

CHILDREN AND FAMILIES OVERVIEW AND SCRUTINY PANEL 11 JANUARY 2022

UPDATE ON THE ASSESSMENT PATHWAY FOR CHILDREN AND YOUNG PEOPLE WHO MAY HAVE AUTISM

Summary

1. The Panel is to be provided with an update on the Umbrella assessment and diagnostic pathway for children and young people who it is considered are, or may be, on the autistic spectrum.
2. Representatives from the Herefordshire and Worcestershire Clinical Commissioning Group (CCG), the Herefordshire and Worcestershire Health and Care NHS Trust (HWHCT) and Worcestershire Children First (WCF) have been invited to attend the meeting.
3. In addition, the Cabinet Members with Responsibility for Children and Families and for Education have also been invited.

Background

4. This Service has been part of ongoing Scrutiny since 2017 (agendas and minutes of previous meetings are detailed in the background papers below).
5. The Umbrella Pathway has been developed to provide an assessment process for all children and young people presenting with neuro-developmental difficulties which may be due to Autism Spectrum Disorder (ASD). This does not include Attention Deficit Hyperactivity Disorder (ADHD). The Umbrella Pathway was redesigned during 2016 with implementation of the changes in January 2017.
6. The pathway provides a multidisciplinary assessment which includes agreed referral criteria, triage and multi-professional planning. Following the agreed assessments, a diagnostic discussion takes place and a decision made regarding the child's strengths and difficulties and any associated diagnosis. A final report is completed and shared with the child young person and family at a level appropriate to the child, young person's age and cognitive ability. For children who are not given a diagnosis, a report is written to identify strengths and difficulties including recommendations for ongoing needs.
7. It has been the service's aspiration to have a maximum wait time of 6 months and a business case was approved and improvements are being implemented in order to achieve this. However, despite some improvements in waiting times there have been numerous challenges in achieving the 6 month maximum waiting time.
8. In March 2020, COVID-19 resulted in all Umbrella Pathway assessments being cancelled due to a Government directive to stop non-essential services. Some professionals were redeployed to front line acute care.

9. As a response to COVID-19, an increased support offer was developed for children and young people and their families by the Speech and Language Therapy (SLT) Team. This was accessible by those with an autism diagnosis, undergoing assessment or whose difficulties were in line with autism traits. Feedback from families has been positive. Families who were not previously known to SLT have also benefited. Online resources were also made available which have been accessed by high volume of people.

10. Following initial lockdown, clinicians who had not been redeployed (mostly Community Paediatricians) focused their clinical Umbrella Pathway working hours to non-patient facing activities to support the pathway. This included triage and planning and diagnostic discussion.

11. A further change was implemented September 2020 with the introduction of triage for all referrals received rather than discussion at a planning meeting with more than one clinician. This change has released clinical time back into other elements of the pathway and removed delays between referrals being received and reviewed by clinicians as there is no wait for a planning meeting. Referrals are triaged on a rota basis to ensure all clinicians have an oversight of referrals. There is an opportunity for the triaging clinician to discuss more complex referrals with other pathway clinicians at the end of each diagnostic discussion meeting.

12. Trials of virtual assessments were also initiated in order to minimise additional waiting times within the umbrella pathway. Limitations were experienced according to the age of the child with greater success in the teenagers. Development of new/adapted assessment tools were also implemented by SLT. These were introduced in September 2020 but are only suitable for specific young people.

13. Following a review in February 2021, a commissioner-led task and finish group was established to support the services contributing to the Umbrella Pathway to implement the actions directed by Integrated Commissioning Executive Officers Group (ICEOG).

14. The CCG provided funding of £104,374 to HWHCT and WCF for additional capacity to clear the backlog of cases awaiting diagnosis.

15. There has been a recent change to the clinical and service leadership within HWHCT, which has provided some internal challenge to the current delivery of the service. The Clinical Director is a Consultant Paediatrician who has extensive experience (12 years) in neurodevelopmental diagnosis.

16. The focus of the task and finish group was to ensure that all children referred prior to 1 April 2021 completed the pathway, and additional investment was made to provide the capacity required.

Current position

17. HWHCT confirmed that the baseline investment is sufficient to maintain a 6-month diagnostic pathway at the current rate of demand.

18. Two cohorts of children on the waiting list were identified. Cohort One were referred prior to 1 April 2020 (225 children were in the cohort in April 2021) and

Cohort Two prior to 1 April 2021 (304 children were in the cohort in June 2021) see Table 1 below.

19. The service provided the task and finish group with child-level information for both cohorts, detailing the assessments required, the diagnostic meeting and final feedback appointment with the family. This information was reviewed monthly by the group.

20. A change in clinical leadership within the Community Paediatric service facilitated a review of the current pathway with internal challenge on the purpose of the individual assessments required to support a clinical decision on the diagnosis for the child.

21. All cases were reviewed to confirm the actions required to complete the pathway. This reduced the number of assessments required for some children where sufficient information was available to support clinical decision-making.

22. The task and finish group focussed on improving the efficiencies of the service, leading to a proactive approach to managing appointments and receipt of clinical information from each assessment completed. Clear standards were set within the Standard Operating Procedures for the service including a consistent approach to the management of cancelled appointments.

23. The pathway commences with a comprehensive Neurodevelopmental assessment of the child, which may provide sufficient information for a diagnosis to be made. This assessment will also determine if further information is required, and any additional assessments necessary to support the clinical diagnosis.

24. A member of the Umbrella Multi-Disciplinary Team (MDT) is now the allocated case worker for each child. They are the point of contact for the family, collate the information from the individual assessments, present the case at the diagnostic meeting and feedback the outcome to the family. They are also responsible for providing the written report on strengths and areas of support for the child.

13. The Reduction in backlog of cases is given below:

Table 1

	Total in Cohort One	Total in Cohort Two
29-04-21	255	
13-05-21	244	
03-06-21	214	304
08-07-21	172	286
09-08-21	85	240
07-09-21	30	208
06-10-21	12	169
03-11-21	3	93
20-12-21	2	39

14. Of the two remaining cases in Cohort One, one family did not attend the initial appointment in September and further assessments are now required. The second child has been offered appointments which have been declined and has been

further impacted by staff having to isolate due to Covid. The second child is scheduled to complete the pathway in the first week of January 2022.

15. HWHCT have provided assurance that the service has the capacity to complete the remaining cases. Of the 39 remaining cases in cohort two, 18 will complete the pathway by the end of the first week in January. A further 12 are scheduled for diagnostic discussion by the end of the first week in January and we anticipate that feedback will be provided shortly afterwards and therefore the pathway completed by the end of January.

16. The remaining 9 all have dates scheduled for assessments and these are being prioritised by staff. There is capacity in January for diagnostic discussion and feedback for these remaining 8 cases as soon as their assessments are completed. This will be monitored by commissioners to ensure there are no barriers to the service being provided as agreed.

17. The redesign of the pathway has significantly reduced the need for the Complex Communication Needs Team (CCN) to provide assessments, releasing their capacity to provide support for children in their education setting. The demand for CCN assessments has reduced from 185 assessments requested in 2018 to 20 over the past 12-month period. The anticipated future demand is 24 per year.

18. A support facilitator with lived experience of a child with autism has been employed by HWHCT to co-ordinate access to support for parents following completion of the Umbrella Pathway. The role is part-time and will focus on signposting rather than direct delivery of support.

19. On completion of the pathway, families are also signposted to the Worcestershire Local Offer. A leaflet with details of the Local Offer is included with the report which is sent to families. Some children will remain under the care of a paediatrician, for example if on medication or have other clinical conditions requiring medical management.

20. Families of newly diagnosed children in future will be offered an opportunity to attend a virtual workshop about the health implications of having a diagnosis of Autism. This will then inform the ongoing support offer to be administered and facilitated by the support facilitator role, with support from appropriate clinicians.

Next Steps

21. Maintain the revised referral process with evidence of full graduated response is included in referrals with information from parents and schools is actioned and monitored.

22. Refresh of capacity and demand modelling to ensure the current and future changes in the process are reflected. Monitor milestones of recovery and monitor achievement, negotiating and implementing urgent actions in the event of any slippage – ongoing.

23. Identify children and young people who are less complex or demonstrate strong traits of autism at the outset in order to fast track them to prompt diagnostic discussion. (Example child recently referred to pathway and received diagnosis within 6 weeks of referral) - ongoing

24. Assurance on the continued improvement in access and time taken to conclude the assessment and diagnostic pathway is provided regularly at system level meetings including ICEOG, Special Education needs and disability (SEND) Improvement Board and internally within the Herefordshire and Worcestershire Health Care NHS Trust.

25. National Health Service England (NHSE) are requiring all Integrated Care Systems (ICSs) to deliver a 3-year plan for Learning Disabilities and Autism (LDA). Within this programme funding is available to commission post-diagnostic support for autistic people and a project is progressing to co-produce the specification and procure a service from 1 July 2022.

26. Additional funding has been secured to support 14-25 year olds who are newly diagnosed and at risk of experiencing a crisis and hospital admission. This is also part of the LDA Programme delivery.

27. Each Local Authority (LA) is leading the development of an Autism Strategy following publication of the National Strategy this summer. Worcestershire needs to focus on ensuring children and young people can receive the educational and other support they require at the point of need, rather than requiring a clinical diagnosis.

Purpose of the Meeting

28. The Children and Families Overview and Scrutiny Panel is asked to:

- Consider the information in this report and determine whether it would wish to carry out any further scrutiny; and
- Agree whether it would wish to make any comments to the Cabinet Member with Responsibility for Children and Families.

Contact Points

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Background Papers

In the opinion of the proper officer (in this case the Assistant Director for Legal and Governance), the following are the background papers relating to the subject matter of this report:

[Agenda and minutes of Council 9 November 2017](#)

[Agenda and minutes of Overview and Scrutiny Performance Board 24 May 2019](#)

[Agenda and minutes of Children and Families Overview and Scrutiny Panel 25 September 2019](#)

[Agenda and Minutes of the Children and Families Overview and Scrutiny Panel 13 November 2020](#)

[All agendas and minutes are available on the Council's website here](#)