

## Neuro-developmental/Umbrella Pathway Patient Experience session

10 October 2016

### 'You Said, We Did' Update

Many thanks for participating in this session.

We have looked at all your comments and summarised these below, together with the actions we will take.

<b>You said:</b>	<p style="text-align: center;"><b>Workforce</b></p> <ul style="list-style-type: none"> <li>• Gaps in the knowledge of some professionals</li> <li>• Children would benefit if signs of autism were recognised at an early age</li> <li>• Ensure that all professionals understand the pathway</li> <li>• Lack of recognition in Primary School. Felt "fobbed-off"/attachment issues etc; given potentially "harmful" advice; felt like it was trying to "prove me wrong"</li> <li>• Concerns not listened to by professionals – GP</li> <li>• School – children masking difficulties at school      they are not recognising the difficulties</li> <li>• Reluctance to label/diagnose too young by professionals</li> <li>• Earlier recognition – before there are specific issues</li> <li>• Not believed or listened to by professionals</li> <li>• Difficulties for parents to communicate if they are also on spectrum</li> <li>• Info/checks by HV at younger age/what to look out for and what to do</li> <li>• Concerns that issues will not be accurately assessed/recognised</li> <li>• Other professionals e.g. Family Support Workers being upskilled to offer support &amp; advice e.g. Solihull approach</li> </ul>
	<ol style="list-style-type: none"> <li>1. We are talking to the council's Learning and Development Manager to clarify training available to all groups of professionals, including health visitors and GPs, and produce a refreshed training plan to include basic awareness raising through to more specialist training.  Timescale: Training plan to be agreed by January 2017</li> <li>2. Worcestershire Health and Care NHS Trust to provide clear information to all professionals about the diagnosis process and how to refer.  Timescale: March 2017</li> <li>3. Worcestershire Health and Care NHS Trust to undertake further work with parents to produce parent friendly leaflets and information.</li> </ol>

	<p>Timescale: March 2017</p>
<b>You said:</b>	<p style="text-align: center;"><b>Transparency</b></p> <ul style="list-style-type: none"> <li>• Timescales need to be flexible and transparent</li> <li>• Transparency why can't parents attend planning and diagnosis meetings?</li> <li>• Share update with parents from Planning Meeting</li> <li>• Could parents be involved in Planning Meeting</li> <li>• Regular updates about waiting times – expectations</li> </ul>
	<p>1. We will produce information for families that is clear about how long you may have to wait for diagnosis and when you can expect updates.</p> <p>Timescale: March 2017</p> <p>2. Worcestershire Health and Care NHS trust will consider the diagnosis process and whether parents can be more involved.</p> <p>Timescale: March 2017</p>
<b>You said:</b>	<p style="text-align: center;"><b>Communication</b></p> <ul style="list-style-type: none"> <li>• Final letter – scary &amp; leaflets. Final letter needs to be softly softly/ more info on support that is available</li> <li>• Communication between professionals e.g. between GPs, CAMHS and Schools</li> <li>• Lack of dialogue</li> <li>• Gap between initial referral onto pathway and anything happening</li> <li>• Not communicated to about waiting time</li> <li>• Mixed messages about waiting times</li> <li>• Not being given clear explanation about why different assessments are chosen/needed</li> </ul> <p>Feeling that progress is not being made/moving forward</p>
	<p>1. We will make sure that professionals work together to agree a process where families just have to talk to one person.</p> <p>Timescale: March 2017</p> <p>2. Worcestershire Health and Care NHS Trust will consider with parents different options for sharing the final diagnosis information.</p> <p>Timescale: March 2017</p> <p>3. Worcestershire Health and Care NHS Trust to consider how information is shared across agencies with consent from parents.</p> <p>Timescale: March 2017</p>

<b>You said:</b>	<p style="text-align: center;"><b>Support</b></p> <ul style="list-style-type: none"> <li>• No support without specific diagnosis</li> <li>• Anxiety – some intervention not appropriate</li> <li>• Concern about stigma of diagnosis from parents/wider family</li> <li>• Making it clearer to parents who/where to go and what professionals' roles are</li> <li>• Support and understanding for parents even if diagnosis not needed/too early - strategies</li> </ul> <ul style="list-style-type: none"> <li>• More support/direction post diagnosis</li> <li>• SEN support – reasonable adjustment</li> <li>• (Absence from school, sick note, GP letter)</li> <li>• Having someone to be able to contact to discuss issues/concerns/progress</li> <li>• Needing strategies &amp; support while waiting</li> <li>• Strategies – tips, sensory strategies</li> <li>• Emotional support for parents - someone to go to for advice; troubleshooting</li> <li>• Information about how to tell your child</li> <li>• Follow up sessions with psychologist to help explain to child</li> <li>• Family approach – dealing with parents understanding their own traits/how whole family can adapt</li> <li>• Signposting to support and information/advice</li> <li>• Help to explain to wider family</li> <li>• Clarity about what is available</li> <li>• Help for the child to understand their diagnosis in a positive way (difference)</li> </ul>
	<ol style="list-style-type: none"> <li>1. Commissioners to consider developing a toolkit for professionals to encourage autism friendly environments and be able to identify needs and provide or refer to appropriate support.  Timescale: February 2017</li> <li>2. Commissioners to consider the provision of support pre/during and post diagnosis and develop a commissioning plan.  Timescale: February 2017</li> <li>3. Primary care commissioners to be contacted to discuss the absence from school/sick note suggestion.  Timescale: February 2017</li> </ol>