**Autism Pathway ‘Have Your Say’ - Feedback from Parents/Carers**

1. The referral for an assessment - is it useful to provide this to parents? Who does the referral and do they already have access to the form? I think an information sheet should be provided with it if the form is relevant to parents.

2. If a child receives a late diagnosis (age 11+) and it is a standalone autism diagnosis then all those workshops are not available and providing information of them only serves to frustrate parents that they have missed out on that valuable information (I am speaking from experience on this point!) I don’t think it should be a one size fits all pack.

3. We received our diagnosis privately and the pack we received included lots of links and recommendations for further reading/research which we found very useful.

4. Could a sheet be included about Cumbrian support organisations ran by parents/carers e.g Sendac, bee unique etc.

5. A list of Autism websites for info would be helpful.

6. My son got his diagnosis 8 years ago and I was given a leaflet with some generalised websites on and some book recommendations. This is a huge improvement on that! However, even as an experienced parent, if I got handed this, it does seem like an overwhelming amount of information to get at one time.

7. The one thing I wished we were offered as a parent when we got the diagnosis was a follow up appointment about a fortnight later. This would have given me time to process the diagnosis. Look at some information and form any questions I wanted to ask.

8. Is all this information given at once as a pack or is it split depending on which area in Cumbria you are in for the relative options? Sifting through information to find the bits that apply can be off-putting.

9. Splitting the pack to make it less daunting.

10. Getting the generalised information at diagnosis (NAS info and CCC what it means/doesn't mean, family support contact numbers).

11. A second diagnosis follow-up appointment to discuss any questions and to look at services/courses/self-referrals available would, I think work well. It then feels like a plan (pathway) in action; that you haven't just been left to figure it out and co-ordinate it yourself which can feel like a mammoth task even when you have the info.

12. I feel these are extremely useful to parents of school aged children, however, I still believe there are too many different paths to take. In our case, we have a son who is 18 and a lot of the attached isn't applicable.

13. Having access to one person who can point you in the right direction would be beneficial, a case worker perhaps? Our son was diagnosed at 14 years old and it was horrendous trying to take in the diagnosis and then have to negotiate our way through all the information to decide what was the best way forward.

14. The most valuable and positive thing to come from our son's diagnosis has been having access to Karen Dickie from Mencap. We attended the 'What Now' course and have had support from Karen since then. She is amazing, so supportive and caring and even though she is incredibly busy, she always finds time for us.

15. Too often, we are introduced to someone, or given details of someone, who may be able to help/support our son's needs, and once that is dealt with, they are no longer accessible to us. This is incredibly hard to deal with. It has the feeling of being given something in one hand and then having it snatched away again. So hard to take.

16. There are often too many people involved e.g. I was passed from one person to another to another trying to gain access to support for our son with his anxiety and no one could really help. This caused us, as a family, a lot of heartache. It fell to our family GP to bridge the gap until he was 18 to get us through the most difficult thing we've had to deal with as a family.

17. Education is another source of worry for us. We were extremely lucky to have fantastic support from our son's school. They were so tuned in to his needs and looked after him incredibly well. Since leaving school, the support has been less than impressive. It often appears that the support he has don't have much idea about autism. There is a lack of options for post 16 autistic young people in terms of education. The school had achieved so much with our son and now he is literally going backwards in terms of learning.

18. I have not one good word for the service that I received in Cumbria the whole service needs reviewed there is no support no continuing support is a dreadful service that just abandoned my child sorry to be so negative but the service is horrific compared to services in the North East.

19. I have one quick comment regarding the behaviour support from the Learning Disability and Behaviour Support Service. As background (redacted) His behaviour and needs were such that he moved to a 52 week residential accommodation/ school last year as we could no longer manage his behaviour. We were getting support though the LDBS Service with a visit every month or so to discuss strategies - which was excellent. When the nurse left the service we were told that it was a time limited intervention and they would stop the support. I know that money is a problem but it was one of the few professionals involved who understood our situation. She visited our child in school and home, but the meetings were with us as parents. I appreciate that there may become a point when then there is not much new that the professional can say, but in our situation the meetings were like a pep talk to keep going, to keep trying the interventions. We really valued the support. When it stopped it felt like they were saying " well we have done all we can do and there is nothing more we can suggest" - it felt like we were being abandoned to an increasingly fraught situation.  It was probably inevitable that our child would need residential accommodation at some point, but more support and acceptance of our situation might have helped a little? I did attend some of the courses but most were set up after I had delved deep into the world of SEN.