

Worcestershire County Council

**Additional papers: Update on the Assessment Pathway
for Children and Young People who may have Autism
(Item 6)**

Agenda

Overview and Scrutiny Performance Board

**Friday, 24 May 2019, 10.00 am
County Hall, Worcester**

All County Councillors are invited to attend and participate

This document can be provided in alternative formats such as Large Print, an audio recording or Braille; it can also be emailed as a Microsoft Word attachment. Please contact Democratic Services on telephone number 01905 844963 or by emailing democraticservices@worcestershire.gov.uk

DISCLOSING INTERESTS

There are now 2 types of interests:
'Disclosable pecuniary interests' and **'other disclosable interests'**

WHAT IS A 'DISCLOSABLE PECUNIARY INTEREST' (DPI)?

- Any **employment**, office, trade or vocation carried on for profit or gain
- **Sponsorship** by a 3rd party of your member or election expenses
- Any **contract** for goods, services or works between the Council and you, a firm where you are a partner/director, or company in which you hold shares
- Interests in **land** in Worcestershire (including licence to occupy for a month or longer)
- **Shares** etc (with either a total nominal value above £25,000 or 1% of the total issued share capital) in companies with a place of business or land in Worcestershire.

NB Your DPIs include the interests of your spouse/partner as well as you

WHAT MUST I DO WITH A DPI?

- **Register** it within 28 days and
- **Declare** it where you have a DPI in a matter at a particular meeting
 - you must **not participate** and you **must withdraw**.

NB It is a criminal offence to participate in matters in which you have a DPI

WHAT ABOUT 'OTHER DISCLOSABLE INTERESTS'?

- No need to register them but
- You must **declare** them at a particular meeting where:
You/your family/person or body with whom you are associated have a **pecuniary interest** in or **close connection** with the matter under discussion.

WHAT ABOUT MEMBERSHIP OF ANOTHER AUTHORITY OR PUBLIC BODY?

You will not normally even need to declare this as an interest. The only exception is where the conflict of interest is so significant it is seen as likely to prejudice your judgement of the public interest.

DO I HAVE TO WITHDRAW IF I HAVE A DISCLOSABLE INTEREST WHICH ISN'T A DPI?

Not normally. You must withdraw only if it:

- affects your **pecuniary interests** **OR** relates to a **planning or regulatory** matter
- **AND** it is seen as likely to **prejudice your judgement** of the public interest.

DON'T FORGET

- If you have a disclosable interest at a meeting you must **disclose both its existence and nature** – 'as noted/recorded' is insufficient
- **Declarations must relate to specific business** on the agenda
 - General scattergun declarations are not needed and achieve little
- Breaches of most of the **DPI provisions** are now **criminal offences** which may be referred to the police which can on conviction by a court lead to fines up to £5,000 and disqualification up to 5 years
- Formal **dispensation** in respect of interests can be sought in appropriate cases.

Overview and Scrutiny Performance Board

Friday, 24 May 2019, 10.00 am, County Hall, Worcester

Membership

Councillors:

Mr C J Bloore (Chairman), Mrs E A Eyre (Vice Chairman), Mr A A J Adams, Mrs J A Brunner, Mr A D Kent, Mrs F M Oborski, Mr P A Tuthill and Ms R Vale

Co-opted Church Representatives (for education matters)

Bryan Allbut (Church of England)

Parent Governor Representatives (for education matters)

Vacancy (Secondary)

Agenda

Item No	Subject	Page No
6	Update on the Assessment Pathway for Children and Young People who may have Autism	1 - 10

Agenda produced and published by the Head of Legal and Democratic Services, County Hall, Spetchley Road, Worcester WR5 2NP. To obtain further information or hard copies of this agenda, please contact Alyson Grice (01905 844962)/Samantha Morris 01905 844963 email: scrutiny@worcestershire.gov.uk

All the above reports and supporting information can be accessed via the Council's website [here](#)

This page is intentionally left blank

OVERVIEW AND SCRUTINY PERFORMANCE BOARD 24 MAY 2019

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

Summary

1. The Overview and Scrutiny Performance Board (OSPB) is asked to note this update on 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 by commissioners to the Integrated Commissioning Executive Officers Group, 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. Following this, a report was presented to OSPB in February 2018.

4. Since this time, the actions have been implemented and impact monitored and there has been further engagement with parent carers. There have also been significant local and national events since the February 2018 OSPB meeting, including the following.

5. In March 2018, Worcestershire was subject to a local area inspection of services for children and young people with Special Educational Needs and Disabilities (SEND) by Ofsted and the Care Quality Commission, which resulted in the requirement for a Written Statement of Action by WCC and Worcestershire CCGs, to address significant areas of concern.

6. The NHS Long Term Plan was published in January 2019, which includes a commitment to increased investment in children and young people's mental health services and identifies priorities in relation to autism including a commitment to work towards achieving timely diagnostic assessments.

Autism Spectrum Disorder

7. 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.

8. 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.

9. Worcestershire's Joint Strategic Needs Assessment (JSNA) Profile on children with SEND in Worcestershire was published in December 2018 and estimates that, based on national prevalence estimates, there are 1235 children with autism in Worcestershire in total, of whom 1111 are school aged. The total number of children in Worcestershire with any neurodevelopmental disorder, including for example Attention Deficit Hyperactivity Disorder, Cerebral Palsy and Epilepsy as well as autism, is estimated to be between 3705 and 4940.

National and local frameworks for assessment of Children for Autism

10. The National Institute for Health and Care Excellence (NICE) has published guidance on "Autism Spectrum Disorder in under 19s: recognition, referral and diagnosis." The Umbrella Pathway is the Worcestershire pathway in line with this guidance, for assessment of children for ASD and is managed by Worcestershire Health and Care NHS Trust. It may involve assessments by several professionals, often in more than one setting, for example clinic, school or home.

11. Access to the Umbrella Pathway is through referral by a defined list of health and education professionals. If the referral is accepted for full assessment then the child is seen by two or more professionals, dependant on the nature and complexity of their difficulties. The professionals involved could include: community paediatrician, speech and language therapist, clinical psychologist, occupational therapist, specialist teacher for autism or educational psychologist.

12. Following assessment, professionals meet to review information and make a decision about whether the criteria for a diagnosis of autism are met. Feedback is given to parents/carers and a report provided, which will include recommendations, whether a diagnosis is given or not.

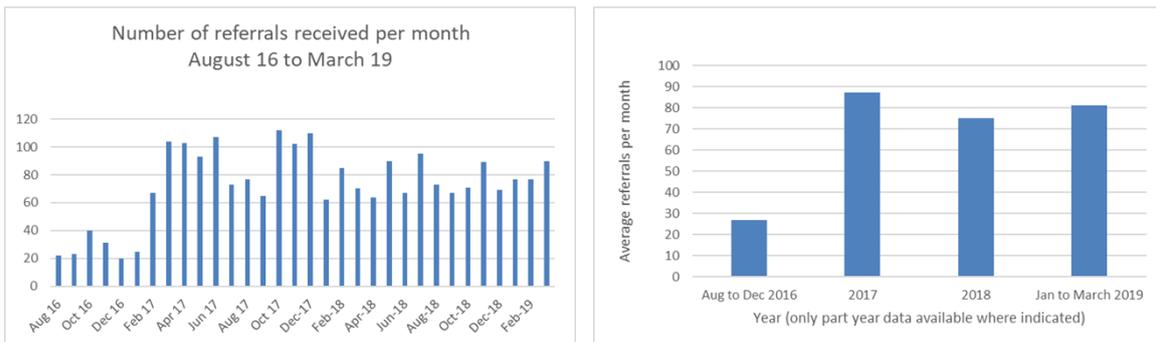
13. The Umbrella Pathway is a pathway of assessment and diagnosis and is not commissioned as a service in its own right. Where it is considered that a child may have autism, appropriate support should be available before, throughout and after any assessment process, regardless of whether the assessment process results in a diagnosis of autism or not. The support should be relevant to the presenting needs

and symptoms of each child and may be provided by a range of education, health, care and third sector providers

Information about demand for assessment in Worcestershire

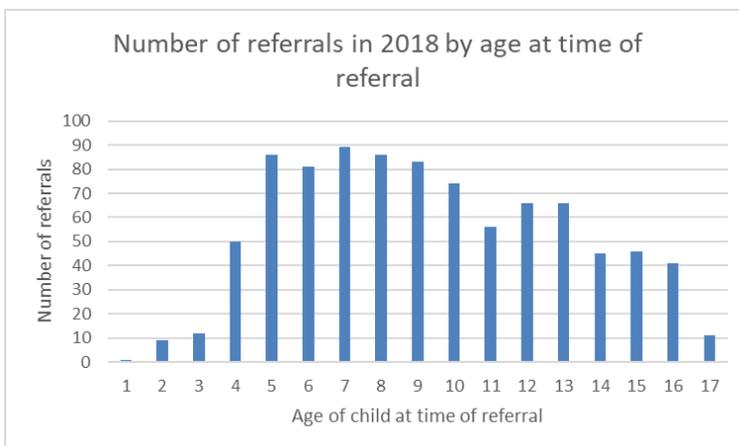
14. The report to OSPB in February 2018 advised of a significant increase in referrals to the Umbrella Pathway over recent years, which had led to a review and recommendations made.

15. Data on referrals to the ASD Assessment 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 2017 there were 1038 referrals. This is more than a four-fold increase. Bearing in mind that the Worcestershire JSNA suggests expected prevalence of 1235 children with autism in total in Worcestershire, which would suggest around 69 newly diagnosed children per year, this is higher than may be expected and it may be suggested that it is unlikely that all the children referred will have autism. Referrals per month since August 2016 and average referrals per month in each year are shown below and a particularly marked increase is notable since 2017:



16. Since the review and recommendations implemented in 2018, there has been a small fall in the number of referrals received, with 902 referrals received in 2018 (a 13% reduction from the previous year).

17. The number of referrals received by age at time of referral is shown below and indicates that requests peak for children in the age group 5 to 9 years:



Timescales for the assessment process

18. 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. 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. Partners should be providing appropriate support to meet the child's needs throughout this time and not deferring any support pending the outcome, as the Umbrella process is one of diagnostic assessment, not intervention.

19. The time taken to complete the Pathway can vary considerably, being influenced by a number of factors including time needed for information gathering and the nature and location of assessments needed. Of all cases which completed the process in 2017, the average time on the Pathway was 327 days and of all cases which completed the process in 2018, the average time on the Pathway was 372 days.

20. The increase in time taken for cases completing the Pathway in 2018 reflects the increased number of referrals in preceding months, as many cases being discussed in 2018 would have been referred in 2017. It is anticipated that with measures implemented to ensure appropriateness of referrals received and accepted, alongside additional investment by the CCGs, the length of time taken to complete the Pathway will reduce in due course.

21. Intelligence from regional networks and forums suggests that many other areas are also experiencing high demand and long waiting times for completion of autism assessment, but there is no national monitoring of this in order to provide comparable data. However, this is acknowledged as a national issue in the new NHS Long Term Plan (published January 2019) which gives a commitment to improving time taken for diagnostic assessment and support for children and families, stating the following:

22. "Children and young people with suspected autism wait too long before being provided with a diagnostic assessment. Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to **reduce waiting times for specialist services**. This will be a step towards achieving timely diagnostic assessments in line with best practice guidelines. Together with local authority children's social care and education services as well as expert charities, we will jointly develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process." (paragraph 3.33, The NHS Long Term Plan)

23. The NHS Long Term Plan references the research article "Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom" by Crane, Chester, Goddard, Henry and Hill, first published in March 2015.

24. This article reported that a sample of 1047 parents completed an online survey about their experiences and opinions regarding the process of attaining a diagnosis of autism spectrum disorder for their children. The results revealed that parents usually waited a year from when they first had concerns about their child's development

before they sought professional help. On average, there was a delay of around 3.5 years from the point at which parents first approached a health professional with their concerns to the confirmation of an autism spectrum disorder diagnosis.

Outcomes of referral and assessment

25. Following additional information gathering and clinical discussion at a Planning Meeting, not all referrals will be accepted for a full ASD assessment. Of the 902 referrals received in 2018, 706 (78%) to date have been accepted for assessment, 161 (18%) discussed at a Planning Meeting and not accepted as appropriate for assessment and 35 (4%) not yet considered at a Planning Meeting.

26. Not all children who are assessed will receive a diagnosis of ASD. Over the past few years in which data has been routinely provided, the diagnosis rate of those assessed has been between 65 and 70%.

Summary of the 2017/18 Review of the Umbrella Pathway and recommendations arising from it

27. The Review of the Umbrella Pathway process which was previously reported to OSPB noted a range of possible reasons for the increase in referrals to the Umbrella Pathway, including an increase in awareness and an incorrect perception that the Pathway was a gateway to other support and services.

28. The Review considered that, in some cases, referrers may be referring 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. This is not consistent with advice in the NICE guidance "Autism Spectrum Disorder in under 19s: recognition, referral and diagnosis" to "consider the possibility of autism if there are concerns about development or behaviour but be aware that there may be other explanations for individual signs and symptoms".

29. The Review also found that some referrals to the Umbrella Pathway contained insufficient evidence that there are difficulties or behaviours across a range of areas that would indicate possible autism. This is also not consistent with advice in the NICE guidance, which is for a professional to consider referral to another service if they have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism. The NICE guidance also advocates a period of 'watchful waiting' before referral for autism assessment in some circumstances.

30. The Review noted that 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.

31. 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.

- 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.

32. A new data reporting dashboard has also been developed by Worcestershire Health and Care NHS Trust, to enable better monitoring of the number and appropriateness of referrals and track progress and timeliness of the process for those children accepted for assessment.

Further Improvement Actions and Developments in 2018-2019

33. As noted above, significant events since the previous report to OSPB have included the Local Area SEND Inspection in March 2018 and the publication of the NHS Long Term Plan in January 2019.

34. In response to the areas of weakness identified by OFSTED and the Care Quality Commission following the SEND inspection, Worcestershire County Council and the CCGs were required to submit a Written Statement of Action (WSOA). Implementation of the WSoA and the broader strategy for children with SEND in Worcestershire is overseen by a SEND Improvement Board which includes a wide range of agencies, services and stakeholders including the Worcestershire parent carer forum, Families in Partnership. The WSoA includes several areas of improvement work which will have a positive impact for children who are diagnosed with or it is considered may have autism and their families. Furthermore there has been some specific engagement with parent carers of children with autism which has identified some key concerns that we are starting to address. Some specific initiatives and developments are summarised below.

35. **Improved SEND Local Offer.** The Local Offer identifies services, support, resources, activities and events available to families and carers of those with SEND. The content of the Local Offer has been reviewed, amended and improved, in co-production with parent carers and other stakeholders. Promotion materials for the new improved Local Offer have been widely distributed and a series of Local Offer roadshows for parent carers were held in November 2018. There has been a significant increase in the number of users visiting the Local Offer webpages. There were 234 returning visitors and 163 new visitors to the site during August 2018, rising to 500 returning visitors and 361 new visitors during January 2019.

36. **Embedding the Graduated Response.** This is a key theme of the WSoA, responding to the need to strengthen mainstream education provision and work with

schools and other settings to build their skills, experience and inclusive capacity in meeting the needs of children with SEND, including those who have been diagnosed with or may have autism. A new Graduated Response document has been produced and consulted upon. This is intended to be used as a tool for schools and settings and health and other partner agencies working with them and to be a resource for parents, carers and young people to inform and guide in relation to the education of children and young people with SEND. The document contains specific guidance for schools and settings about autism.

37. **School level inclusion profiles.** These have been developed since the SEND inspection. They provide information at individual school level about their school population as a whole and specifically relating to those receiving SEN support or with an Education, Health and Care Plan, including the educational attainment and moves of students. They also summarise the value of the school's notional SEN budget, pupil premium grant and any SEN top up funding that they receive.

38. **Assessment and Planning.** This is a key workstream of the WSoA which focuses largely on addressing criticisms of the Education, Health and Care Plan (EHCP) process including lack of parental confidence in this system. Some parents and schools have previously believed that if autism is suspected then it is essential to secure a diagnosis through the Umbrella Pathway before an EHCP can be requested or agreed. This is not the case but may have been a driver in the increase in referrals to Umbrella Pathway, so this workstream has given an opportunity to clarify pathways for EHCPs.

39. **Updates to Special Educational Needs Co-ordinators (SENCOs).** There have been a number of meetings and initiatives to support and inform SENCOs since the publication of the WSoA, including a presentation about the Umbrella Pathway changes by the lead commissioner for children's services and children's service manager of Worcestershire Health and Care Trust at a SENCO Inclusion Network meeting in November 2018.

40. **Further communication with primary care, schools and stakeholders.** A letter was shared with the February 2018 OSPB meeting that had been circulated to GP practices about the revised referral process for the Umbrella Pathway. Following feedback from GPs, a further letter was sent in March 2018 and both letters were also shared with Schools as part of a regular update by the Assistant Director of Education and Skills. The information has also been shared with key partners, including Worcester University colleagues with responsibility for training a range of professionals about inclusion and education, through the local SEND Training and Development Network.

41. **Additional health funding for the Umbrella Pathway and mental health and emotional wellbeing services.** Waiting times for child and adolescent mental health services (CAMHS) have improved over the last year. The CCG has successfully bid for non-recurrent funding from NHSE to increase capacity and further reduce waiting times for CAMHS, reduce waiting times for the Reach 4 Wellbeing service and the Umbrella Pathway and pilot training for parents on autism and anxiety. The training for parents began in May 2019 and we have received some very positive feedback from parents about the training helping them to have a greater understanding of their child's needs and strategies to support them. In line with the NHS Long Term Plan, the CCG is also investing additional recurrent resources in mental health, emotional

wellbeing and autism assessment services in order to ensure that the improvements achieved with the non-recurrent funding can be maintained. Worcestershire Health and Care Trust is being asked to include a plan to ensure that staff are appropriately trained and skilled to meet the needs of children and young people with autism, as part of its business case for this funding, in response to feedback from parent carers and other stakeholders that children with autism have previously been excluded from access to the Reach 4 Wellbeing service in particular.

42. *Early help and intervention including support for parents.* There is a recognition in the SEND improvement work of the importance of early help, support and intervention for children and families with emerging special educational needs. It is acknowledged that for some, this will prevent needs escalating to a level where specialist support is needed. The parenting providers in Worcestershire now offer some courses specifically designed to support and equip parents of children with autism. Parents can self refer on to these courses. The current training sessions being offered for parents about autism and anxiety are being led by Autism West Midlands and will be evaluated with a view to identifying funding to maintain them if evaluation is positive. This would help to address a concern about lack of post-diagnostic support which has been raised by parent carers and others.

43. *Audit of recent referrals to the Umbrella Pathway.* A recent audit by the Principal Educational Psychologist of a sample of referrals to the Umbrella Pathway from schools indicated that most included evidence of external professional involvement but none showed evidence that a robust graduated response had been put in place for the child which involved school following an assess-plan-do-review cycle over time. As a result, the referral paperwork is being reviewed to clarify the appropriate evidence and information required to support a referral. This will also help to reinforce and embed the importance of and responsibility upon all schools in terms of implementing a graduated response to emerging special educational needs so that children and young people receive help and support as soon as possible, which should not be contingent upon them first receiving a diagnosis. In addition, the questionnaires to parents and schools which help support the decision making about whether an autism assessment is appropriate will be requested at an earlier stage in the process in the future.

Conclusion

44. The Board is asked to note the further work undertaken and planned in relation to autism assessment of children and young people 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

Alyson Grice/Samantha Morris, Overview and Scrutiny Officers Tel: 01905 844962/844963

Email: scrutiny@worcestershire.gov.uk

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/>

Local area SEND Written Statement of Action:

http://www.worcestershire.gov.uk/info/20546/local_offer_news_and_updates/1614/send_inspection_and_peer_review/1

NHS Long Term Plan:

<https://www.longtermplan.nhs.uk/>

Worcestershire JSNA Profile on Special Educational Needs and Disabilities can be found here:

http://www.worcestershire.gov.uk/info/20122/joint_strategic_needs_assessment/1473/jsna_publications_by_category/2

Agenda and minutes for 28 February 2018 meeting of Overview and Scrutiny Performance Board can be found [here](#)

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

This page is intentionally left blank