all been involved with this work.

#### **Analysis of key issues and of risks**

##### **(1) Demand:**

The average number of referrals each month is estimated to be between 60 and 70; this figure is an average that may fluctuate on a month by month basis. The majority of referrals are from schools which creates seasonal variation due to school holidays. More recently, referrals have been lower due to schools being closed to most children in response to Covid-19. In March there were 64 referrals to the pathway but in April this reduced to 12.

There is an opportunity to put in place the new pathway prior to schools re-opening more fully in September and seek to avoid referrals returning to higher levels. For the purposes of modelling, however, it has been assumed that referrals will reduce to an average of 40 a month. This is an ambitious target if considered in relation to the pattern of referrals prior to school closures.

RDaSH estimates that 80% of current referrals are screened to progress on to the full diagnostic pathway. The introduction of a multi-disciplinary team will improve the screening and diagnostic process and may reduce the number of children who progress to a full technical diagnosis.

##### **(2) Healios – Pilot Evaluation:**

In September 2019 Governing Body approved a proposal to pilot an alternative digitally enabled Autism assessment with an organisation called Healios. 120 Autism assessments were commissioned from Healios as part of the wider action plan to reduce waiting times within the RDaSH CAMHS Neurodevelopment Pathway. The contract was drafted, agreed and then signed with Healios in early November 2019. A Contract Variation was agreed with Healios in March 2020 for an additional 100 Autism assessments for Rotherham patients aged 7 to 90 years old and to allow Sheffield Health and Social Care to refer adults to Healios.

The key milestones to mobilise the Healios offer are shown on the timeline below:

<b>Date Completed</b>	<b>Action</b>
October 2019	<ul style="list-style-type: none"><li>• RDaSH &amp; Healios Clinicians Meeting</li><li>• Identifying cohort against Healios eligibility criteria</li></ul>
November 2019	<ul style="list-style-type: none"><li>• Additional Administrative Support identified within RDaSH</li><li>• MOU between RDaSH and Healios agreed</li></ul>

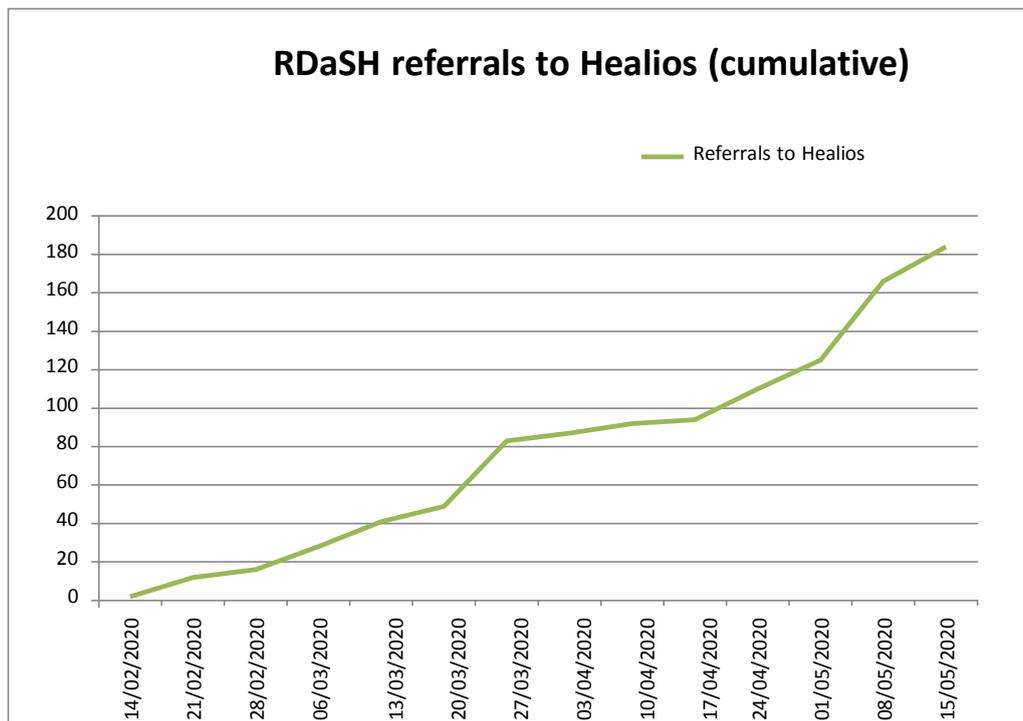
December 2019	<ul style="list-style-type: none"> <li>Narrative for RDaSH and Healios to work together included in Contract Variation</li> <li>RDaSH staff training to use Healios portal to share patient data securely.</li> </ul>
January 2020	<ul style="list-style-type: none"> <li>Data Processing Agreement between RDaSH and Healios agreed</li> <li>Letters, key messages and FAQs agreed</li> <li>Initial phone calls to 4 families w/c 6 January 2020</li> <li>25 families contacted by letter w/c 13 January 2020</li> </ul>

There was a delay sending out larger numbers of letters to families in January and early February. This was caused by information governance issues raised by RDaSH in relation to sharing the ND waiting list with RMBC. The sharing of patient details with RMBC was to support the screening of those with known safeguarding concerns who would not be suitable for a digital model of diagnosis. This was resolved in early March.

It should also be noted that letters to offer a service from Healios were sent to those who had waited the longest first and that feedback from Healios was that generally those who wait the longest are more likely not to choose an alternative but continue to wait with the current provider.

**(3) Delivery:**

The first referral from RDaSH to Healios was made on 27 January 2020. The graph below shows the number of referrals received by Healios on a weekly basis.



Over the whole period 640 letters have been sent to all families who met the eligibility criteria for the Healios offer, to see if they would like to access an on-line assessment. The response rate to letters sent and referrals made varies weekly but over the whole period stands at 29%.

Families who received a letter also had a follow up phone call to prompt a response and answer any questions. Feedback from these follow up calls suggests that families needed longer than originally anticipated to make a decision.

Contract performance reporting from Healios as at 12 May 2020 shows:

- Average wait from referral to first appointment is 15.4 days
- 30 Assessments completed
- 125 Assessments in progress
- 75% of completed assessments resulted in a diagnosis of ASD
- 6 referrals rejected that did not meet the eligibility criteria
- 3% DNA rate

Feedback from parents whose Children and Young People have accessed Healios has been overwhelmingly positive. (Data below is for April 2020)

Healios Friends and Family Score: <b>Likelihood of recommending the Service.</b>	
Agree a lot	83.67% (41)
Agree a bit	2.24% (6)
Undecided	4.08% (2)

In summary, ***the pilot has shown that introducing an alternative route for a technical diagnosis is positive and well received by service users.*** Maintaining this option as part of the pathway would also be aligned with the guidance in Future in Mind (which refers to 'harnessing digital technology'), and more recent national guidance during COVID 19, which promotes the use of digital pathways. There is an opportunity to build on the confidence and trust that families have in the Healios offer, particularly in the context of the increased use of digital during the recent lockdown arrangements.

There is a short-term risk that families who have already received a letter with an offer to access Healios continue to come forward whilst having no capacity within the RCCG/Healios contract to meet this demand. See Financial Implications (section 2: element of pathway redesign requiring additional non-recurrent investment) for more information on the mitigation of this risk.

#### **(4) Pathway Re-design:**

**The vision for the new pathway is that children who present with neuro-developmental difference should have their needs met and be supported to thrive at the earliest opportunity and regardless of whether they have a formal diagnosis.** This vision was commended by the recent Peer Challenge although the team noted in their feedback that it was not yet shared and understood across the wider system of provision for children.

The CCG has mapped the pathway in full, to understand the support that is available to children who present with some neuro-developmental difference, and to understand some of the drivers and incentives for seeking a technical diagnosis.

The pathway mapping revealed that there were many services that became available following a technical diagnosis, including post-support services commissioned by the CCG. It was also apparent that support provided in schools when behaviours that indicate neuro-developmental difference begin to emerge, is inconsistent, variable in quality and not connected to the RDaSH CAMHS team.

The new pathway is set out in Appendix 1. The key features of the pathway are as follows:

#### **(5) Whole system understanding:**

The Local Authority has the licence to deliver training from the Autism Education Trust. This is split into three levels to build understanding across a whole organisation (e.g. a school or other primary provider), provide resources appropriate to specialist workers (e.g. a special educational needs coordinator) and to inform system leaders (e.g. headteachers and leaders of local children's services). The Local Authority have previously charged for delivery of the training to cover the cost of room-hire and officer time. It is proposed that a programme is designed to roll out the training at all levels across the Rotherham place free of charge. The cost of room-hire and officer time will be funded by the Local Authority who have ring-fenced the required budget from transformation funding. Multi-Academy Trusts will be asked to engage in the offer on a 'train the trainer' basis to ensure that knowledge is embedded within organisations. The Autism Education Trust are positive about Rotherham's plans and have expressed an interest in working in partnership to understand the impact that this whole system approach might have.

Plans are now being re-visited in the context of Covid-19 and the challenges of delivering face to face training to larger groups.

#### **(6) SENCO Toolkit:**

Where a child presents with behaviours that make it difficult for them to thrive in a learning environment, including signs of neuro-developmental difference, it is good practice to start an SEN Support Plan. This approach is guided through publication of a 'graduated response' on the SEND Local Offer, however guidance may be difficult to engage with and is certainly used inconsistently.

It is proposed that TRFT Therapy Services undertake a piece of work to develop an SEN Toolkit with clear guidance in the format of an interactive PDF that includes downloadable resources. This approach will seek to address need as it emerges without the need for a technical diagnosis. It will also support a consistency of approach and a clear audit trail that can be shared with a clinical team should they become involved in future. The new pathway would require education providers to evidence interventions at SEN Support level before a referral for technical diagnosis was accepted.

To ensure children are receiving the right support at the right time, and children who may need a prompt diagnosis of ADHD are identified, it is proposed that RDaSH clinical time that is currently targeted to the Peer Support Service drop-ins is re-allocated to advise SENCOs in schools.

#### **(7) Evidence-Based Workshops and Targeted Family Support:**

Parent Carer Forum are currently commissioned by the CCG to provide a peer support service. This includes a weekly drop in (supported by clinical staff) and targeted support on a 1:1 basis for some families. The service is currently term time only. Note: the delivery model of the Peer Support Service has changed during COVID 19 with drop-ins delivered virtually via Zoom. RDaSH are not currently supporting drop-ins via Zoom due to Information Governance concerns

The Autism Information and Advice Service is commissioned by the CCG to provide post-diagnostic support comprising two sessions with each family.

The Disability Family Support Team are an RMBC-funded core service that form part of the Early Help offer. The Autism Information and Advice Service is now structurally embedded within the Disability Family Support Team.

It is proposed that the contracts with both services are amended to enable the delivery of evidence-based programmes of support co-delivered in groups by the Autism Information and

Advice Service and Parent Carer Forum. The proposed offer is 'Stepping Stones' – an evidence-based programme of advice and support for parents of children with autism. The modules cover areas such as healthy sleep routines, communication and interaction support, social support, sensory difference and teen life.

**Comment [WU1]:** This has already been changed in the RPCF contract but not yet for AIAS.

Group sessions will identify families who might need additional targeted support and a referral route to the 1:1 offer provided by parent carer forum will meet this need.

No additional investment is required to support these changes to the pathway.

**(8) Multi-Disciplinary Team:**

There is currently no formal connection between the support that children receive prior to diagnosis and the technical diagnosis process. Given that the technical diagnosis relies on contextual information about the child, this is an inefficient approach, that also relies on children and families re-telling their stories.

It is proposed that a multi-disciplinary team is created, combining resources from education, social care and the clinical neuro-developmental team. Permanent members of the team will include both educational and clinical psychologists. Learning support and disability family support professionals will attend weekly case review and tasking meetings and may be asked to undertake follow-up actions. It is hoped that speech and language therapy and occupational therapy teams will also be represented. The weekly meetings will enable information to be shared that will contribute to the diagnostic assessment. This approach will ensure that the process is efficient and effective and feels joined-up to families.

RMBC inclusion services have agreed that they can support this approach by releasing staff to attend weekly meetings. It is proposed that funding is allocated to fund an educational psychologist for 1 year to pilot the approach. If the arrangement continues it is proposed that the post is joint-funded on a permanent basis by RMBC and the CCG.

This multi-disciplinary team model was developed in North Lincolnshire in September 2019 and is working well. The number of referrals is beginning to stabilise after a period of sustained increase. The cost to the CCG of piloting a multi-disciplinary team for 1 year is £70,000 to fund an educational psychologist in full. In subsequent years the post would be jointly funded with RMBC at a cost of £35,000 to RCGG.

**(9) Capacity for Technical Diagnosis:**

RDaSH prepared a business case in March 2020 that sets out the challenges of matching demand and capacity for technical diagnosis. The paper is modelled based on an average number of referrals per month of 60-70 and existing capacity to complete 15-20 diagnoses per month. Additional staffing equivalent to 3.8 FTE psychologists and a 1.0 FTE coordinator is proposed to increase the diagnostic capacity to 40-50 per month. The total investment to support the new commission is £282,700. However, this proposal does not take account of the multi-disciplinary team which will support a more efficient process as well as adding staffing resources.

It is therefore proposed *to support the business case in part* as follows:

PAY	wte	Band	Mid point
Principal Clinical Psychologist	0.80	8b	£59,191
Assistant Psychologists	1.00	B4	£30,118

Pathway Co-ordinator	1.00	B3	£26,254	£26,254
<b>NON PAY</b>				
Additional Costs (travel, phones, laptops, courses)			£23,113	£23,855
<b>TOTAL COST</b>			<b>£138,676</b>	<b>£143,128</b>

**(10) Embedding Choice in the Pathway:**

In order to reduce the waiting list over time, provide patients with choice and flexibility in terms of how they engage with the diagnostic process, and align with the aspirations set out in Future in Mind to embrace digital options, it is preferred that a digital provider becomes a permanent feature of the pathway.

To achieve this, it is proposed that RCCG directly commissions Healios for a further 12 months to embed this choice within the pathway and continue to reduce the waiting list. The rationale for this approach is as follows:

- Allows RCCG to manage the risk of the existing waiting list;
- Ensures that the positive outcomes achieved by Healios during the pilot period are sustained for a further 12 months;
- Provides an opportunity to review the position in 2021/22 pending the development of new technologies in the market to support a digital approach;
- Provides an opportunity to review the position in 2021/22 when the impact of the overall changes to the pathway are known.

**(11) Anticipated Impact – Waiting List Trajectory:**

There are many variables linked to the modelling so the trajectory mapped below relies on multiple assumptions. These are that:

- The CCG pilot with Healios (delivery to date) will reduce the waiting list by 120
- The additional capacity procured by the CCG from Healios (shared with the adult pathway) will reduce the waiting list by 64
- That business as usual delivered by the RDaSH CAMHS ND pathway team will reduce the waiting list by between March and August by 100 (20 per month for 5 months).

Based on these assumptions the waiting list at the start of the new pathway in September 2020 would be **1011**

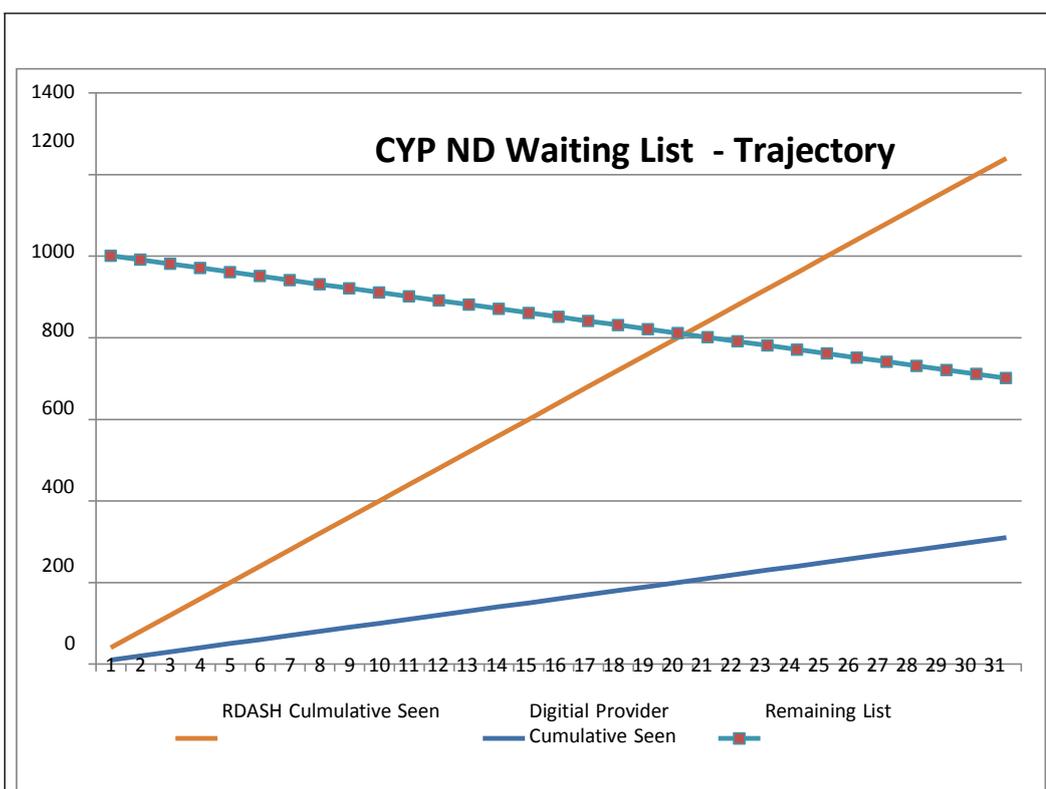
- It is then assumed that there will be capacity from the MD team and the RDaSH team to provide 45 diagnoses each month, and
- There will be sufficient resource to purchase additional diagnostic capacity from a digital provider for at least 12 months.

Modelling has also assumed that the new pathway will reduce referrals for a technical diagnosis to 40 a month. (If referral rates remain at a pre-Covid level of 60 to 70 a month; at least 20 new children will be added to the waiting list each month).

Based on these assumptions, by the end of March 2021 the waiting list would be 946. The reduction in the waiting list after this time will depend on the total capacity to complete referrals. Assuming that the rate of referral holds at 40 per month, and the rate of diagnosis remains at 55 per month, by the end of March 2023 the waiting list would be: 546 (10 months approximately).

**Comment [WU2]:** Can we say its permanent as that commits CCG to find ongoing funding in future years? Maybe for the "medium to long term"

**Comment [WU3]:** I'm not really clear what this bit costs. Is it the 72K mentioned above? Are we giving them the choice of deciding on another clinical psychologist or Healios?



RDASH performance team have provided an alternative trajectory based on slightly different assumptions. The assumptions link the capacity with the number of posts available in the team, but do not assume any efficiencies based on the introduction of a multi-disciplinary team. The RDASH prepared trajectory is included as appendix 2 to illustrate the many variables involved in producing a realistic trajectory.

Once additional resource has been agreed and mobilisation commenced assumptions can be revisited and the trajectory refined to support robust contract management.

**(12) Peer Challenge Response:**

The Peer Challenge notes some immediate actions that are required to provide assurance that Rotherham has gripped and responded to the challenges presented by demand for the neuro-developmental pathway. The preparation of a target trajectory is addressed within this report. The implementation of recommendations outlined in the report will need to be accompanied by a communications plan to ensure that the new pathway is well understood across the system. There is also a need to provide assurance of the arrangements in place to support children and families whilst they are waiting for an assessment and this will require a further targeted piece of work.

**Patient, Public and Stakeholder Involvement:**

Rotherham's Parent Carer Forum are commissioned to provide peer support via weekly drop-in sessions, providing an opportunity to seek parental views in relation to service delivery and any proposed changes. Parent Carer Forum and Voluntary Action Rotherham are also represented on the Social, Emotional and Mental Health Strategy Delivery Group, including a sub-group that has undertaken the mapping, analysis and re-design work for the Neuro-Developmental Pathway.

The SEND Peer Challenge letter confirmed that parents had been involved with the pathway re-design.

In relation to patient feedback to the Healios service, the experience of service questionnaire asks: what was good about your (child's) care? Responses were as follows:

*"I feel like any point I mentioned was taken in and viewed and looked at"*  
Young Person 12-18 years of age

*"they were very helpful when i opened up"*  
Young Person 12-18 years of age

*"The clinician really persevered with my child".*  
Parent/Carer

*"Assessor put my child at ease"*  
Parent/Carer

Negative feedback was around length of appointment (there is a three hour session included in the observations) and time the family had waited prior to the referral to Healios.

**Equality Impact:**

An Equality Impact Assessment is attached as Appendix 2.

Comment [WU4]: I'll write one for you to include with this report.

**Financial Implications:**

The re-design of the current neuro-developmental pathway is largely cost neutral and will be achieved through re-focusing existing specifications.

**1: Elements of pathway redesign not requiring additional investment:**

The following elements of the pathway redesign where **no additional RCGG investment is required.**

- Autism Education Trust Licence – costs covered by RMBC
- Stepping Stones Training – costs covered by RMBC
- Autism Information & Advice Service – costs covered by RCGG (£54,000 CAMHS local transformation plan)

**2: Element of pathway redesign requiring additional non-recurrent investment:**

RCGG Proposed non-recurrent investment 2020/2021			
Provider	Activity	Cost	
RMBC	AET Training roll out	£4,000	
TRFT	SEN Support Toolkit development	£8,000	
TRFT	IT / Design (for SEN Support toolkit)	£14,000	
RMBC	Educational psychologist (MDT)*	£35,000	
Note: £88,704	<b>TOTAL</b>	<b>£61,000</b>	200/21 non-recurrent funding has previously been approved in relation to the RCGG/Healios contract.

Comment [WU5]: I thought the Ed Psych was costing CCG 60k in 20/21 then splitting costs with RMBC for 21/22? Just checking....

\* It is proposed that the full time Education Psychologist (who will be part of the MDT) will be funded 50% from non-recurrent funding and 50% from recurrent funding in 20/21. In subsequent years it is anticipated that RMBC will provide 50% of the funding for this post.

### 3. Investment in the Digital Pathway

It is proposed that funding of **£171,424** is allocated to procure capacity from Healios. This equates to 124 assessments based on the unit cost during the pilot phase. It is recommended that RCCG makes a direct award to Healios based on the positive outcomes of the pilot and the size of the current waiting list. This procurement arrangement will also ensure that there is no gap in availability of provision and no waiting list will form for the digital pathway.

### 4: Element of pathway redesign requiring additional recurrent investment:

<b>RDaSH Additional ND Pathway Staffing</b>	<b>wte</b>	<b>Band</b>	<b>Top of scale</b>
Principal Clinical Psychologist	0.80	8b	£62,902
Assistant Psychologists	1.00	B4	£30,118
Pathway Co-ordinator	1.00	B3	£26,254
RDaSH Non Pay: Additional Costs (travel, phones, laptops, courses)			£23,855
<b>RDaSH STAFFING COST Total</b>			<b>£143,128</b>
<b>RMBC Educational Psychologist (MDT)*</b>			<b>£35,000</b>
<b>TOTAL COST</b>			<b>£178,872</b>

\*see note above on split of costs for Educational Psychologist.

At the time of writing this report NHS Providers are currently being paid through a block arrangement as part of the COVID-19 arrangements. No additional investment to RDaSH or TRFT to support pathway re-design can be made under the block arrangements and therefore the timing of mobilising the recommendations in this report are difficult to specify. The costs provided here are based on a full year of delivery and may need further revision in the light of subsequent NHS England guidance.

#### Human Resource Implications:

There are no human resource implications for RCCG.

#### Procurement:

The additional in-year capacity from Healios was procured through a tender waiver, granted to enhance the adult diagnostic pathway. The capacity purchased through this procurement route was shared between adults and children's to respond to the existing demand for the children's pathway that had been identified.

It is proposed that a further direct award is made to Healios for the next 12 months; the rationale for this is to manage the risk of the existing waiting list, limit the recurring commitment in a quickly evolving digital market and to prevent a new waiting list developing for the digital provider.

All other investments proposed will be achieved through a contract variation process or amended service specification with an existing provider. The providers are TRFT, RMBC and RDaSH CAMHS.

#### Approval history:

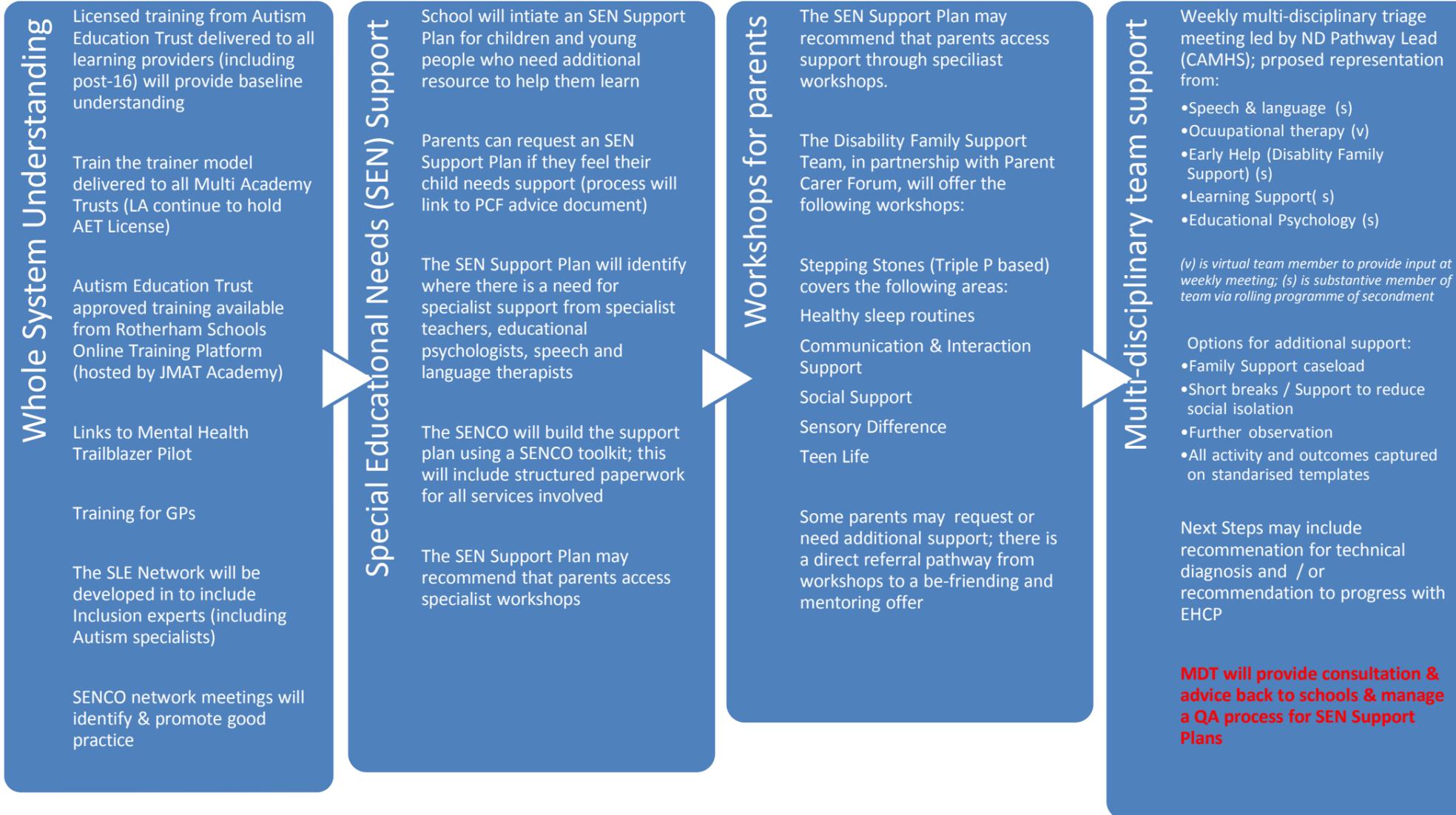
**Recommendations:**

Governing Body is asked to

- Note the updated position statement on the current waiting list and the impact of the pilot to offer an online pathway via Healios;
- Approve the proposal to re-design the pathway to reduce demand and ensure that the needs of children who present with neuro-developmental difference are met, regardless of whether they have a diagnosis of autism;
- Approve the proposals for recurrent and non-recurrent funding for the re-design of the Children and Young People's Neurodevelopment Pathway.

**Paper is for Approval**

**Rotherham – Proposed Neuro-Developmental Support Pathway (February 2020)**



### Rotherham Neurodevelopment Improvement Trajectory

As at the end of May 2020, there were a total of

- 1,135 children awaiting assessment on the Neurodevelopment pathway
- 130 children remain with Healios with RDaSH committing to send a further 45 children during June 2020

Referrals for the period April 2019 to March 2020 were 677 with average referrals 56 per month. However, due to covid-19 and the closure of schools referrals have reduced to 16 in April and 15 (estimated) for May. It is anticipated that referrals will be held by schools and a surge will re-occur once schools transition through to full operation.

Service capacity currently supports throughput at a rate of 20 assessments per month. In view of this, it is apparent that the additional capacity suggested will increase the throughput to 52 per month from December 2020. The consequence of this will see a small increase in the waiting list until November 2020 however, at this point should the average referrals decrease to 45 a month (due to front-end pathway changes) this will seek to reduce the waiting list by 7 per month.

The following trajectory is based on the agreement of both the funding and pathway changes which have been discussed during May 2020 with RMBC, RCCG and RDaSH.

Month	Starting figure	Assessments - Existing team	Healios RCCG	New Post Clinical Psychologist (Lead)	New Posts 2 Clinical Psychologist	Educational Psychologist	New Post Assistant Psych and Coordinator	Healios RDaSH	Average Referrals	Cross Boundary Children	Waiting List Trajectory
May-20	1,335	20	130					0	15	84	1,116
Jun-20	1,116	20						45	56		1,107
Jul-20	1,107	20						0	56		1,143
Aug-20	1,143	20		6				0	56		1,173
Sep-20	1,173	20		6		6		0	56		1,197
Oct-20	1,197	20		6		6		0	56		1,221
Nov-20	1,221	20		6		6		0	45		1,234
Dec-20	1,234	20		6	14	6	6	0	45		1,227
Jan-21	1,227	20		6	14	6	6	0	45		1,220
Feb-21	1,220	20		6	14	6	6	0	45		1,213
Mar-21	1,213	20		6	14	6	6	0	45		1,206
Apr-21	1,206	20		6	14	6	6	0	45		1,199
May-21	1,199	20		6	14	6	6	0	45		1,192
Jun-21	1,192	20		6	14	6	6	0	45		1,185
Jul-21	1,185	20		6	14	6	6	0	45		1,178
Aug-21	1,178	20		6	14	6	6	0	45		1,171

#### Assumptions -

- Funding is maintained for the period outlined for the New posts within RDASH into 2020/21
- Funding is made available to RDaSH to commence recruitment by end of June 2020.
- Staffing levels remain the same, no vacancies and sickness
- Referral numbers into service remain aligned to the above projection
- The AP and Co-ordinator will release clinical time for the Clinical Psychologists to support completion of additional assessments
- Current trajectory will see the waiting list reduce at a graduated rate by 7 per month dependent on successful recruitment.

*Leading the way with care*

It is noted that the present approach remains focused around the prioritisation of children on the waiting list deemed to be higher risk, with recognition that this will increase the waiting times for those with a lower risk profile, and whilst this is not ideal, it is a necessary approach to manage clinical risk.

**Prepared by**

Jill Fairbank  
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Borough Wide Service Manager

Darren Brierley  
Consultant Clinical Psychologist

## Equality Impact and Engagement Assessment Form

**Complete this section**

**Please retain one copy, and pass one copy to both the Equalities and Engagement leads**

### Section one – Project or plan details

1.1	<b>Project Title:</b>	
	Children and Young People's Neurodevelopment Pathway: Action Plan to Reduce Waiting Times	
1.2	<b>Project Lead:</b>	<b>Contact Details:</b>
	Beki McAlister	Rebecca.mcalister@nhs.net
1.3	<b>This activity /project is:</b>	
	Policy – Project – Plan – Other - Review	
1.4	<b>Describe the activity/project</b>	
	<p>This Equality Impact Assessment (EIA) is in relation to the proposed re-design of the Children and Young Peoples Neurodevelopment Support Pathway (CYP ND Pathway). It builds upon the EIA considered by the Equality &amp; Diversity Group in August 2019 in relation to a proposal to commission an additional provider for digital assessments of Autism for Children and Young People in Rotherham.</p> <p>The changes being considered are:</p> <ol style="list-style-type: none"> <li>1) To increase whole system understanding through the delivery of training at all levels across the Rotherham place free of charge.</li> <li>2) Development of a SENCO toolkit to ensure children are receiving the right support at the right time, and children who may need a prompt diagnosis of ADHD are identified.</li> <li>3) Evidence-Based Workshops and Targeted Family Support to empower families with skills and strategies to help manage neurodevelopmental differences and behaviour. (note: an EIA has been considered and approved for changes to RPCF Peer Support Service)</li> <li>4) Development of a Multi-Disciplinary Team including an educational psychologist to increase capacity and enrich the collection of contextual information to support assessment.</li> <li>5) Increasing capacity for technical diagnosis within RDaSH CAMHS through additional staffing.</li> <li>6) Continue to offer choice through a digital provider of ASD assessments.</li> </ol>	
1.5	<b>Timescales</b>	
	At this point it is difficult to say when all the recommendations may be actioned due to COVID-19s impact on contracting and delivery. However it is intended that the new pathway is established prior to schools re-opening more fully in September 2020.	
2	<b>Equality Impact Assessment</b>	
2.1	<b>Gathering of Information:</b> This is the core of the analysis; how might the project or work impact on protected groups, with consideration of the General Equality Duty. Please add any general information here.	
	<p>The key principle behind these changes is that children who present with neuro-developmental difference should have their needs met and be supported to thrive at the earliest opportunity and regardless of whether they have a formal diagnosis.</p> <p>Taken together the changes will:</p> <ul style="list-style-type: none"> <li>• Increase capacity for technical diagnosis – in the long terms this will lead to a reduction in the number of Children and Young People waiting assessment.</li> <li>• option.</li> </ul>	

- The diagnostic process will be streamlined through more joined up processes that allow more contextual information to be shared with the technical diagnosis team.
- Families will be able to access support, guidance and training regardless of diagnosed status.
- Allow families to continue to be offered a choice of a “traditional” assessment or a digital assessment.

The pilot to offer choice through a digital assessment has been well-received by families. Between January 2020 and May 2020, 640 letters have been sent to all families who met the eligibility criteria for the Healios offer, to see if they would like to access an on-line assessment. The response rate to letters sent and referrals made varies weekly but over the whole period stands at 29%. Families who received a letter also had a follow up phone call to prompt a response and answer any questions. Feedback from these follow up calls suggests that families needed longer than originally anticipated to make a decision.

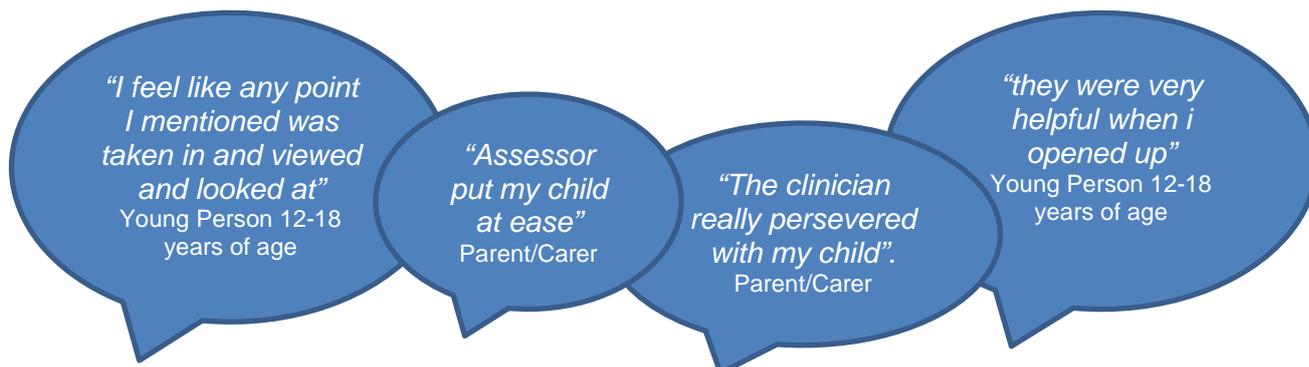
Contract performance reporting from Healios as at 12 May 2020 shows:

- Average wait from referral to first appointment is 15.4 days
- 30 Assessments completed
- 125 Assessments in progress
- 75% of completed assessments resulted in a diagnosis of ASD
- 6 referrals rejected that did not meet the eligibility criteria
- 3% DNA rate

Feedback from parents whose Children and Young People have accessed Healios has been overwhelmingly positive. (Data below is for April 2020)

Healios Friends and Family Score: <b>Likelihood of recommending the Service.</b>	
Agree a lot	83.67% (41)
Agree a bit	2.24% (6)
Undecided	4.08% (2)

In relation to patient feedback to the Healios service, the experience of service questionnaire asks: what was good about your (child’s) care? Responses were as follows:



Negative feedback was around length of appointment (there is a three hour session included in the observations) and time the family had waited prior to the referral to Healios.

Of the 180 Children and Young People referred from RDaSH CAMHS to Healios 12% were Asian, 65% were White British, 23% chose not to disclose their ethnicity.

There is no national benchmarking data on waiting times for Children and Young Peoples' Neurodevelopment assessments (although there is an intention to introduce one in the NHS long term plan.) Therefore it is not currently possible to do any comparison work to better understand the

experience of those waiting in terms of gender or ethnicity in Rotherham compared to the rest of England. We do know however that other areas across Yorkshire and Humber are also experiencing high levels of referrals for Neurodevelopment assessments.

There is a lack of research about the experience of people from black, Asian and minority ethnic (BAME) groups and Autism however the National Autistic Society produced a report in 2014 that suggested that it was even harder for BAME groups to get a diagnosis and appropriate support.  
<https://www.autism.org.uk/about/bame-autism.aspx>

With regard to ADHD there are no statistics available for prevalence in children and young people. However in adults, there was found in 2014 that there was no difference between ethnic groups  
<https://www.ethnicity-facts-figures.service.gov.uk/health/mental-health/prevalence-of-adhd-among-adults/latest>

The Rotherham Joint Strategic Needs Assessment states that 8.1% of Rotherham's population is from a BAME background. It also states that the current prevalence of Autism is approximately 1% of the population. This would very roughly equate to potentially 211 people of all ages with Autism and therefore is a relatively small sample size for reliable analysis. Taking this into account engagement with families to understand their experiences might give more insight.

2.2

**Screening**

Please complete each area)	What key impact have you identified?			Information Source
	<b>Positive Impact</b> - will actively promote or improve equality of opportunity.	<b>Neutral Impact</b> - where there are no notable consequences for any group.	<b>Negative Impact</b> negative or adverse impact causes disadvantage or exclusion. <b>If such an impact is identified, the EIA should ensure, that as far as possible, it is either justified, eliminated, minimised or counter balanced by other measures.</b>	What action, if any, is needed to address these issues and what difference will this make? For example: <i>At this point no action is required. Further EIA screenings will be developed in future once there are recommendations to assess.</i>
Human Rights	N	Y	N	
Age	Y	N	N	
Carers	N	Y	N	
Disability	Y	N	N	
Sex	N	Y	N	
Race	N	Y	N	
Religion or belief	N	Y	N	
Sexual Orientation	N	Y	N	
Gender reassignment	N	Y	N	
Pregnancy and maternity	N	Y	N	
Marriage/civil partnership (only eliminating discrimination)	N	Y	N	
Other relevant groups	N	Y	N	

3

**Engagement Assessment**

3.1	<p><b>What is the level of service change?</b> – see diagram 3 above</p> <p>If your project is classed as a ‘significant variation’ (level 3) or ‘major change’ (level 4) please contact <a href="mailto:england.yhclinicalstrategy@nhs.net">england.yhclinicalstrategy@nhs.net</a> for a preliminary discussion to support planning and agree whether the service change needs to follow the NHS England Service Change Assurance process.</p> <p>The assurance process generally looks at the ‘case for change’ The key players in the process include overview and scrutiny teams, and the clinical senates. You can also refer to the DH guidance: (please note that level 4 changes will require considerable long term planning and this DH guidance is mandatory for all level 4 changes) <a href="http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/nhs_public_involvement_-_hempsons_stp.pdf">http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/nhs_public_involvement_-_hempsons_stp.pdf</a> DH 2013</p>
	<p><b>Circle or highlight the appropriate level of service change</b></p> <p>Level 1</p>
	<p><b>Add additional information and rationale for this scoring below</b></p> <p>Within the NHSE criteria as set out above, the level of engagement required is level 1.</p>
3.2	<p><b>Who are your stakeholders?</b></p> <p>Consider using a mapping tool to identify stakeholders - who is the change going to affect and how? Complete below or attach or link to a mapping document</p> <p>Rotherham Parent Carer Forum  Rotherham patients and their families  RDaSH CAMHS  RMBC Inclusion Services  Rotherham Social Emotional and Mental Health Strategy Group  Rotherham Autism Partnership  Rotherham Schools</p>
3.3	<p><b>What do we already know?</b></p> <p>What do you already know about peoples’ access, experience, health inequalities and health outcomes? Use intelligence from existing local, regional or national research, data, deliberative events or engagements.</p>
	<p>As set out in section 2.1</p>
	<p><b>Describe any existing arrangements to involve patients and the public which are relevant to this plan/activity and/or provide relevant sources of patient and public insight?</b></p> <p>How will the insight available to you help to inform your decision?</p>
	<p>The CYP ND Pathway action plan is now being re-freshed to show progress made in 2019/20 and to identify and measure progress in relation to the pathway re-design. As part of that process the following will be identified:</p> <ul style="list-style-type: none"> <li>○ Ways to engagement with BAME children, young people and their families to understand, inform and improve the pathway</li> <li>○ What performance data would help us understand and improve the experience and outcomes for BAME children and young people in relation to the pathway.</li> </ul> <p>In addition, the re-freshed action plan will include how the changes to the pathway will be communicated to families and other key stakeholder groups.</p> <p>A series of engagement events took place in June and July 2019 to inform the pathway re-design and part of the development of the All-Age Autism Strategy. These were facilitated by the Rotherham Parent Carer Forum.</p> <p>The SEND Peer Challenge letter confirmed that parents had been involved with the pathway re-</p>

	<p>design.</p>  <p>Enc 4 - FINALlettertootherh.</p> <p>Rotherham's Parent Carer Forum are commissioned to provide peer support via weekly drop-in sessions, providing an opportunity to seek parental views in relation to service delivery and any proposed changes. <b>The Parent Carer Forum is required to establish a baseline for access to the peer support service in terms of age and ethnicity and to improve accessibility of these groups through the development and delivery of an engagement plan (as part of the contractual requirements in 2020/21).</b></p>
	<p><b>Briefly describe how the existing or proposed engagement will be 'fair and proportionate', in relation to the activity?</b></p>
	<p><b>The pathway has developed as a result of engagement with a variety of stakeholders; stakeholders involved throughout development</b></p>
3.4	<p><b>Reaching out to overlooked communities</b> Are additional arrangements for patient and public involvement required for this activity and in particular will you ensure that 'seldom-heard' groups, those with 'protected characteristics' under the Equality Act, those experiencing health inequalities are involved</p> <ul style="list-style-type: none"> <li>• Seldom-heard groups Yes/No</li> <li>• Nine Protected Characteristics Yes/No</li> <li>• Health inequalities Yes/No</li> </ul> <p>If yes, please provide a brief outline of your approach and objectives for any additional patient participation targeted at these groups</p>
	<p>No</p>
	<p>Do you need to make any of your resources accessible (i.e. for people with learning disabilities, sight impairments, or alternative languages?)</p>
	<p>Changes to the pathway will be contracted with existed provider on the standard NHS contract documentation – this includes the requirements to make delivery open and accessible for people with additional needs.</p>
3.5	<p><b>What resources do you need for this?</b> Consider the sections above</p> <ul style="list-style-type: none"> <li>• The timescales</li> <li>• The need to reach overlooked communities</li> <li>• Accessible materials</li> <li>• Gaps in knowledge</li> </ul>
	<p>No additional resources have been identified as being needed at this stage.</p>
4	<p><b>Feedback and Evaluation</b></p>
4.1	<p>How will you use the feedback – who does it need to be shared with? Feedback will be shared through the SEMH strategy group to ensure that actions are informed by families wishes/ feelings and ideas.</p>
4.2	<p>Provide a brief outline of how the information collected through patient and public participation will be used to influence the plan/activity. Report to go through RCCG governance route; and those of partners where appropriate.</p>
4.3	<p>How will the outcomes of participation be reported back to those involved? Through the mechanisms already in place to support the Rotherham All-age Autism Strategy</p>
4.4	<p>How will you assess the ongoing impact of the change on patients and the public after it has been completed? Through appropriate contract KPIS.</p>
5	<p><b>Engagement and Equality Impact Plan</b></p>

	Action	Approx. Timescale	Lead	Deadline	Comments/ progress
6	Form details				
	Completed by:	Rebecca McAlister			
	Job title:	Senior Contract Manager			
	Date	12/06/20			
		Amended 16.07.20 following feedback			
	Reported to				