

Umbrella (Neurodevelopmental) Pathway - Parent Feedback

October 2016

Healthwatch Worcestershire finds out what people think about health and social care services and uses the feedback to make recommendations to services about how they could improve.

Through our engagement over the past year and through our 2015 CAMHS Survey, we received feedback from parents relating to Autism and related neurodevelopmental conditions, including:

- Delays in gaining a diagnosis
- Concerns about availability of appropriate support
- Lack of information available to parents during and after diagnosis

Following on from this we are continuing to gather further information from parents about the process of gaining a diagnosis as part of our current survey and engagement on health and emotional wellbeing information, advice and support.

The Umbrella Pathway in Worcestershire

The Umbrella Pathway (Neuro-Developmental Assessment) has been developed to provide an assessment, management and care process for all children and young people presenting with neuro-developmental disorders which may be due to Attention Deficit Hyperactivity Disorder, Autism Spectrum conditions and other difficulties such as developmental co-ordination difficulties, sensory processing and 'tic' disorders.

-Worcestershire Health and Care Trust website

As part of the process of redesigning the Neurodevelopmental Pathway, we were asked by commissioners to support them in organising a parent feedback session. The following information has been put together to help feed into this process.

The following feedback has been gathered from 40 parents, in a variety of ways:

- Responses to date of our current ongoing Parent Survey - 22 parents have completed the questions relating to diagnosis process (combination of on-line and paper copies)
- Feedback from 15 parents as part of group discussions at Autism West Midlands' Special Interest Club in Kidderminster and Additional Needs Parent Support Group at Blossom Vale Children's Centre in Pershore
- Feedback given by 3 further parents individually to HW

❖ Referral into the Pathway

Barriers

Being believed and not blamed - The most commonly reported barrier from conversations with parents was that they felt their concerns about their child had not been fully understood or believed when they first recognised them and sought help. A vast majority said that they felt that professionals involved had made them feel, either directly or indirectly that they were worrying unnecessarily or that the difficulties experienced were as a result of their parenting.

'The default position seems to be that the parents are to blame'

'Wasted years at Primary School' whilst trying to gain understanding and identify the issue.

Child was 'within the normal range'

'Learnt behaviour'

'Terrible twos'

'They'll grow out of it'

Professional knowledge and understanding - Many parents said that they did not feel that the professionals who they initially sought help and advice from, in particular GPs, Health Visitors and Teachers, had a good enough understanding of Autism and other conditions to be able to identify if this was the issue or to refer their child on to someone who would.

Understanding of the referral pathway - Parents did not feel clear information had been given about how to seek advice and support for concerns about a child once they are in school. As part of HWW wider Parent Survey, responses to date show that only 9 of 41 parents felt they had been given enough information about School Nurses and how to access the service. Some parents also reported that professionals, in one case a GP, had been unsure about the appropriate referral route. Some parents who had gained a referral via a School Nurse to a Paediatrician reported that due to their limited capacity this had taken place without a face to face meeting and had required some chasing.

Delays and miscommunication about referrals - Some parents told us that there were delays getting initial appointments with professional about concerns, because of miscommunications about whether or not a referral had been made or received. Others reported long waiting times for appointments due to capacity of services. We were also told about delays and confusion about referral on to the Umbrella

Pathway itself, once it had been identified this was appropriate. With a couple of parents saying that their child was not put onto the Umbrella Pathway, despite them feeling they should. Many said they had to chase appointments and push to get appointments they needed.

Parents' understanding and experience - A couple of parents said that it was difficult to know if there was an issue for concern, due to 'being a first time mum' and that issues became more apparent when able to make a comparison with a younger sibling.

What went well?

- Professionals recognising traits and concerns at an early age, resulting in referrals at an early stage.
- Parents carrying out research and / or having prior knowledge of Autism / other conditions, so they recognised the need for diagnosis and appropriate support

What would make a difference?

Professional knowledge and understanding

- All professionals working with children from Early Years and through school having an understanding of neuro developmental conditions
- An approach from professionals that ensures parents feel listened to and supported and not judged. "*We need someone on our side*"
- Professionals having an understanding of appropriate referral pathways to gain diagnosis and support

Information for parents

- Parents have clear information about who they should speak to about concerns about their child and how the referral and diagnosis process works
- A way of tracking referrals and progress on line that have been made

❖ Experiences within the Pathway

Barriers

Delays causing a long wait for diagnosis - Although some parents said that once on the Pathway the process was relatively quick, many said that they had a long wait for the eventual diagnosis. Some said that this was due to waiting for a specific report from one professional.

'It took a long time to get reports together...weeks go by before we hear anything'

'It took over 18 months despite school and health officials being in absolute agreement that X needed a statement and extra help'

'My child has not yet received a diagnosis and it is nearly a year since the first referral'

Lack of information and updates - Many parents said that despite some initial information about the process, they were still not clear about how long this should take and that updates and progress during the process were only as a result of them chasing it.

What would make a difference?

Information and communication with parents

- More detailed information about the pathway and what to expect
- A way of tracking progress e.g. on line
- Being given a point of contact / details of different professionals involved and their role
- Alternative ways of contacting professionals involved other than phoning in office hours e.g. email contact

❖ Experiences after Diagnosis

Barriers

Lack of information - Parents felt that they had been given very little information at the point of diagnosis:

'An irrelevant photocopied pack'

'Once diagnosed no support or information given. I had to find my own support groups'

'Very poor, I had to rely on library and internet'

Parents felt they needed further input and advice about how to support their child, rather than the diagnosis being the goal. Many told us that the groups and support they had become involved in and the information they had gained about their child's condition had been through their own research. Some parents expressed concern that not all parents are in a position to seek and identify information and available support.

Lack of ongoing support - A number of parents said they felt that the diagnosis was seen as the end of the process and that there was no ongoing support available. Some also felt that further consideration needed to be given to the reports produced, in terms of the wording and recommendations, to make it a more sensitive and useful resource for parents.

Lack of availability and potential cuts to services and support - e.g. Autism West Midlands clubs for children and parent support groups run by Children's Centres. Parents who we spoke to at both of these groups were concerned about whether or not they would continue, due to current financial constraints. Concerns were raised by members of the parent support group at Blossom Vale Children's Centre about the suggestion that the group would need to be run by parents themselves to be able to continue. They felt that this is less likely to happen than when a group has a shared locality and pre-existing relationships - such as a local toddler group.

What has helped?

- Attending parent support groups - meeting others with shared experiences and who can provide useful advice
- Clubs and workshops for children to develop their understanding of Autism

What would make a difference?

Information for parents -

- About the diagnosis and tips about how to support the child for both parents and for teachers / others e.g. out of school clubs etc.
- That provides a standardised overview, but can be individualised to reflect the individual child
- About support groups
- About potential funding and additional support available
- About what support should be provided in schools

Support for parents -

- Hands on support available for parents about how to manage child's behaviour and how to support them. Where appropriate having support available in the home.
- Access via phone, email or on line to a professional for advice as issues occur and to help problem solve before issues escalate.