

OVERVIEW AND SCRUTINY PERFORMANCE BOARD 28 FEBRUARY 2018

ASSESSMENT OF CHILDREN AND YOUNG PEOPLE WHO MAY HAVE AUTISM

Summary

1. The Overview and Scrutiny Performance Board (OSPB) is asked to consider the outcome of the Review of the assessment and diagnostic pathway for children and young people who it is considered are, or may be, on the autistic spectrum. This pathway is known in Worcestershire as the Umbrella Pathway.

Background

2. A Notice of Motion in respect of Diagnosis of Children with Autism was considered at Council on 9 November 2017. The outcome was that Council resolved as follows:

"That Council notes the length of time it can take in Worcestershire from point of referral to diagnosis for a child to be diagnosed with autism. Council notes the Umbrella Pathway is experiencing high demand. Council notes that a group of education and health commissioners and providers are currently looking at the reasons for the huge increase in referrals and how the pathway can be made as efficient and timely as possible for children. The Review is scheduled to conclude by the end of January 2018. Council therefore requests OSPB to consider looking at the outcome of the Review and liaising with the Children and Families Panel for any input they may wish to have and to make any recommendations accordingly".

3. Following the Review of the Umbrella Pathway, a report was made to the Integrated Commissioning Executive Officers Group (ICEOG), made up of Worcestershire County Council and the Worcestershire Clinical Commissioning Groups (ICEOG) in January 2018, as a result of which ICEOG agreed measures to manage the demand of the Umbrella Pathway.

Autism Spectrum Disorder

4. Autism spectrum disorder (ASD) is the name for a range of conditions that affect a person's social interaction, communication and imagination. Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autistic people see, hear and feel the world differently to other people. All autistic people share certain difficulties, but being autistic will affect them in different ways.

5. The National Institute for Health and Care Excellence (NICE) advises that although autism was once thought to be an uncommon developmental disorder, recent studies have reported prevalence rates of at least 1% in children and young people. The

National Autistic Society website advises that the latest prevalence studies of autism indicate that 1.1% of the population in the UK may be on the autism spectrum.

Assessment of Children in Worcestershire

6. The Umbrella Pathway is the Worcestershire pathway for assessment of children for ASD and is managed by Worcestershire Health and Care NHS Trust. It is a resource and time intensive pathway which may involve assessments by several professionals, often in more than one setting, for example clinic, school or home, in order to comply with the appropriate NICE guidance 'Autism spectrum disorder in under 19s: recognition, referral and diagnosis'. A link to the NICE guidance is included in the Background Papers section at the end of this report.

7. Access to the Umbrella Pathway is through referral by a defined list of health and education professionals; it is not a self-referral service. The information in the referral, together with further information gathered, usually from parents and school, will be used to decide at a multi-disciplinary planning group meeting whether or not to accept a referral for full assessment. If the referral is accepted for full assessment then the child is seen by two or more professionals for the Umbrella Pathway Team, dependant on the nature and complexity of their difficulties. The professionals involved could include:

- community paediatrician, speech and language therapist, clinical psychologist, occupational therapist; these services are commissioned by Clinical Commissioning Groups and provided by Worcestershire Health and Care NHS Trust (WHCT)
- specialist teacher for autism or educational psychologist; these services are commissioned by WCC or education settings and provided by Babcock Prime.

8. Following this, professionals meet to review information and make a decision about whether the criteria for a diagnosis of autism are met. Feedback is then given by a key professional from the Assessment Team (or occasionally another professional if the child is under their ongoing care) to parents/carers and a report provided, which will include recommendations, whether a diagnosis is given or not.

9. The Umbrella Pathway is a pathway of assessment and diagnosis and is not commissioned as a service in its own right. The contributing services commissioned by the Clinical Commissioning Groups from WHCT include the requirement to contribute to this Pathway. Specialist Teachers for Autism in the Babcock Prime team are also commissioned by WCC to contribute to the assessment process. In some cases, a school has already sought support from the Babcock Prime Autism/Complex Communication Needs team or Educational Psychology team prior to referral to the Umbrella Pathway; in these cases, the information and assessment from that intervention may contribute to the Umbrella assessment and thus shorten the length of time taken for the whole process.

Timescales for the assessment process

10. NICE guidance indicates that the autism diagnostic assessment should be started within 3 months of the referral to the Autism Team but does not include a recommendation of the maximum timescale for completion of the process. The

Umbrella Pathway currently complies with this standard In Worcestershire, it is made clear to referrers and to parents/carers that the whole process may take months to complete and that the actual timescale for each child may vary. The leaflet for parents/carers of children accepted on to the Pathway states that in most cases the full assessment process may take about twelve months and gives a contact point if they wish to speak to someone about their child's assessment. This and other leaflets about the Umbrella Pathway are available in the Background Papers section at the end of this report.

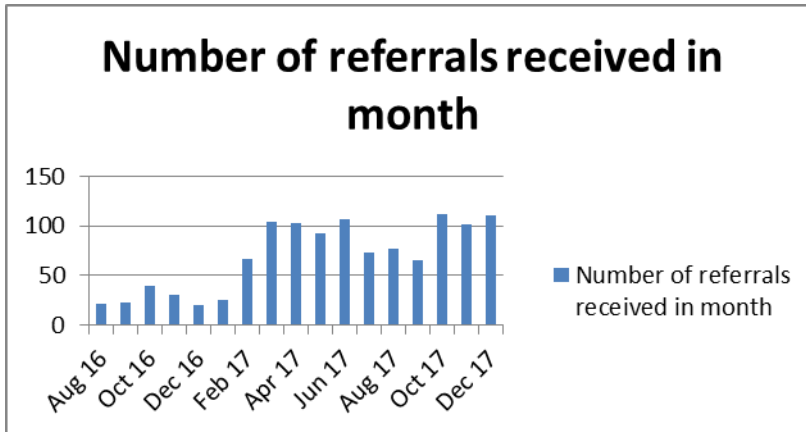
11. The time taken from point of referral to the point at which it is agreed if the criteria have been met for ASD diagnosis for each child and the report fed back to the parents can vary considerably. This is influenced by a number of factors including time needed for information gathering and return of questionnaires and the nature and location of assessments needed. Of those children discussed at Umbrella diagnostic meetings in November and December 2017, the range in time on the Pathway was from 79 days to 721 days and the average was 379 days. Of all cases discussed at diagnostic meetings in 2017, the average time on the Pathway was 327 days.

Increase in demand

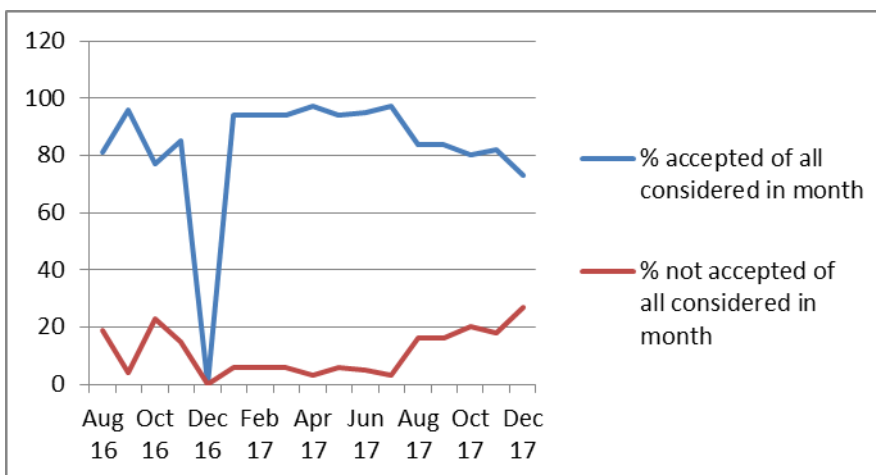
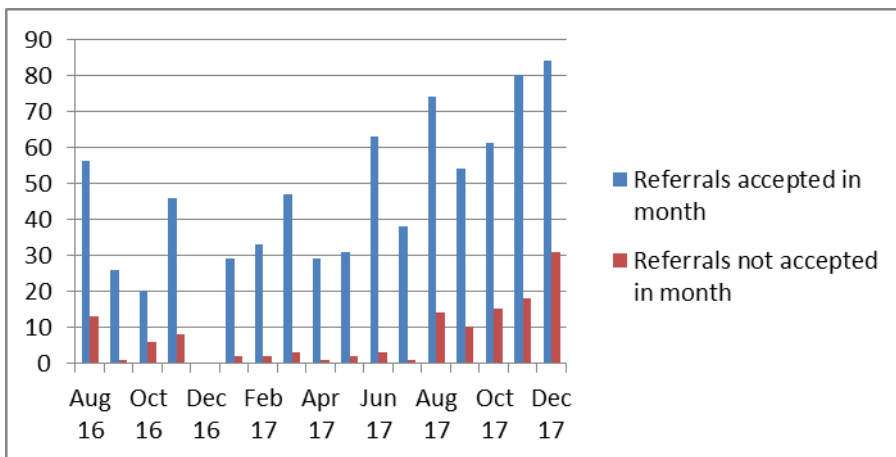
12. Nationally and locally there has been an increased awareness of ASD over recent years. This may be one of the contributory factors to the significant increase in the number of referrals to the Umbrella Pathway. As there is a fixed resource in terms of health professionals' time available to contribute to the assessment and diagnostic process, the time taken to complete the process is likely to increase with this increasing demand, as indicated by the figures given above.

13. Health and education commissioners have contributed additional resources to help cope with increased demand by funding additional staff time to contribute to assessments over the last 18 months, but this is not sustainable in the long term. A monitoring group comprising health and education commissioners along with providers meets quarterly and has considered reasons for the increase in demand and what measures can be taken to manage this. This has been supported by an additional task and finish group meeting including health professionals who are involved in delivering the Umbrella Pathway, in order to ensure appropriate clinical input to the Review.

14. Data on referrals to the ASD Assessment and Diagnosis Pathway was not consistently reported prior to August 2016, but there is some historical information to enable comparison. Figures from 2008 to 2010 suggest that at that time, around 190 to 225 referrals were received county wide per year. By contrast, in the year December 2016 to November 2017 there were 948 referrals. This is more than a four-fold increase and represents more than 1% of the Worcestershire school population of 78,318 (source: School Census, January 2017) being referred to the Pathway for an ASD assessment in one year alone. Bearing in mind the expected prevalence levels, this is higher than may be expected and it would seem very unlikely that all the children referred will have autism. The increase has been particularly marked in the current calendar year, as shown below.



15. Following additional information gathering and clinical consideration, not all referrals will be accepted for a full ASD assessment. The following graphs show the breakdown of those accepted and not accepted for full assessment by month (note – the number of referrals accepted or not accepted in month may not total the number of referrals received in month, as not all are considered at a multi-disciplinary planning meeting in the month they are received). The proportion of those not accepted has been increasing in recent months, which would suggest an increase in the number of inappropriate referrals:



16. Of those cases accepted for full assessment, not all will receive a diagnosis of ASD at the conclusion of the process. The most recent full year data available is for

assessments completed for cases referred in 2015, where 281 cases concluded with a diagnosis given and 162 without, a diagnosis rate of 63.4%, meaning that more than 1 in 3 children who completed the pathway did not receive a diagnosis at the end of it.

Reasons for increase in demand

17. The Review of the Umbrella Pathway process has considered a range of possible reasons for the increase in referrals to the Umbrella Pathway, including the following:

18. **Increased awareness** - There is increased awareness, both nationally and locally, of ASD. Whilst this is generally a positive and helpful thing, it also increases the likelihood that ASD will be suspected or assumed in isolation of consideration of other possible explanations for a child's symptoms or behaviour.

19. **Perceived as gateway to other support and services** – the Umbrella Pathway is an assessment and diagnosis pathway, however there is anecdotal evidence that some people may incorrectly believe it acts as an automatic 'gateway' to support and services. There is a risk therefore that some referrals to the Pathway are being made instead of and/or in advance of offering early intervention and graduated response approaches that could be supporting the management of symptoms and/or behaviours which may or may not in fact be attributable to ASD. Whilst it is important that assessment and diagnosis for ASD is offered where this is clearly indicated, it is equally important that other diagnoses and issues are explored where indicated and also that support be offered for presenting symptoms as early as possible. Help and support should not necessarily be contingent upon a child being diagnosed with ASD. The National Autistic Society website advises that "Getting benefits and support is supposed to be based on what a person appears to need, not what diagnosis they have. So you can apply for benefits and support for your child whether or not they have an autism diagnosis." The website notes that a child may be entitled to community care, extra help at school and benefits and that a parent/carer may also be able to claim Carer's Allowance. A link to the website is included in the Background Papers section at the end of this report.

20. **Perceived as gateway to support for educational settings** - Babcock Prime is commissioned by Worcestershire County Council (WCC) to deliver a number of educational support services to schools, some of which are free of charge to schools whilst others are offered as 'traded services' which schools can choose to purchase. Access to Babcock Prime's Autism/Complex Communication Needs (CCN) team is currently only provided free of charge to schools for children and young people with a diagnosis of Autism and a Worcestershire LA Statement of Special Educational Needs or an Education Health and Care Plan. If a school wishes to seek advice and support for a child who has symptoms or behaviours which may be suggestive of ASD (but for which there could also be other explanations) as part of their graduated response to the child's needs then the school would have to fund this. Some schools are doing this, either by purchasing a service from Babcock Prime or another provider or by employing their own specialist teacher; however, evidence suggests that some are not. Babcock Prime is commissioned separately to undertake assessments of some children in an educational setting as part of the Umbrella Pathway and data from April to August 2017 indicates that where such assessments were requested, only 14% of the children were already known to the Team. It may be reasonable to

expect this figure to be higher if schools were more regularly accessing the Autism/CCN team as part of a graduated response to need.

21. Evidence of quality and compliance issues with completion of referral form

- There is a detailed and robust referral form for the Umbrella Pathway, which seeks supporting evidence in relation to several areas of functioning and daily living where a child who may have ASD could be experiencing difficulties and symptoms. The Review noted that some referrals were being initially accepted and further information gathering completed, even if the form has not been fully completed. This would be identified and the referral potentially rejected when further information gathering has been undertaken and it has gone to a multi-disciplinary planning meeting; however, the emphasis needs to shift to the point of initial triage and to offer assurance that referrals are not considered if they do not meet an appropriate threshold.

22. Referral routes opened up - Access to the Umbrella Pathway has been opened up in the past year, with GP referral enabled and more cases passed from community paediatrics at triage without having been seen first by that service. With hindsight, this has added to the number of referrals where there is insufficient information to make a realistic judgement about whether a child is likely to have ASD and, for some children, taken out the opportunity to assess for and rule out other causes including medically related issues and to take a history which would give valuable insight in to this.

23. Lack of evidence of early intervention and graduated response to support signs and symptoms that could be suggestive of a range of needs and diagnoses, not just ASD – NICE guidelines and diagnostic criteria manuals such as the DSM-V and ICD-10 make it clear that at times children presenting with symptoms or behaviours which may resemble autism in whole or part may be more appropriately understood through a different diagnosis or indeed no diagnosis at all. Different difficulties and diagnoses which may account for some or all of the behaviours seen in children where autism is being considered include:

- attachment difficulties;
- response to trauma;
- inadequate parenting;
- speech and language difficulties;
- learning difficulties;
- mental health difficulties, particularly high anxiety leading to inflexibility and avoidance;
- sensory processing difficulties;
- sensory loss such as hearing or visual impairment;
- English as an additional language.

24. The Review considered that, in some cases, referrers may be too quick to refer for ASD assessment based on a specific or small range of needs or symptoms, rather than exploring other possible explanations and/or offering early intervention or graduated response support and/or employing a period of 'watchful waiting' first.

25. Summary of findings - The review group was mindful that, for those children, who have ASD, it is in their interests to allow them access to an assessment and diagnostic pathway which is as timely and efficient as possible. The review group concluded that this aim is currently being hampered by the number of inappropriate

referrals being received. This is evidenced by the increasing number of referrals which are not accepted for full assessment and by the proportion of children who do not receive a diagnosis at the end of full assessment. Whether children have ASD or not, it is in their best interests to receive the support and help they need as soon as possible.

Recommendations arising from the Review

26. The outcome of the Review included recommendations to ensure that appropriate referrals are made to and accepted for the Umbrella Pathway only when other possible causes have been addressed, appropriate support provided and there is a strong indication of possible ASD. This should in turn mean that the Pathway process will in the future be completed in a more timely way for those children who access it. These recommendations were accepted by the ICEOG on 15 January 2018 and referrers have been advised of their implementation. The impact of this on actual activity will be monitored monthly in order to take an informed view of whether or not the demand can be managed within existing resources/capacity.

27. In summary, the recommendations arising from the Review were as follows:

- All referrals to the Umbrella Pathway must include evidence that an early intervention and/or graduated approach response has been considered and implemented in relation to the presenting difficulties and needs of the child, rather than an assumption that ASD is the cause. These will vary according to need but may for example include: signposting and access taken up to courses and resources to support parenting; single agency/professional intervention offered and taken up where appropriate for specific need, eg speech and language therapy for communication need or occupational therapy for sensory difficulties; adjustments made or support provided in educational placement. (Note: the letter sent to referrers following the Review contains links to information and services that can be accessed in relation to this recommendation and is available in the Background Papers section at the end of this report).
- Referrals which do not demonstrate the above and/or do not include significant evidence indicating the likelihood of ASD will not be accepted for assessment on the pathway.
- Referrals to the Umbrella Pathway should only be accepted if made or supported by professionals who are involved in the assessment pathway.
- Data and Key Performance Indicator reporting on the Umbrella Pathway will be reviewed in order to ensure that the actual demand and time taken to complete the process can be appropriately monitored over time, as the current data reporting does not fully facilitate this. Additional information has been requested for future reporting.

Conclusion

28. Demand for the Umbrella Pathway is high. Arising from the recent Review, some reasons have been considered and are known for this, as described in this Report. Some actions have been taken to manage demand and ensure that only appropriate

referrals are considered for the full assessment Pathway. In particular, the importance of early intervention and a graduated response to the presenting symptoms and behaviours of children and young people is recognised. This is also acknowledged and supported by the recently published Worcestershire Special Educational Needs and Disability (SEND) Strategy.

29. Appropriate information will be reported to commissioners on a monthly basis and quarterly meetings of a monitoring group comprising the relevant commissioners and providers from health and education will continue to meet, in order to closely review the impact of the recent changes.

30. Feedback from children, parents and carers will continue to be monitored by use of methods including the NHS Friends and Family Test and review of complaints, compliments and feedback received. Healthwatch Worcestershire has previously supported commissioners in parent/carer engagement in relation to the Umbrella Pathway and will also be consulted on the outcome of this Review.

Purpose of the Meeting

31. The Board is asked to consider the outcome of the Review of the assessment and diagnostic pathway for children and young people who it is considered are, or may be, on the autistic spectrum and determine whether it would wish to carry out any further Scrutiny or make any comments to the Cabinet Member with Responsibility for Children and Families.

Contact Points

County Council Contact Points

County Council: 01905 763763

Worcestershire Hub: 01905 765765

Specific Contact Points for this report

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Background Papers

In the opinion of the proper officer (in this case the Head of Legal and Democratic Services) the following are the background papers relating to the subject matter of this report:

NICE Guidance Autism spectrum disorder in under 19s: recognition, referral and diagnosis

<https://www.nice.org.uk/guidance/cg128/chapter/Recommendations>

The National Autistic Society webpage on Diagnosis for Children:

<http://www.autism.org.uk/about/diagnosis/children.aspx>

Worcestershire Health and Care NHS Trust webpage on the Umbrella Pathway (includes links to information and leaflets for families and professionals)

<http://www.hacw.nhs.uk/our-services/childrens-community-health-services/umbrella-pathway/>

Leaflets and Information available from the Umbrella Pathway webpage



Umbrella Pathway - Young people leaflet.pdf



Umbrella Pathway - Autism Assessment Leaflet.pdf



Umbrella Pathway - After Diagnosis leaflet.pdf



Umbrella Pathway webpage Worcestershire Information & Support Groups handout.pdf

Letter to General Practitioners, February 2018 (includes guidance on early intervention and graduated response that may be offered)



2018-02-16 Ltr to
GPs re Umbrella Path