



UPDATE ON NEURODIVERSITY WAITING TIMES PROGRAMME

SHEFFIELD HEALTH AND CARE PARTNERSHIP BOARD

11 DECEMBER 2023

Author(s)	Rachel Dillon, Strategic Programme Manager, Sheffield Place, SY ICB, and Kate Gleave, Deputy Director of Children and Young People and Urgent Care, Sheffield Place, SY ICB
Sponsor	Meredith Teasdale-Dixon, Director of Children’s Services, SCC Anthony Gore, Clinical Director SY ICB
Purpose of Paper	
<p>Improving all age neurodiversity waiting times is a key priority for Sheffield Health and Care Partnership for 2023/24. A programme brief was presented and approved at the HCP Board meeting in August 2023 describing the programme’s aims, milestones and risks. Paper-C-Neurodiversity-Waiting-Times-Programme-Brief.pdf (sheffieldhcp.org.uk)</p> <p>HCP has requested an update on for its December meeting on the progress of the programme, with a specific focus on the CYP actions being taken and the investment required.</p> <p>A slide deck accompanies this covering paper focuses on CYP. It covers the current position, impact of the actions we’ve put in place and progress to date, the key milestones which have been prioritised because of the urgent challenges, an indication of the resource allocations required, and the key risks and issues Sheffield currently faces.</p>	
Key Issues	
<ul style="list-style-type: none"> • Imperative that we provide more support for the CYP, their families and their professionals to meet need – before people consider a referral, whilst they wait for an assessment and following a diagnosis; • Complex commissioning and provider landscape with a multi-agency response required to address the issues; • Very significant waiting times for our patients that currently will continue to increase and will take multiple years to address; • The support we have already put in place is beginning to meet need but requires expansion and sustainable funding; • The team are considering creative solutions, some of which pose significant challenge to particular stakeholders; • Proposals to implement these solutions will be brought back to the next meeting. 	





Is your report for Approval/Consideration/Noting	
Sheffield Health and Care Partnership Board is for consideration.	
Recommendations/Action Required by the Sheffield Health and Care Partnership Board	
<ul style="list-style-type: none"> To note the impact and progress made; To consider the risks and issues regarding this challenge; To note the resources we need in this city to support and empower our families; To receive proposals to rationalise the bottlenecks and place the support offer on a sustainable basis at an early 2024 HCP meeting to align with planning round discussions. 	
What assurance does this report provide to the Sheffield Health and Care Partnership Board in relations to the ambitions of the Health and Wellbeing Strategy 2019-2024	
	Please ✓
Every child achieves a level of development in their early year for the best start in life	✓
Every child is included in their education and can access their local school	✓
Every child and young person has a successful transition to independence	✓
Everyone has access to a home that supports their health	
Everyone has a fulfilling occupation and the resources to support their needs	
Everyone can safely walk or cycle in their local area regardless of age or ability	
Everyone has equitable access to care and support shaped around them	✓
Everyone has the level of meaningful social contact that they want	✓
Everyone lives the end of their life with dignity in the place of their choice	
Are there any Resource Implications (including Financial, Staffing etc)?	
The resource implications are summarised in the slide deck and are included in more detail within Annex 1.	
Have you carried out an Equality Impact Assessment and is it attached?	
An EIA has not been completed for the whole programme at this stage, however, they are being completed now for new projects and will be completed as a priority by project teams as work progresses.	
Have you involved patients, carers and the public in the preparation of the report?	
CYP and adults, parents and carer engagement involvement has shaped the programmes' aims and objectives. The projects within the programme brief have/are/will include CYP and adults, parent and carer involvement.	





UPDATE ON NEURODIVERSITY WAITING TIMES PROGRAMME

SHEFFIELD HEALTH AND CARE PARTNERSHIP BOARD

11 DECEMBER 2023

1. Context

There are significant waiting times for CYP and their families to access care in our neurodiversity services. This is a situation, that every area of the country is facing and all parts of the Sheffield system are struggling to manage. It requires input and change from all partners within the system and given the scale of the issue, will take multiple years to ameliorate.

Demand for CYP Autism and ADHD assessments has increased from 1486 referrals in 19/20 to 4216 referrals in the year to June 23 (a 284% increase). Waiting times for assessment have significantly increased as a result and this is currently being compounded by the challenges associated with national ADHD medication supply issues. We know that this rise in demand is due to a number of reasons, both locally and nationally. These include:

- Awareness has increased (which is a positive movement) via the media.
- Whilst children and young people do not technically need a diagnosis for a school to put in place adjustments or additional support to meet their needs, a number of schools will not implement support without a diagnosis and are telling parents that they need to seek an assessment.
- There is also a perception that SCFT is the only place to access support, via a diagnosis.
- Financial support and access to respite is contingent on having a diagnosis.
- The restrictions of COVID for children and young people meant less social interaction, communication and stimulation which has impacted on optimal brain development.
- Now that waiting lists are so long, children and young people are being added to the waiting list as a first step.
- There have been associated increases post pandemic in all child developmental services i.e. Speech and Language Therapy, Community Paediatrics, Sleep and Parent and Infant Relationship Services (PAIRS).

At the end of October 2023, there were 936 CYP waiting for an ADHD assessment (longest wait 91 weeks) and 1695 CYP waiting for an Autism assessment (longest wait 94 weeks for pre-school, 106 weeks for school age). There are an additional 3600 children in the single point of access process (awaiting questionnaire returns) or grading. There are also circa 2,200 patients awaiting an ADHD follow up appointment.



It should be noted that within SCFT, ADHD is counted as a consultant-led service which means that it is subject to the national referral to treatment times requirements – the current target is to wait no more than 65 weeks by the end of March 24. Without any additional assessment capacity, there are expected to be almost 500 patients waiting over 65 weeks at the end of March.

All the above activity is commissioned and paid for by NHS England Specialist Commissioning via a combination of the fixed (block) element (for Outpatient follow-ups and non-Consultant led Firsts) and the national Elective Recovery Fund (ERF) calculations (for Consultant-led First Outpatients) which attracts additional funding for activity, but at a lower cost than a historically agreed local tariff. Discussions regarding transfer of the commissioning responsibility for the activity are ongoing but it is assumed ERF will continue beyond this year or there will be a similar system to incentivise reducing waiting lists.

2. Work undertaken since August 2023

There are bottlenecks or constraints in every part of the pathway because of the challenges that young people and their families encounter with all parts of the system. Work is required on all of these to improve the waiting times situation by both slowing referral demand and by increasing assessment capacity. Over the last few months members of the programme team have worked together to address these by:

- drafting and securing bids for funding from various sources (see Appendix 1);
- developing and trialling various additional support offers for parents and CYP;
- evaluating the Autism in Schools project;
- exploring other models of support and assessment within South Yorkshire and nationally;
- exploring options to secure additional external assessment capacity;
- improving the assessment pathway by reviewing processes and stratifying follow ups;
- commencing mapping of the pre-assessment support pathway and the actions necessary to enable SENCO referrals.

The work undertaken in partnership by the Children and Young People Neurodevelopment Transformation Task and Finish Group to understand what support families need, to increase the amount of support available to families and professionals and to improve the accessibility of this support, regardless of diagnosis, is now starting to realise the intended outcomes. However, the majority of this support has been funded from non-recurrent or short-term pots of money which will run out during 2024/25. These support offers would also benefit from greater co-ordination.

More recently, the Task and Finish Group have reflected on the worsening waiting times situation and the highest scoring risks and issues (see Appendix 3). As a result, the Group have chosen to prioritise what it considers to be the three most important actions from the plan given recent developments and the current context. These are:





- To update the current list of support available (pre and post diagnosis) and advertise this (by January 24);
- To design an expanded support offer and central hub (to provide support at all stages) (by April 24);
- To secure additional alternative assessment capacity (by April 24).

We know that families and professionals are still often unaware of the recently introduced and expanded range of support available to meet their needs. We also know that families and professionals would benefit from the development of these offers into a more co-ordinated approach with additional navigation support. Given the scale of the assessment challenge, the scale of the support available also needs to be increased and its long-term sustainability secured. It is anticipated that this will require significant investment and an indication of the scale of funding required is included within the slides. A request for this funding will be made to the HCP Board early in the New Year.

SCFT colleagues continue to undertake internal work to increase assessment capacity wherever possible, however given the scale of the challenge, additional external assessment capacity is also required.

3. Next steps

The longer-term milestones and benefits are outlined in the slides. In the shorter term, it is proposed that a paper is brought back to an early 2024 meeting of the HCP Board to outline the case for additional multi-million-pound investment and proposals to rationalise bottlenecks.

4. Recommendations

The HCP Board is asked to:

- To note the impact and progress made;
- To consider the risks and issues regarding this challenge;
- To note the resources we need in this city to support and empower our families;
- To receive proposals to rationalise the bottlenecks and place the support offer on a sustainable basis at an early 2024 HCP meeting to align with planning round discussions.



Appendix 1

Additional CYP Resources secured and required

	2023/24 £k		2024/25 £k - TBC		2025/26 £k - TBC		Funding sources
	Recurrent	Non-Recurrent	Recurrent	Non-Recurrent	Recurrent	Non-Recurrent	
Autism in Schools provision		111		111		TBC	National bid/Sheffield LDA SDF
Peer Support Service	70		70				Regional LDA funding
ADHD post diagnosis offer							SCC already in budget recurrent funding
ADHD pre diagnosis offer		77	77				Joint Commissioning pot
Comms campaign		30	TBC				Public Health Grant
VCS first contact point in Ryegate		50	50				Regional LDA funding
Central Support Hub (Northpoint model)			350	200			
HEE training		61					Health Education England
Total support offer funding	70	329	497	311	0	0	
Additional Autism and ADHD assessment capacity and clinical investment	800						NHS England funding sought. SCFT confirmed
Total assessment/clinical management funding	800						

Funding confirmed
Funding sought
No funding





**Additional Adult Resources listed in original HCP Paper
Current Position**

Proposal	Amount	Funding source	Progress
Band 8 adult nursing post identified through Strategic Development Funding (SDF)	£64k	SDF	In post
Autism Support Hub identified through SDF funding	£45k	SDF	£45k agreed per year for two years

In addition to the above funding in adults, there has been agreement in Sheffield place SYICB to reinvest resources from Firshill Rise inpatients into adult learning disability clinical community services. This service works with adults who are autistic but who also have a diagnosis of learning disability with an IQ of 69 and under.





Appendix 2

Progress on Key CYP Milestones

	High Level Milestones	Implementation	Progress to Date
	Additional £800k of staffing into Neurodisability services.	<ul style="list-style-type: none"> September 2023 	<ul style="list-style-type: none"> £500k now utilised on neurodisability nurses, psychology, community paediatricians. Hard to recruit nurses. Exploring Helios for extra capacity
	Gain a common understanding across South Yorkshire and nationally of current model evidence	<ul style="list-style-type: none"> November 2023 	<ul style="list-style-type: none"> New SY MHLDCYP ND steering group Key set of objectives agreed: <ul style="list-style-type: none"> Improved clinical / operational and workforce models. Develop sufficient skilled workforce capacity to meet demand. Improved pre- and post-assessment support. Improved access to benchmarking and quality assured data Understanding of other provider models such as stratifying waiting list and Referral support etc. (Harrogate and Calderdale)
	Deliver Communications Campaign to increase understanding and awareness	<ul style="list-style-type: none"> January 2023 July 2024 	<ul style="list-style-type: none"> Support offer being updated ready to be advertised by December 2023 Video with key message being scoped ready for dissemination early 2024. (All Age) Seeking funding to deliver wider communications campaign (All Age)
	Review options around the independent provision.	<ul style="list-style-type: none"> April 2024 	<ul style="list-style-type: none"> SCFT is in discussion with NHS England regarding seeking additional in NHS England now considering additional funding.
	Provide a new approach to meeting need time (pathway for pre-assessment support)	<ul style="list-style-type: none"> September 2024 April 2024 	<ul style="list-style-type: none"> Now brought forward because of unprecedented demand. Designed by April 2024 Secured non recurrent funding to continue and expand several support for another 12 months

Adult Specific Milestones and Main Risk

RAG	High Level Milestones	Implementation	Progress to Date		
	To improve crisis response to adults with autism through the development of a lead nurse for care to act as an interface with the adult autism services and the Home Treatment/Adult Teams	<ul style="list-style-type: none"> In post by October 2023 	<ul style="list-style-type: none"> Post in place Working alongside SPA/Crisis Resolution Home Treatment service 		
	Development of Adult Autism Support Hub.	<ul style="list-style-type: none"> November 2023 	<ul style="list-style-type: none"> Go live on 20th November 		
	VCS led Adult Autism diagnosis Waiting List project	<ul style="list-style-type: none"> December 2023 	<ul style="list-style-type: none"> Timeline has slipped due to a delay in releasing funding Partner organisations have met and begun scoping training needs and developing delivery plans 		
	Redesign of Adult Learning Disability/Autism community team through reinvestment of inpatient services.	<ul style="list-style-type: none"> November 23 	<ul style="list-style-type: none"> Redesign model approved to implement 3 year redesign and enhancement of community services for people with LD/A 		
Main Risk			Likelihood	Consequence	Score
Risks associated with increased referrals via Patient Choice and increased social media focus and the turnover of new students arriving in Sheffield each year at 2 universities. Currently 40% referrals through this route come from the 2 University practices		<ul style="list-style-type: none"> Work to start to review a adult ADHD tiered pathway across primary and secondary care. Communications Campaign to increase awareness and support available for people. SYICB focus on ADHD referral pathways/ waiting times & Sheffield place focus on contracts and flow into private providers through 		4	16





Appendix 3

Risks CYP

		Likelihood	Consequence	Score
1. There is a risk of insufficient capacity to undertake initial assessments due to unprecedented demand increases and prioritisation of ADHD follow ups (due to medication) resulting in significant numbers over 65 week waits for ADHD and 2 year waits autism assessments.	Modelling being undertaken with SCFT to understand impact of flexing between new and follow up (FU) capacity in ADHD. Any slippage in assessment investment to be focused on ADHD FU. Continue to developing a new model of care to meet demand outside of a clinical setting. Continue to pursue additional investment from NHS England and procure private capacity.	5	4	20
2. There is a risk that a new model of care for neurodiversity is not developed fast enough due to unprecedented levels of demand resulting in limited clinical and managerial capacity prior assessments and not having capacity to contribute to the development of a new model care.	Use clinical input into development of model development as efficiently and effectively as possible. Focus on pathway redesign and potential private capacity in Autism where pathway is not as complex as ADHD.	4	4	16
3. There is a risk that we can't secure recurrent investment due to financial restraints resulting in not being able to achieve additional capacity in new model of care	Develop robust and strong business cases to secure investment. Articulate the positive impacts our current projects are achieving and communicate these widely. Pursue current avenues for funding whether recurrent or non recurrent via ICB and NHS England.	4	4	16

Issues CYP

		Impact	Priority
1. The prioritisation of ADHD medication management due to medicine shortages has resulted in significant reduction in ADHD assessments	Working with ICB pharmacy colleagues.	High	High
2. There is an issue that Sheffield place is not able to invest in SCFT due to the CYP Autism and ADHD services being commissioned by NHS England resulting in limited opportunities for the ICB to contractually help	SCFT is in discussion with NHS England regarding seeking additional investment. SY ICB is in discussion with NHS England about the transfer of the contract to the ICB.	Medium	High
3. There is an issue reported in Sheffield Parent Carer Forum's 2023 survey report that parents reported their children and young people with SEND are affected by anxiety and/or depression.	Provide and communicate the support which is available to families including access to mental health support.	Medium	High

