

Draft Umbrella Pathway Leaflet and Information

Parent and Carer Feedback

13th April 2017

Following our engagement and parent surveys, in October 2016 Healthwatch Worcestershire provided feedback from parents and carers about their experiences of the Umbrella Pathway and helped to organise a session that parents attended to give further feedback.

One of the issues raised was the need to improve information given to parents about the process and an action agreed following the meeting was for feedback to be sought from parents to revised information. Healthwatch Worcestershire agreed to support this and explained the variety of ways this could be done based on the time scales available to us.

Gathering parents' feedback

Given the limited time available and that this coincided with the build up to and start of the Easter school holidays, the drafts were sent out to parents who attended the original parent session and to parent support groups for comment. We feel that having been given longer to gain feedback about the drafts would have enabled more parents to be consulted and enabled more to respond. We could also have gained further feedback through face to face engagement. Having waited for several months for the drafts, there was concern from a number of parents about being asked for feedback at the final stages of development with a limited time scale.

Parent comment: "...this is tokenistic, tick box exercise and parent-carer feedback is not really wanted or valued... It suggests that you have no idea what parents (and particularly parent carers) do; our time is precious and invaluable, we do not sit around waiting to give feedback on demand because we have nothing else to do, we are caring for our children, working and managing family life. Please take this in to consideration when planning future genuine and meaningful consultation with parents."

General feedback about the new information

Overall, parents feel that the leaflet and information pack are written in a clear way and a great improvement on information they had been given previously. In addition to specific feedback about the drafts HWW received more general feedback from parents in response to our request, about the Umbrella Pathway and this again highlighted concerns about lack of information about the pathway.

Umbrella Pathway: Information for Parents

Feedback suggests that this is a helpful information pack that is an improvement from what has been issued previously.

Parent comment - "I especially like the information sheet as it clearly explains that it is a complicated process and the reasons why it takes a significant amount of time to reach conclusions. It is important to manage expectations.

I am pleased to see that there is space for the details of a professional for you to contact regarding your child's assessment. I had no such contact and felt very frustrated at not being able to find out how my son's assessment was progressing."

Suggested areas for improvement -

Please see attached version of the information, which has suggested amendments and issues highlighted by one of the parents who provided feedback.

Main themes reported in the feedback received, both written and by phone indicate the importance of managing expectations. Many parents felt they had been led to believe at the point of diagnosis there would be support available and this had not necessarily been the case. Concerns have been raised about what other changes are being made to the Umbrella Pathway, alongside new information being produced to ensure that the information and assurances are correct.

Parents also felt that in addition to contact details of someone to speak to about the progress of the assessment it would be helpful to know where they may be able to get support from local groups and individuals who have been through the process.

Other specific comments made in the feedback include -

- *I feel the section about the autistic spectrum (what it is) would be better at the start - some parents may be worried about why their child has been referred and not know very much about ASC.*
- *Is there an alternative to parents completing a form for their child? Some parents may find this quite daunting (eg: they may have dyslexia) and might prefer to talk with someone - it's important that parents are not excluded from the process so it must be made accessible and this should be explained in the leaflet.*
- *"Some may see your child at school or nursery. You are encouraged to attend appointments with your child so they feel safe and secure." To be honest, this would make me think "What on earth are they going to do to my child?" so maybe it could be worded a little differently - it is important that parents are involved, but they shouldn't feel they are only there as a bodyguard!*

- *What do parents do if they don't agree with the diagnosis (or not)? I like the explanation that there may be other conditions which need assessing, but this mustn't be used as a reason to delay diagnosis or assistance to a family who may be struggling.*
- *I do feel that the leaflet gives the impression there are lots of very important professionals who will be discussing your child but you, the parent, will be involved by completing a questionnaire - you will be on the periphery and your views will be acknowledged but they won't be important. It's known that many children on the autistic spectrum act differently at home to the way they behave at school, often managing to hold things together at school and then having a meltdown at home. I may be being cynical here, but it's vital that parents - who know their children best - are involved and that they feel involved, rather than just waiting around for a verdict.*
- *The leaflet tries to manage expectations, which is good. However, "the full assessment process takes up to and sometimes a little longer than six months" - is this realistic? One person told me their child was still waiting for a diagnosis after almost a year.*
- *I do think you need to be specific about it just being a diagnostic pathway and that at the end of it you are basically given a "yes" or "no" answer, and that it is not the job of the pathway to offer any solutions to difficulties the child is experiencing due to their being "on the spectrum". I for one, thought that at the end of the pathway there might be some specific signposting to agencies/professionals who might be able to help, and of course this was not the case (I'm afraid the photocopied list of website addresses I received does not count).*
- *I am hoping that as you are revising the information available at the start of Umbrella, the next stage will be to put in place some really useful and meaningful information and support to families after the diagnosis process is complete.*
- *They do give the overall impression that parents are on the edge of it all and must wait for the judges' verdict, their only input being a questionnaire.*

The Umbrella Pathway - Patient Information Leaflet

Feedback on the layout suggests that although the front cover is nice and colourful, it means that the other three pages have quite a lot of information crammed in. Spacing out the information / bullet points would make it more readable. If this leaflet is to be available on the website it would be helpful to have a printer friendly version, to save on ink consumption.

It is a good idea to give contact details to raise a concern, complaint or comment on the leaflet.

Other specific comments included:

- *Use of 'Patient Information Leaflet' - Is this title needed? Is the use of term 'patient' appropriate in this context? Could it not be a general leaflet, used by all, including professionals? Previous feedback to HWW suggests that other agencies, including schools and GPs could benefit from information explaining the Umbrella Pathway.*
- *Use of 'symptoms' in first paragraph, rather than traits or signs.*
- *This says the process can take "up to" six months. It would be better if both documents had the same timescale (if it can sometimes take longer, please say so on this leaflet - and please be realistic in both leaflets).*
- *It lists the people who can make a referral. There should be something about how parents can challenge any decision to not make a referral. It should also be stated (and made clear to professionals) that a child does not have to be in school for a referral to be made - this includes children/young people who are educated at home. If this is no longer the case, there should be a reason given for this discrimination and an avenue decided for home educating families to access the process. In the section about what happens after a referral it talks about contacting the educational setting - it should be made clear that this does not give a reason to exclude home educating families (who are the educational setting!).*
- *SENCOs and CAMHS - both these acronyms need explanation, some parents will not know what these are!*
- *It also states that the professionals may provide support, care or treatment - this verges on contradicting the Parents' leaflet which states that there is no treatment.*
- *This leaflet says that a diagnosis will be shared with an educational setting. This seems appropriate - but the parents' leaflet says this will happen if the parent has given permission. It seems inconceivable that an educational setting would not be informed so this needs to be made clear in the parents' leaflet. Perhaps it could be explained why this is important in this leaflet (so that appropriate support can be put in place).*
- *It's also stated that advice will be given. If this is true, it needs to be included in the Parents' Leaflet.*