



Independent Review of the North East Lincolnshire Access Pathway

April 2019



healthwatch

North East Lincolnshire

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What is Healthwatch?

Healthwatch North East Lincolnshire (HWNEL) is the independent champion for people who use health and social care services. Healthwatch exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. Healthwatch share their views with those with the power to make change happen. We also help people find the information they need about services in their area. Healthwatch have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people. In summary, Healthwatch is here to:

- Help people find out about local care.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government know what people want from care.
- Encourage people running services to involve people in changes to care.

Why this subject?

The North East Lincolnshire Access Pathway was introduced in the local area in April 2018. The Access Pathway is intended to support children aged birth to 19 years where their broader needs around communication and interaction, cognition, and learning & social, emotional and mental health difficulties need support. The aim of the Access Pathway is to provide a multi-modal model of care which considers a holistic approach rather than a single agency working in isolation. Such an approach aims to consider a wider range of services and support to meet individual need. For instance the pathway will consider the social needs alongside the clinical needs of a child and not either in isolation.

In July 2018, Ofsted and the Care Quality Commission (CQC) conducted a joint inspection within North East Lincolnshire to judge the effectiveness of the area in implementing the disability and special educational needs reforms as set out in the Children and Families Act 2014.

Within this report the Inspection Team highlighted the strength of the Access Pathway as:

Diagnostic assessments of autism for children and young people aged over 5 years old are comprehensive and timely. Assessments are evidence-based, use national guidance and are informed by best practice. Reports given to families are detailed and include information about support provided by local and national groups, as well as practical advice and guidance. Importantly, however, these strengths do not mitigate widespread concerns about the effectiveness of post-diagnostic support for children and young people who have autism and their families.



The report stated that an area for improvement was:

While there is a shared belief in the potential of the single access pathway to facilitate better and more timely assessment and improved access to services, the implementation of these new arrangements lacks coherence. Indeed, this fundamentally important element of the local area's arrangements for identifying, assessing and meeting the needs of children and young people who have SEN and/or disabilities is currently in disarray.

Following implementation of the Access Pathway, local health and social care commissioners delivered a review of the Pathway's development. This review included:

- Consultation with the Access Pathway Development Group.
- Independent listening event with parents/carers of children and young people with SEND.
- Co-production event linked to the outcomes of the SEND inspection.

Both parents and professionals with experience of the Access Pathway articulated that they felt the roll out of the pathway was too rushed but have voiced a strong commitment to support in getting it right. It was also strongly articulated that any further development of the Access Pathway needs to be done collaboratively with parents throughout the process. For this reason, Healthwatch North East Lincolnshire were asked to carry out independent research of the pathway to understand further what has worked well and what not so well, and to help identify areas to focus on as part of future co-production developments.



Approach

Following initial consultation with the local commissioners of the Access Pathway, Healthwatch North East Lincolnshire conducted a range of research to obtain an understanding of how the Access Pathway is intended to operate. This involved the following:

- A review of the commissioner produced guidance including the Protocol and Practice Guidance, the Practitioners Toolkit, The Screening Checklist, and other supporting document used during the pathway, for example the Early Help Assessment.
- Assessment of the feedback so far received by commissioners during their review to date.
- A review of the SEND inspection report and SEND Written Statement of Action.
- A review of the previous minutes of the Access Pathway Operational Development Group.
- Attendance at the Access Pathway Operational Development Group.
- Shadowing of the Access Pathway Panel meetings.
- 1:1 meetings with the North East Lincolnshire Director of Children's Services, the North East Lincolnshire Commissioning Lead for Perinatal and Children's Mental Health, and the CCG Commissioning Project Support Manager for Children & Families.
- Participation in SEND Project and CO-Production Workshops.
- Attendance at the SENCO Forum and SEN Executive Board.

On assessing the day to day complexities that families with children with developmental needs face, along with the various stages involved in the Access Pathway, we realised that we would need to break our review down in to small stages, in order to allow families to effectively share their views, and allow for the more granular details of their experiences to be aired. For this reason, a series of focus groups were held, that were split into the following areas of focus and which followed the Access Pathway process:

Focus Group 1:

- Parental initial Concerns identified with a child's development
- Concerns identified via statutory assessments
- Initial concerns identified by an alternative identifier.
- Initial self-help/prevention and routes for obtaining further help.
- Accessing Universal services and universal plus services
- Coordination of Support

Focus Group 2:

- Early Help Assessment
- Families First Access Point (FFAP)
- Access Pathway Panel

Focus Group 3:

- Panel Decision & Individual Support Plan
- Referral to package(s) of support
- Review of progress
- Post Pathway Support

The Focus Groups were arranged at intervals between January and March, taking place at different times of the day to support attendance by as many families as possible. For those who could not attend a focus group, a questionnaire was also developed and widely circulated. To ensure effective analysis of all feedback received, the questionnaire followed the same format as the Focus Groups.

The lines of enquiry at each stage of the pathway followed the same framework as follows:

- Detailed what should be happening at that stage.
- Provided key questions to help prompt respondents as to what they experienced during this stage.
- Asked respondents to write down what actually did happen to them during this stage.
- Asked respondents what other help they would have liked to have received, or could have been improved during this stage.

A fourth focus group was also arranged to enable children and young people using the services to attend and share their views. A range of tools were developed to facilitate children being able to provide such feedback in an interactive way. In addition to this, two versions of a questionnaire were developed targeted at differing abilities, along with instructions for parents to enable them to support their children in completing the questionnaire. Furthermore, a session was held at Grimsby Institute, providing the opportunity for younger people at the upper age range to share their views.

Finally a questionnaire targeted at professionals was also developed, and as circulated to those who work with children and young people with additional needs or who have experience of the Access Pathway.

The Focus Groups and questionnaires were promoted extensively and via numerous routes across North East Lincolnshire to obtain maximum engagement. These included via:

- Healthwatch North East Lincolnshire's website, newsletter and social media.
- North East Lincolnshire Council and CCG's website, newsletter and social media.
- Carers Support Service
- North East Lincolnshire Parent Participation Forum
- Parent Groups, childcare settings and Family Hubs
- Children's Disability Team
- Young Minds Matters
- SENCOs
- Voluntary sector organisations



Limitations

In total 51 parent/carers participated either at a focus group or through the online questionnaire. 30 young people participated in a focus group and 11 professionals completed the questionnaire. A further 30 professionals also shared their views and opinions via the SENCO Forum and the Access Pathway Meetings.

Despite widespread promotion, during the research process we encountered difficulties ascertaining children and young people's views and opinions. Whilst Healthwatch spoke to students at Grimsby Institute, we are aware that the numbers are not a representative view of the children and young people who have been through the Access Pathway or accessed services in general. Furthermore, the focus group that that was organised for children and young people, did not have any children in attendance. It did however provide an opportunity for parents/carers to attend a session outside of normal working hours.

Although responses rate was lower than we had hoped, an extensive range of rich feedback has been collected, which can help inform service developments moving forwards. Furthermore, there are a number of individuals now engaged in contributing to the co-production of services, and as the impact of this involvement starts to develop, it is hoped this will encourage further participation moving forwards.

Experiences and Feedback

During the Focus Groups, parents and carers had the opportunity to discuss their experiences of each stage of the pathway in small groups. Each participant was also encouraged to write down their personal experiences to ensure the quieter voices were able to share their views. Any general feedback and discussions held was also collated on flip charts by the facilitators of the event. The following information is a compilation by pathway stage, of the feedback that was shared at both the focus groups and via the questionnaires.

Stage 1: Initial Concerns with a Child's Development

This stage in the Access Pathway relates to the very first point that a concern for a child's development was identified. The concern may relate to a number of presenting behaviours such as speech, interaction, emotional difficulties, or motor skills. Participants to the workshops and surveys were asked about initial identification in order to set the scene and understand how this initial identification influenced their journey and direction through the pathway. Participants were asked to consider if it was themselves or someone else who first picked up on a potential concern; the child's age at the point of identification; what broadly the concerns were; and what was their first course of action.

We received the following feedback in relation to this stage:

"My first concern was during Year 6 at Canon Peter Hall primary school. I asked if my child could be tested for anything. Paperwork was completed by OAI, and a single assessment completed and I was told I had to complete the Triple P (Positive Parenting Program). I also called the Family Hub and told them I am trying to get my child diagnosed with ADHD and was put on the parenting puzzle course."

"We noticed our child was different to other children at 2 years old as he didn't sleep or interact with others. When he started reception at age 4 it was pointed out that he wasn't meeting milestones and an educational psychologist brought in thought he had dyspraxia and low muscle tone. We then visited the GP who referred to C.D.C and we saw Dr Kumar who diagnosed A.D.H.D at the age of 6. He supported us with medication and issues with school including getting E.H.C.P. Even though A.S.D was mentioned, we didn't pursue a diagnosis until the age of 12 and have since had to go down the pathway."

"Identified initial concerns included hyperactivity, impulsive behaviour, shouting, tiredness, staying in push chair, and difficulties in new situations such as busy places, new people, and nursery. Our GP referred us to Grimsby paediatrics, who then referred us to the Sheffield sleep clinic. A sleep study was carried out, which showed nothing in particular but did have a busy night. Sheffield referred back to Grimsby and mentioned both ADHD and ASD and that an assessment was needed at Grimsby Hospital. Grimsby Hospital told us he would grow out. Eventually we were referred to CAMHS. Still have ongoing concerns; predominantly school issues, bullying, change, and new situations. Still under paediatrics who wants a further assessment but for this they need the school to back up concerns for it to be taken



further. Paediatrician feels he functions well and controls his outbursts he would be mild so possibly wouldn't get an assessment."

Further comments included:

- Raised my concerns with my child's teacher.
- Concerns were identified by the health visitor when my daughter was 8 months old.
- My child at 3-4 years old had excessive temper tantrums.
- My daughter was delayed in learning and the nursery queried whether she had ADHD.
- Mental health deterioration.
- Delayed overall development with obsessional behaviours and routines.

Parents were asked to consider what were what the biggest issues they encountered during this stage. Responses included:

"Professionals bringing their own opinion."

"We had support from Dr Kumur but once he left we struggled until our child was placed at Cambridge Park and referred to Young Minds Matter for Anxiety."

"Lack of support from school- reporting year after year the same issues, but information and strategies not continued or documented. Not listened to or understood as yet from 2011-2018 no further assessments have been done."

When asked what else could have helped them during this stage, respondents replied with:

- Parenting Course. Also the access pathway needs to include the parent.
- Better communication between services.

Of all of the responses we received, there were some parent/carers who had been through the former pathway process and some who had journeyed through the new Access Pathway. A common theme however remained across both the old and new pathway, in terms of difficulties being reported with accessing the correct information at the right time.

Stage 2: Concerns Identified via Statutory Assessments

This stage of the pathway recognises that there are a number of statutory assessments that takes place during a child's development, which may result in an initial identification of development concerns. Such assessments include development checks as part of the Healthy Child Programme, Year 2 Ages & Stages Questionnaire, the Early Years Foundation Stage Profile, or the Nelson Assessment. Participants were asked to consider if they were aware of these assessments taking place and whether they felt involved in the process.



“Development checks and year 2 Ages and Stages were carried out either at home and at Scartho Children’s Centre, and Early years and observations in school were carried out. A common assessment framework meeting was carried out which was initiated by the Family Hub nursery nurse with the backing of the health visitor. Only had one of these and nothing came from it and I was told he would grow out of it and to let natural development and brain development happen first.”

“Many assessments took place and I was not told until the reports came back. Sometimes I was called in to talk to professionals.”

Further comments included:

- Not aware of any assessments taking place.
- Early Years and profile assessment was carried out
- Development check was carried out
- Nelson Assessment
- Ages and stages questionnaire.
- Not sure as I am not aware other assessments were carried out

When asked what were the biggest issues encountered during this stage; responses received included:

- Communication between services and school.
- Feeling like I was making it up/not being listened to. CAMHS picked up some concerns with anxiety but not the triggers. (We felt that our child had) possibly border line Asperger’s but does not fit the tick box exercise.
- Depending on the teacher, depended on the help we received. We did receive an EHCP after three years of asking for one to be applied for.
- Not being informed of assessments outcome.
- Not being aware of assessments.

When asked what else could have helped them during this stage, respondents replied with:

- The school to stop punishing my child for his condition
- Schools to accept parents’ concerns
- Schools to work with the child
- Schools to understand interpersonal skills better
- Teachers to understand SEND children better
- Schools to have more training on EHCP and assessments
- Embrace the talents of SEN children and young people

The majority of parents were not aware of the different types of assessments nor were they fully aware of the outcomes of these assessments. In discussions held during the focus groups, the lack of awareness of assessments appeared to be due to the fact that professionals do not refer to them assessments as they are integrated in to day to day practice. Also there appears to be no common language used, with professionals



referring to assessments as checks or just by the first part of the name, which in turn has caused confusion for families. Parents/carers also reported confusion with different reports and recommendations stemming from the different assessment processes, and felt that these could be better coordinated to ensure that messages and feedback are consistent.

Stage 3: Initial Concerns Raised by an Alternative Identifier

This stage in the Access Pathway refers to the fact that there are other individuals and professionals involved in a child's care who may also identify initial concerns with a child's development. Such individuals could include a health visitor, childcare provider, school nurse or teacher. Parents/carers were asked about if anyone else identified the concerns, how these were communicated to them, and whether they felt adequately informed.

With regards to who the identifier was, responses received included:

- Issues were identified by my daughter's teacher
- Health Visitor
- SENCO at nursery identified concerns
- Health Visitor

With regards to what happened next, parents advised:

- Referred to the GP
- SENCO referred me to my GP

For the majority of respondents to our research, it was mostly parents who had initially identified issues. For those where another person had, it was usually before the child had started school and was not seeming to be reaching their developmental milestones.

Stage 4: Initial Help

This stage of the Access Pathway recognises that parent/carers need support at the initial point of concern. The natural first steps for parent/carers may be seeking information from a care professional; self-researching via available methods; or undertaking additional activities with the child. In order to understand where parents may initially look for self-help information, participants were asked to consider whether they had accessed information themselves i.e. via the internet/telephone calls or whether a professional had signposted them to information or a particular service.

We received the following feedback in relation to this stage:

"I contacted my GP and went to a local Children's Centre, who did help with some cards and tried to get further assessments. The Nursery Nurse who came to my house also helped with strategies. Sheffield children's sleep Charity Centre came in, but concluded that bedtime routine and environment were not an issue. CAMH's did



some CBT with my child; some new strategies were mentioned and commented about strategies that my child had developed himself and ones that me and him could work on together.”

“Referred to the School nurse for advice.”

“Told to speak to the GP by the school.”

“Spoke to my child’s school.”

“I had to find the information out myself.”

“Concerns were passed onto a paediatrician.”

“Tried to find more information myself but it was difficult.”

“I have made an appointment to see my GP.”

“We was referred to CAMHS and only waited 1 month for an appointment.”

“Early intervention is not accessible. If it was more accessible it may take the strain from some of the other stages of the pathway.”

When asked what else could have helped them during this stage, respondents replied with:

- People with no medical experience making decisions about my son needs to stop.
- Professionals to have a better understanding of where to refer and how.
- None medical professionals making medical decisions.
- A better understanding of SEND.
- Felt the buck always stops with no further assessment. Everything my son was initially told he would grow out of he hasn’t. My child being seemingly ok at school. I feel he copes at school but not with school.
- School didn’t give me any information about where to go for support as they dismissed my concerns and told me my son was ‘a lazy academic’.
- A named contact so I could ask questions without repeating my story.
- Normalisation and help to develop necessary skills.
- Wasn’t sure where to go for help.

On the whole, feedback from participants suggested that support at this stage is not always consistent, and is dependent on the knowledge of the particular professional they make contact with.

Stage 5: Getting Further Help

This stage of the pathway recognises that initial self-help methods may not provide a sufficient level of information or support that parents/carers may require, and may be reliant on professionals providing more support or direction. Respondents were asked to consider the type of support they were offered at this stage, how useful they found it to be and whether any further assessments were provided.

Parent/carers gave the following comments:

“Word of mouth is most often the way parents get their information e.g. peer support groups.”

“Had no idea what support was available.”

“I have always asked for further help but have not received any.”

“I waited 8 months before seeking further support.”

“I haven’t asked for further help as unsure where to go.”

“After 1 month my child was referred to CAMHS.”

“After a couple of months I spoke to my health visitor again.”

“Was referred to Dr Wilson but took till my child was 13 to get a diagnosis of autism.”

“I went to GP got told it was Paediatrics that dealt with ADHD. I already had a Paediatrics appointment. Paediatrics said CAMHS so I called and spoke with CAMHS to be told single assessment. Only help I’ve had is from my Son’s Pastoral Manager and SENDIASS. Pretty much no other help unless they’ve been requested e.g. special advisory and educational psychologist. Applied for educational health care plan.”

“Special advisory did report with recommendations. Ed psych did report with recommendations. Supposedly recommendations were emailed out to teachers yet at parents evening some teachers weren’t aware of certain things e.g. needs overlay, scribe, laptop, etc.”

“School nurses and Occupational therapist not referring as they don’t have the correct paperwork.”

Parent/carers again gave mixed responses to this stage. Some found they had gone back to the professional with whom they had raised their initial concern and was then referred to another professional. Some however did not know where to go. Overall parent/carers reported that they found it difficult to navigate different agencies and information.

Stages 6 & 7: Accessing Universal Services & Universal Plus Services

At this stage of the Access Pathway, there are a range of universal services in place that can support specific developmental needs. These may include sensory rooms, toilet training, brain gym and rhyme time. Respondents were asked if they were aware of these services; which, of any of these services they were referred or signposted to; how long they utilised the service; and how useful they found them.

The following comments were gathered from parent/carers:

“Don’t know about these services. Don’t understand the difference (between universal and universal plus). Professionals don’t know all services available, don’t know if it is for you to access or to refer.”

“Feel always have to chase up referrals/access. Find that you have already tried a lot of these approaches already but have to go through motions to get a pathway.”

“Referred to Portage.”

“PPP outdated.”

“Referred to Physiotherapy.”

“Was signposted to language and we accessed this support. We also accessed sensory room facilities. We also had our Health Visitor to contact when we needed advice and support.”

“Referred to family Hub but felt the advice I was given I was already doing those strategies.”

“Have accessed out of school activities.”

“Nursery had language through listening in for the class.”

“School nurse has been in touch since reception but no help.”

“It only took a couple of weeks to access and they were excellent.”

“Attended the Early Bird Programme.”

One parent also reported that they had been referred to Portage but due to waiting lists could not access support as the child was now too old.

When asked what else could have helped respondents during this stage, comments included:

- I wasn’t told of any services so do not know.
- I had no way of knowing what was available.

- Don't know what universal services mean so an explanation would be useful.
- Support group is really helpful.
- Peer support is really helpful.
- Courses should be centred on the child/ with additional needs - more specific.
- Change name of Parent Programme.
- More specific support/courses for specific conditions when diagnosed.
- Not sending parents of Special Educational Needs children and young people on inappropriate courses. It would be helpful if they were more specific to circumstances. Not generic courses.
- An Autistic Spectrum Disorder specific parent workshop would be helpful
- Not insisting on attending parenting courses, and not calling them parenting courses.
- Information to be readily available/list of accessible support services.
- If there are courses/services they should be available to all across the patch.
- Better signposting to suitable services.
- Advertise support more widely.

The majority of respondents were not sure what was meant by the term 'universal service', nor the difference between 'universal services' and 'universal plus services'. Whilst these terms may be more targeted at professionals, a lot of the respondents were not aware of the existence of the individual services that sit within this pathway stage.

Respondents raised a lot of comments relating to parenting programmes and other courses available. Some parents reported that they found the parenting programmes of use and used the strategies that they had learnt, whereas other parent/carers felt they had been forced to attend the courses in order to access other services and support. Those who attended the Triple P largely reported that this was not suitable for them and did not learn anything. For those that attended the Parent Puzzle or Stepping Stones the responses were more positive, with many commenting that they had gained in confidence. A lot of the respondents however reported that they felt they had to attend courses unnecessarily in order to progress to the next stages of the pathway.

Comments made specifically in relation to training and parenting programmes included:

"Parenting classes are demeaning and patronising."

"Parent Puzzle was valuable and it gave me confidence."

"Triple P is useless. Behaviour training is more parent friendly and easier to understand."

"Not all parents need parenting courses. The courses are too generic, most parents of SEN children need more specific and tailored courses."

Stage 8: Coordinating Support

This stage of the discussions picks up on earlier comments raised by parents/carers regarding having a central contact who was responsible for coordinating their support. Respondents were asked if they had a central contact at this stage; how well informed they felt other professionals involved in their child's care were; and how easy it was for them to raise any queries.

During general discussions, parent/carers said that they would benefit from having a named contact at this stage to help them navigate through services and find what their child needs at the right time. Parent/carers commented that things can change when their child goes through transitions in their life and so may need different types of support, and therefore suggested having an easy contact point is key.

Stage 9: Early Help Assessment (EHA) - Process

Following utilisation of self-help and other local support available, the Early Help Assessment (EHA) is the next step which aims to help professionals to think about the best support for a child and the family. In order to enter the Access Pathway at this point, an EHA must be completed. The assessment can be requested by a parent/carer or be instigated by a professional across the health and social care sector, including education. Parent/carers cannot complete and submit this themselves, but instead has to be completed by a professional. The assessment does however have to be completed alongside the parent and with their permission. The assessment aims to give a holistic view and consider what other factors in a child life may be impacting on their behaviour, emotional responses or ability to interact. At this stage of discussions, participants were asked to comment on the process for initiating an EHA, including how they knew about the EHA process; who instigated it; and how supported they felt during this stage. Comments received included:

"In all honesty no idea!"

"A parent should know where to go and who to ask for support and advice."

"Pupil support manager did it."

"No professional help was offered"

"School were doing their best to support her, I felt she needed professional help and diagnosis"

"Pupil support manager at school completed the EHA."

"Our EHA was completed in a week after the process started."

"Still waiting for outcome."

"The whole process is not simplified and support is rubbish because no-one communicates. I am still waiting for a response."



“The EHA was completed before we were accessing universal services. School was still saying that our daughter hasn’t got any issues within school apart from being behind in reading and writing. Took 8 weeks for the form to be completed start to finish by pastoral care teacher at school. Pastoral care teacher instigated and completed the EHA form and stated that our parenting skills are causing our daughter’s issues.”

“Doctor said he needed referring to the pathway as school had an educational psychologist assessment showing he has ASD so the school nurse was asked to fill in the EHA form but didn’t know how. Received a shocking letter from FFAP saying that concerns had been raised about my children and not from the EHA. Made to feel like it was my fault”.

A peer support worker commented;

“Lots of delays. Tried for two years but as soon as the young person turns five, it is up to school nurse. School nurse never there. Parent has been waiting since before Christmas to sign the form but nothing is happening. Issues with sleep that are ongoing, nothing being done! Blaming parent and blaming anxiety - not helpful!”

Another parent had found that several EHA had been completed and she had not always been aware. She said;

“First EHA was done by the hospital. I was unaware they had and they didn’t know what they were doing. My second EHA was instigated by my son’s incontinence nurse (again she didn’t know what she was doing). My Daughter was under CAMHS at the time. I don’t know what universal services is! Nothing has been met as I am still waiting. Took my family hub worker a few weeks to amend the EHA to be able to access the disability pathway. The family hub workers are better than the professionals and very supportive and helpful.”

Another parent stated;

“EHA carried out (at Grimsby hospital) without parent’s awareness.”

Another parent reported that numerous EHAs were being completed by the school even after a diagnosis had been given due to no support being offered. She said;

“CAMHS assessment, around 1 and a half hours, focussed on obsessions so was interactive. Schools continuously doing referrals as paperwork was lost numerous times. Chased FFAP, told waiting for panel decision. No paperwork or communication so unaware of what’s happening. School said no to EHCP even when diagnosis in place.”

One parent also commented that;

“Several people had asked for the EHA to be completed but none knew who did it”.

Some of the participants reported on historical experiences that pre date the Access Pathway:

"We didn't go through an EHA. We first started when my son was 2 years old (four years ago). We did a single assessment and unhelpful parenting courses. We are now awaiting a second opinion at Sheffield Ryegate as CAMHS made a mess of the assessment. School stated different to what they said on their report."

"We didn't go through the EHA; we started our journey when our child was 18 months old and only got a diagnosis in November 2018 (child now 7 years old)."

"My daughter was assessed by the multi-agency when she was three years of age. She was diagnosed with global delay speech and language hypotonia and hypermobility. After that had finished, nothing else happened. All support stopped and we were on our own. Was given paediatrics appointments over 3-6 months. She is now 8 and still in the same position. Last year was diagnosed with dyspraxia and this year a paediatrician has stripped her of all diagnoses apart from global delay".

"I have been having problems with my son since he was a baby as he never liked to be touched. I managed to get him to attend pre-school. Had a multi-agency pathway when he was 3 years old. Nothing was passed onto school (IEP). Know nothing about Early Assessment on ECHP. CHMM gave inconclusive report saying the school and his parents could be making his problems."

When asked what other support they would have liked during this stage in the process, responses included:

- Quicker response about panel decision
- Need to have got a better idea of the pathway as pastoral care teacher did not explain it properly.
- Proper support and listened to by the professionals.
- I'd like extra support.
- More training for professionals about filling in EHA forms.
- More continuous support.
- More communication and direct help for queries.
- Parents consulted at every stage. Not to be made to do a parenting course. Professionals should be aware who is able to complete the EHA. All professionals should be singing from the same hymn sheet.

Stage 10: Early Help Assessment (EHA) - Contents

During this stage of the engagement, discussions moved on to the actual contents of the Early Help Assessment. Parent/carers were asked for their views and opinions on completing the EHA and whether they felt if anything was missing from the EHA and how they felt the EHA could be improved.

Parent/carers gave the following comments on this part of the process:

"The EHA is only as good as the person that fills it in."

"I had not heard of the multi-agency until my daughter went there. Nobody explained what would happen or who would be there and what would come out of it. I don't feel that any agency takes into consideration how the child is at home. It's all about how she behaves at school. Home behaviour doesn't get a look in."

"It was hard, long and difficult to complete the form as the teacher said she had to complete it and we couldn't. Why are details such as the needs of grandparents and a family tree required, when it is not direct to child's behaviour? EHA was not complete when sent to the relevant people as it still needed grades/learning levels to be completed."

"Difficult to capture individual aspects of child on paper."

"The school gathered a lot of information and evidence for the EHA. However this has all vanished. I do not know where the evidence is. I keep asking but get nowhere. Nobody is held accountable or responsible."

"My experience of EHA is poor."

"I feel that it is expected of me as the parent carer to produce the history of my child. This is a lot of pressure."

"When assessments or observations are made, they are quite often made within the family home, which has more often than not been tailored to suit the child. It is generally the environment where they feel the most comfortable, and so I do not feel accurate observations can be made in these circumstances."

"I did not feel there was enough room on the form for some of the information and there were areas which were not covered therefore my concerns were partially missed."

"The form was very ambiguous at times and intrusive."

"It was drawn out and confusing."

"Frustrating and disappointing."

Although a lot of parent/carers raised issues with the Early Help Assessment, some did find report to be informed and included during the process.

"My family hub worker filled in the EHA for me and was always contacting me about it and then I was given a copy to read before sent off. Anything I didn't understand was explained to me by my worker. When it came to the EHA my main problem was the school. My worker had it double checked before submitting. No EHA can ever capture all elements of my child; only meeting and observing can do it."

Other comments received from parent/carers about improvements that could be made included:

- Again more training for professionals on filling out EHA.
- Professional completing EHA needs more training or to really know the child.

- Professional who is completing EHA needs to have a good rapport with the child and strong knowledge and insight of the child's need and situation.
- Professionals properly trained to do an Early Help assessment.
- More information needed.
- To be less intrusive.
- Less confusing, more explanation needed between EHA and EHCP.
- There needs to be some give and take. Instead of just sending the form back they should ring the parent and ask for more information.
- I was not able to discuss age related progress.
- Parents need a lot more participation. They need to be able to include more or give a personal statement.
- General understanding and maybe more on parents' concerns.
- Nothing was mentioned on the form about being referred for possible diagnosis.
- Easier contacts.
- On the EHA there should be an area for 'any other comments/information' which could be a space to document other concerns regarding the child or add other information that is felt relevant to the assessment.

Stage 11: Families First Access Point (FFAP)

The Families First Access Point (FFAP) is a multi-agency team of professionals from Early Help Services, Children's Social Care, health, Young Minds Matters, and policing teams, and has access to consultation from the Specialist Advisory Service in terms of education support. FFAP do not complete Early Help Assessments but takes receipt of them, making sure they are complete, collates information from other systems, and analyses to determine the next steps, including referral on to the Access Pathway Panel for decision.

Participants were asked if following their EHA, whether they were aware of the FFAP and their role and function, and what level of contact they had with the FFAP.

Parent/carers reported mixed experience with FFAP. Some parent/carers did not know who FFAP were or what their role in the process was. Other parent/carers reported paperwork had been mislaid somewhere in the process. For some parent/carers it was a quick and easy process and for others it was a lengthy and dis-heartening process. Responses included:

"School made a referral in May 2018. This went astray so school made another referral in June 2018. This wasn't received so another referral was made in October 2018. I have still NOT had response."

"Waiting several months for response from FFAP."

"Took weeks to hear back from FFAP. When I rang for information they refused to give me any."

"All my child's information was evidenced by school and sent to FFAP. It is now lost in the cloud. No one will tell me anything. Banging my head against the wall. This is since 2017-2018. Every time I approach the school regarding this I get no answers. No communication from FFAP about my daughter."

"Accessed FFAP but didn't realise as I was told it was safeguarding."

"Family hub workers chasing up FFAP as professionals not willing to."

"Letters from FFAP made it sound like I was abusing my child."

"I was contacted by FFAP to say my EHA had been accepted and it would be allocated to an Early Help Practitioner. Approx 2-3 months passed and I was contacted by an Early Help Practitioner. She then informed me that it had taken so long as it was identified that I needed the Triple P (parenting course) so had to wait for a worker who was trained. However the worker identified upon meeting with me for the first time that it was definitely NOT needed and therefore there had been a large unnecessary delay in support being offered to my son."

"School referred daughter (possible ASD). Teacher contacted FFAP, then went on sick leave. Vice principal apparently has been informed but I have heard nothing from FFAP since 2017. No progress, no communication. I am chasing constantly and facing a brick wall. Made face to face appointments and phone calls. I feel we have been lost in the system."

"School made a referral in May 2018 to FFAP for my daughter to be assessed by CAMHS. The referral was misplaced by FFAP. The school made another referral in October 2018 and this has still not been responded to. My Daughter received NO support from any other body. She only has SEN support at school which is being held back because there needs to be an assessment for ADHD and autism. Daughter diagnosed with dyspraxia, developmental delay and a benign tremor. Her consultant suspects possible autistic traits."

"I was contacted by what I can only describe as a rude individual who basically laid blame on me for my son's outbursts saying I was not supporting him properly, despite back up from school. She also spoke to the pupil support manager at my son's school and addressed her in the same awful and inappropriate manner. I have heard nothing since November 2018 about what they wish to do following the EHA being filled in with the schools support".

"Good experience with FFAP for older children."

"I had a very good experience with single point of access and with very good outcomes"

"I heard from FFAP about 3 weeks after my form got sent, however not heard anything since."

"One letter saying my daughter had been referred to the pathway. I am actually presuming FFAP wrote it as it wasn't clear."

"I had a letter from them saying received and looked at about 3 weeks later."

"A few weeks after sending the form off through the school SENCO we received a phone call to say they had been in touch with school with changes to be made to see if there is an improvement. No letter received."

"FFAP are making decisions not just gathering information"

"Issues with FFAP not always giving correct information "

With regards to additional support or improvements to the pathway that parents and carers would like to see at this stage, the responses included:

- More explanation of FFAP's role needed.
- To better understand the role and function of FFAP.
- Explain to parents what the role and function of FFAP.
- When FFAP get the referral at that point information about the process and time line should go out.
- Shouldn't have to wait for FFAP.
- FFAP needs improving for younger children.
- Faster communication/response from FFAP.
- Phone call asking for more information; not just sending referral back.
- To be treated with more respect.
- To be provided with a list of services I could access.
- An earlier diagnosis so correct support can be put into place, not waiting until they are five years old.
- An assessment for ADHD/ASD. More specific support for dyspraxia/benign tremor/developmental delay.
- Better transition through to adult services.

Stage 12: Access Pathway Panel

This stage of the pathway refers to the Access Pathway Panel, which is a panel of multi-disciplinary professionals who meet on a regular basis to consider new referrals and review existing cases. The panel will make recommendations for further screening, or make referrals to the most appropriate service and package of support. Parent/carers do not attend the panel meetings, but instead are represented by the professional who completed the EHA.

Parents reported very different experiences of the Access Panel. Some who had reached Panel had been given the information they required and referrals made for the extra support their families have needed. However for some families it has been confusing with inconsistent advice and support has been given.

Parents gave the following response when asked about the Access pathway Panel and its functions:

"I was booked on courses and then don't hear anything from panel."

"Medical issues down a social route."

"We have not been informed where we are. Our referral has still not been acknowledged. Referrals made in May 2018, June 2018 and October 2018 and still got no response."

"Case went to panel and was told to follow Educational Psychologist's recommendations. I put in a formal complaint and was told that because my Son can function in various activities (getting dressed, cadets, and video games) that this means he does not have ADHD."

"Having gone down the pathway last year we was referred to the school nurse who admitted she had no experience with Special Educational Needs children, who then got in touch with Young Minds Matter who said he didn't meet their criteria. When we went through the pathway he was then accepted."

"I am not aware of it going to Panel. I have requested this due to recent concerns regarding autism and ADHD but Early Help Worker advised against it and said the Panel would reject it due to them classing my living situation as 'unstable' due to me currently living with my dad."

"I am still waiting for a decision."

"I had no idea who to contact so I had to ring around and get advice on a local social media group."

"I strongly believe that the panel should meet the child and/or parent/carers to help them inform their decision rather than just reading an assessment and making a decision. Not everybody is educated how to fill out the EHA correctly and therefore many would get dismissed. Also sometimes schools/professionals are not supportive of the parents' concerns or to the child's support needs, therefore their reports may be bias."

"Professionals should be made accountable for their decisions! Professionals with no registration within a certain field are giving their opinions, which are having an impact on decisions made. However they are then not accountable for consequences of the final decisions made."

"This route is absolutely diabolical, I feel like I am lost."

"I still do not really understand what they intend to do or if meetings have been held which again is frustrating."

"I am a professional who works with children and the Access Pathway. I feel my opinion with regards to other children is taken into account, but not with my own."

"I find it abhorrent that a small group can make decisions based on my child (who I know best) based on questionnaires and a few profiles. Parents should be given the opportunity to be interviewed informally by the Panel. They should be invited to attend. Keeping parents away from the Panel just gives the appearance that the Panel is acting as a gate keepers to referrals. In my case guessing at a diagnosis without even speaking to me. Without ever seeing my child. Then referring me to a

service that could literally do nothing for me. I felt the Panel was offering anything else other than screening.”

“Recommendations are being made by professionals who do not know my child. They are not aware of the full extent of my health needs, including physical and mental health. They are not being held accountable for their recommendations. When a recommendation is made within mental health, it should be by a professional who is aware of my child’s health concerns. Whatever recommendations are made by said professional should be followed up and adhered to. There are too many chiefs and not enough Indians.”

“Family hub worker was brilliant.”

“FFAP member of staff let me know it was going to Panel in a letter after we had had a telephone call.”

“School SENCO let me know it was going to Panel.”

“School nurse let me know it was going to Panel.”

“It took 4 weeks to get a decision from Panel.”

When asked how things could be improved with this stage of the Pathway, responses included:

- Parents should be allowed to present their cases to panel.
- Parents should be involved in the panel decision/have more input in the panel.
- Parents to attend panel meetings, so that they have the opportunity to ensure the full extent of their child’s medical & social needs are taken into account.
- Professionals should not judge every child the same. One size does not fit all.
- Better transparency of process/decisions.
- Quicker response from Panel.
- Decisions made within a more reasonable timeframe.
- Parents to attend panel when the Childs case is presented/present themselves.
- Involve parents more.
- Better communications and more regular updates.
- Acknowledgement of receipt of referral.
- More face to face discussions with relevant professionals.
- Hold professionals accountable for their part in the process.
- More help for parents whilst waiting for pathway results.
- Better case filing, accessible to all professionals who require access to records. Allows for consistency and fluidity of process. Also reduces missed information.
- The pathway is not child-centred. Quite often professionals do not even remember my child’s name a basic health needs are just not being met.
- My Son cannot leave his mental health issues at the door when entering a hospital. Nor can he leave his physical health concerns at the door when he is struggling with his mental health. The two need to be taken into consideration together when assessments are made.

Stages 13 & 14: Panel Decision, Individual Support Plans & Referral to Packages of Support

Following review at the Access Pathway Panel, the panel may decide that a further assessments are needed; multidisciplinary packages of support are required; support is required from one service only; or that the case is not eligible for enhanced support and is referred back to Universal services. Those involved in a child's care should be advised of the decision and the next steps; and if referred to a package of support, then a lead practitioner should be assigned to the child and family.

Parents and carers were asked to comment on their experiences of this stage of the pathway, taking in to account how information was communicated to them; their knowledge of how decisions were reached; what the next steps would be; and whether they had a lead practitioner allocated.

The feedback to this question included:

"Given incorrect phone number on letter."

"Sent a very generic letter."

"Delayed decisions from panel."

"Directed to universal services; I felt I needed specific advice on my child's behaviour."

"CAMHS assessment does not pick up on high function/Asperger's."

"Did not have a central co-ordinator."

"Was unsure of the next steps and who was doing what."

"I found it difficult to juggle all of the appointments to different services."

"Felt overwhelmed."

"My child's case went to panel twice. The second time a school rep attended. Eventually after quite some cajoling the panel reluctantly referred for screening even then I don't believe she is being screened for the correct condition."

When asked how this stage of the pathway could be improved, parents and carers commented:

- Tailored letters - easy read/age appropriate.
- Letters individualised to child rather than a standardised template.
- A Keyworker who manages your case during and post pathway.
- A key worker/lead professional should be appointed to cases within the pathway, who knows the child and family circumstances

- One person to follow the families... start to finish!
- More transparent process.
- A phone call or face to face meeting would have made the decision process feel more personal and given me the chance to ask questions and be signposted to next stage of process. Informed on letter of services to approach however these services are not aware of what to do next.
- A clear indication/recommendation of the support that child needs following assessments.
- Need a central coordinator so the recommendations are carried out.
- Clearer on how to access support.
- Can we just see a doctor who specialises in ADHD/Autism?
- Support following a diagnosis.

Stage 15 & 16 - Review of Progress & Post Pathway Support

The final stages of the Access Pathway relates to the review period. The outcome of the Panel should advise if and when a review should take place and who would be the lead professional responsible for reviewing progress. Parents/carers were asked to consider if they were aware of a review happening; if they felt it took place at the most appropriate time; whether the review adequately involved all parties; and their experiences of the support received.

Finally, parents and carers were also asked about their experiences at the end of the pathway. This stage of discussions asked parents/carers to consider if they were provided with adequate support to move forwards, if they knew where to go to if there was a deterioration; and how re-accessible they found services.

Parent/carers gave the following feedback and comments on the final stage of the Access pathway:

"I expected a lot more support and information following discharge. I just received FFAP's phone number."

"CAMHS will only see you once as you are expected to utilise skills previously taught. However mental health and disorders do not work this way. As the child grows, and situations change mental health can fluctuate and deteriorate, and the child will develop new traits. This should be reflected with ongoing assessments and support packages open to change."

"Recommendations have no ownership, so it is not clear who is responsible."

"More support/case management needed in place for families who have had a poor experience of early pathway."

"Follow up meetings needed following discharge/panel letter."

"Clearer recommendations for support following assessment in closing reports."



Parent Suggestions for Pathway Development

During general discussions, parents and carers did offer headline suggestions on how they felt the pathway could be improved. These included:

- Timeline needed to point out how long the process takes.
- Why do you have to wait until they are five years old?
- Process needs to be more consistent.
- Better communication.
- More training for professionals.
- Criteria to be jargon free and not patronising.
- There should be more flexibility in support.
- Dual/multiple appointments– so the child or young person does not have to hear all the ‘negative’ stuff, eg. 1. Meeting as family 2. Meeting with parents 3. Possible meeting with the child.
- Waiting lists need to be taken into account. You are unable to access certain services until a child is of a certain age, however sometimes by the time the child is at the top of the waiting list, they are too old to access that service and have to wait again for the next one. During these long waiting times, we are receiving little to no support or advice on how to care for our child’s special needs.
- More “screening” time at the clinic.
- A quicker diagnosis.
- Assessment to be more ‘real life’ based.
- Treated as equals, and assessed as individuals.
- Support not discharge after diagnosis.
- Compassion and kindness would go a long way in making the whole pathway and process less frustrating. As parents we understand that waiting lists are inevitable, but when you wait such a long time and go without support and advice, to be treated so badly by professionals and still not given the support or advice you need, it is extremely disheartening and trust begins to be lost.
- Appointments close together not weeks/months apart.
- There should be an easy way to complain/challenge a decision or diagnosis.
- Medical issue to go down a medical pathway and not a social pathway.
- To stop dragging the process out so long and provide support quicker.
- To be moved out of local authorities control and into the health service’s control (not CAMHS).
- Services need to be properly staffed, so that parents are not waiting so long.

Emerging Themes

In addition to feedback received directly relating to each stage of the pathway, general discussions and additional feedback was captured throughout the engagement activity. These experiences related to various specific themes which we have grouped as follows:

Communication

Concerns with communication was raised consistently throughout discussions. Parents and carers reported that “communication is failing at all levels”, and reported there being poor communication back to parents, and also poor communication between agencies. Parents felt that they were not fully informed of assessments taking place with their child, nor were they updated on progress. They also felt that confusion was caused due to “referrals being bounced around all over the place” and information being incorrect or incomplete.

“It sometimes feels like professionals are playing Chinese whispers with my child’s history and medical records. It seems like they are focussing on something unimportant from years ago as though it is a key feature. But they are not aware of recent panel decisions, or key events within my child’s life. Is this due to poor communication?”

When communications were received, some parents found them to be too jargon based, and the instruction unclear

“Appointments are not clear as to whether the child should or should not be there.”

Interaction with Schools

A number of issues were raised with regards to parent interactions with schools. Many parents felt that schools were not consistent in their approach; were poor to communicate; and did not act on recommendations.

“I felt my voice was unheard and dismissed by the school.”

There was also a strong feeling amongst parents that schools had a reluctance to act and also had a strong bearing as to whether their child’s journey along the pathway was progressed.

“If schools don’t support you, you can’t get any further with FFAP.”

Interaction with Professionals

Supporting a child with potential additional needs and ensuring they receive the required support is undoubtedly a challenging and emotional time for parents and carers. Some of the parents we spoke to felt as though professionals did not always communicate with them sympathetically, and sometimes felt as though lines were



blurred as to decisions professionals were making, particularly if they had not directly assessed a child.

“Professionals can be condescending and think they know best but they are communicating incorrect information regarding Asperger’s and ASD.”

“Professionals lacking in knowledge of ASD e.g. misdiagnosing with ADHD and dyspraxia.”

“Professionals are bringing their own personal opinions to pathway meetings; this comes across as judgmental.”

“Professionals should keep person opinions to themselves and only share their PROFESSIONAL opinion!”

“Professional’s attitudes need to change. Dismissive and aggressive when they are supposed to listen and support.”

“Professionals... should go on the equivalent of a ‘parenting course’...speak nicely to parents!”

“I have waited so long for the support and advice and medical attention my Son and I desperately need, that I have had to try strategies on my own. To then be criticised for trying is so patronising and disheartening, even when they seem to work. What is more frustrating is that the same professionals who criticise, are not offering any alternative solutions or constructive advice.”

Impact on Parents & Carers

Further to their experiences of interactions with professionals, parents and carers spoke at great length about the impact the process has on themselves. Parents repeatedly reported as feeling ‘blamed’, ‘not listened to’ and ‘in limbo’. As primary carer for the child and central to their development, parents often felt overlooked in their voice, and in the value their contributions could make to the assessment process. They also reported as requiring additional support for their own needs, and not just those of their child.

Although we are not the professionals, we are with our children almost every minute of every day, surely that counts for something?

“Care for carers is so important and needs to be signposted more.”

“Time to support with the little things!”

“Believe the parents. They are the experts of their child. Listen to them.”

“We know how our children think/feel– we are the experts as we are often of the same abilities/disabilities.”

Seeking a Diagnosis

Although the Access Pathway intends to offer accessible support for families and children regardless of whether or not there is a recorded diagnosis, there was a lot of feedback from parents that suggests they still feel a diagnosis is needed in order to access support, and in not having it is hindering their progress along the pathway.

“My daughter needs a diagnosis to get the help she needs. They think we want a label for the fun of it. We need a “label” to get the help we need. Unfortunately no “label” no help that’s the way it is.”

“We should not be made to feel driven by a diagnosis! But without a diagnosis we are not able to access support packages within the pathway!”

“Parents should not be judged for wanting a diagnosis. Nor should they be judged if they query a diagnosis, or are hesitant to get one. They should be supported throughout the process as it is very emotionally difficult. Parents and professionals both want what is best for the child, so why does it feel like a fight?”

“There are certain expectations in the standard of health care we expect to receive and they are currently not being met. I feel mental health is treated differently to physical health concerns. With a physical health concern there is no condemnation. If a physical health concern cannot be identified, further opinions would be sought and referrals made. This is not the case with mental health currently.”

“You wouldn't wait to diagnose someone with cancer, why should you wait to diagnose someone with a mental health condition. Medical conditions need diagnosing, so that intervention can begin as soon as possible.”

“We still need to find out if my child has ADHD but I feel as though I’m stuck and don’t know where to go next as it sounds like all the school changes have to happen first.”

Children/Young People’s Feedback

The Healthwatch North East Lincolnshire team attended a session at the Grimsby Institute and spoke to a group of 30 students. Healthwatch asked the students for their views and opinions on support they had received or would have liked to receive when accessing services. Some of the students were aware that they had been through a pathway and have a diagnosis of ASD or ADHD, whereas some students reported as having a diagnosis but were not aware of having been through a Pathway. This question was asked as to ascertain what services the young people had come into contact with and when and how they found accessing those services.

When asked how they feel services could be improved, the responses from young people included:



“Good help to me I believe is the mental health support North East Lincolnshire offers. It’s more regular and made ‘normal’ and less negative and scary to talk about. Less of a negative stigma towards different ages, believing its ‘hormonal’ or ‘puberty’.”

“CAMHS to have more time to spend with crisis patients.”

“Primrose ward at cygnet bury to be shut down.”

*“People to actually give a **** about mental health issues.”*

“Better mental health support.”

“More help and support with mental health” and have “less interruptions.”

“Doctors not laughing at you, especially when they weigh you.”

“More time at a medical practice to see your doctor.”

“Less waiting times, I don’t like waiting.”

“More thorough GP checks.”

“More methods of getting advice.”

“More welcoming attitude.”

“Less waiting times.”

“You can’t be a single minute late or you won’t get seen but they can call you in 15 minutes late.”

“Better communication.”

“The NHS should do more to regularly inform people of ‘walk in services’ etc”

“Better communication between doctors and nurses so time isn’t delayed.”

During discussions, some of the young people reported that they felt let down by mental health services but would like to see support groups for them but in a fun way. Young people, if over a certain age and capability, would like to see the information about them that professionals and their parents see. Young people also reported feeling excluded from the process and want to be more involved in decisions that are made about them.

Professional's Feedback

11 professionals completed the online questionnaire and 30 professionals shared their views via the SENCO Forum and Access Pathway meetings.

Those that completed the online questionnaire included a mix of professions including two Health Visitors, School Nurse, Wellbeing Practitioner, Clinical Psychologist, SENCO, Families First Practitioner, Nurse, Deputy Head/SENCO, Deputy DSL and Speech and Language Therapist.

From the responses received, 4 respondents were not aware of the criteria for the Access Pathway. 8 respondents also stated that they are only somewhat aware of universal services that can support children and families. Two of the respondents also stated that knew who to contact for guidance and advice in more complex cases.

When asked how long it had taken them to complete an EHA the answers varied between an hour and 3 weeks. In response to the question 'could the EHA be made simple', the respondents answered;

"A more simpler referral form."

"Should not always be the school submitting EHA."

"Should be specific to Access Pathway."

"Form is quite complicated."

With regards to the Access Pathway Panel respondents to the Professionals questionnaire stated that:

"The panel felt like an interrogation"

"I was lead author for an EHA, however it was combined with another child in the family, therefore the school nurse with put down as the lead author for both children. I never got sent any information or plans."

"The Panel is very intimidating and scary."

Respondents reported that it took up to 2 weeks for the professionals to receive the information from the Panel, however not all professionals understood why the decision had been made or what their responsibilities are with regards the plan.

Professionals also made the following comments with regards to the Access Pathway:

- Unsure who should complete the form if a child has complex needs.
- Doctors always send the referral form back.
- Lots of processes being changed and advice is not consistent.
- Systems are being flooded and there are too many barriers in place.
- There are inconsistencies with various professionals e.g. CDC and paediatrics.

- 
- Gaps with pre two year olds.
 - More families should be invited to engagement events.

When asked how the Access Pathway could be improved, professionals made the following suggestions:

- The pathway needs to involve...someone who listens, cares and isn't judgmental. Somewhere you can be seen quickly, and be given the time to speak about your concerns.
- More access for drop in appointments/support clinics, eg. out of hours.
- Quick process, easy to navigate, effective, one stop to get families off the hamster wheel.
- More provision for 'drop in' appointments.
- A service which is more understandable for the child, where they can be easily involved. A service which is straight to the point and easily accessible.
- Consistent keyworkers to follow up through the process and follow up actions. 'Duty' drop in system.
- Speedier process.
- Fluidity of information between professional agencies. One stop shop. Easier access for families to services.
- Good help looks like: Knowing that the support is available for everyone who needs it with clear guidelines not written in jargon that some people don't really understand. Not having to wait for weeks for referrals or even months. Also diagnosing is not a one cap fits all, it's individual to the person's needs.
- Open and honest conversations with clear promotion of services and criteria for the public and professionals to utilise and refer into.
- More training needed for social workers and front line staff regarding SEND



Conclusion

Supporting a child with emerging additional needs is unquestionably an emotional and difficult experience for the parents or carers of the child. Parents not only have to face worrying and uncertain times, but also are having to learn about a child's potential additional needs and available services at the same time. The participants in this research have had mixed experiences at all stages of the pathway. Some of these experiences echo those that had already been alerted to local commissioners, and others show further themes emerging.

As expected, the types of concerns identified were different from child to child, and emerged at different stages in their development. In the majority of cases, concerns were identified by parents/carers, but in some instances, these were identified via statutory assessments and/or by a professional involved in the child's development. Many parents reported that they were not aware of these assessments taking place, nor of the outcomes of the assessments.

Parents reported that they were not sure how to access information or where to go for help with their initial concerns, and this was evidenced by the variety of different routes accessed. These included GPs, schools, health visitors, paediatricians and CAHMS. At this early stage in the pathway, parents voiced issues with a feeling of not being taken seriously about their concerns.

There is clearly a lack of knowledge amongst parents of the prevention and early help services available. Whilst some parents had accessed some of these services, they did not necessarily always correlate them to supporting their child's development needs. Other parents felt that they had already implemented some of the methods on offer via their own parental approaches, and therefore felt having to access a similar service was an unnecessary and delaying course of action. On the whole however, parents did welcome such provision and requested both better promotion and signposting to such services. Whilst many of these services are promoted via the Local offer, parents are still not immediately familiar with this, and therefore is not a 'search term' they would associate with.

The various parenting programmes and courses on offer was a particular contentious issue. The term 'parent programme' or 'course' in itself makes parents feel like they are not performing as a parent. The Triple P course was largely criticised, whereas the Parent Puzzle and Stepping Stones received more praise. As parents with children with additional needs, the overarching feeling was that workshops more specific to their child's condition would be more appropriate.

With regards to the Early Help Assessment (EHA), there appears to be a number causes of confusion during this stage. Some parents believed that several EHAs had been completed for their child, with some occurring without their knowledge, and others believed that the EHA had been completed either much earlier or later in the pathway than it should have. Based on their experiences, parents felt that much more training was needed for professionals to complete the EHA, and that a lack of knowledge by



professionals completing the EHA can result in inconsistencies in parent experiences there on in. They also felt that they should be involved more during this stage of the process and there be greater scope for parents to contribute their observations and relevant information. It was also felt that there were unnecessary delays in the process by information not being checked at the time, resulting in them being sent back after submission, due to incomplete information. During the research period, Healthwatch raised with North East Lincolnshire Council concerns that the form was too generic, and we are aware that a new form is now being piloted until September 2019.

Experiences with the Families First Access Point (FFAP) also raised mixed responses. Whilst some parents reported a relatively quick and communicative experience, there were also lots of concerns raised relating to lost paperwork and poor communication with parents. On the whole respondents requested greater information about the role and function of FFAP; a more timely response to EHAs and queries from parents; and for information and timelines to be provided to parents at this point. They also felt that correspondence needed to be worded in such a way in order to understand the information and not feel criticised.

Similar to the EHA and FFAP stages, parents also had mixed experiences of the Access Panel. Some parents received necessary information and had a Professional support them through the process. However other parent/carers have found the system to be confusing and lengthy, and have not been informed if their case has yet gone to Panel. In the absence of professional support, some parents have instead turned to peer support for guidance. Additionally, some parents who have had a crossover of processes, feel the medical route that families had initially started on would have worked better for them. Overwhelmingly, parents felt that professionals should be more accountable for the decisions they are making, particularly when they have had no direct contact with the child, and that there should be greater involvement of parents in the Panel process.

Although a lead Professional should be assigned to families following a Panel decision resulting in a package of support, many parents reported this not to be the case. When speaking to individuals who were supported by a lead professional, they did appear to experience a better outcome. For the other parents, they felt that having a lead professional would be beneficial to them, along with the opportunity to discuss the Panel decision and reasoning for the decision. Again it was reported that correspondence was unclear, and too generic, with not enough information specific to the child. Many of the participants we spoke to had yet to reach the post pathway support stage, but those who had reported the need for greater clarity regarding onward support and point of contact.

Supplementary to the experiences reported at each stage of the pathway, there were further themes that were a consistent issue at all stages of the pathway. Communication emerged as the biggest barrier to parents, in terms of their knowledge of where to go for support, services available, the extent they are kept informed as they travel through the Pathway, and the extent to which they are involved. Additionally, the style of communication that is received has at times been reported to be too



judgemental, unsympathetic, generic, and jargon based. As parents have found communication inconsistent, many have sought out external services and peer support as a route to the clarity they are looking for.

The other overriding theme that has emerged is parents feeling like they need to have a 'diagnosis' in order to access the support they feel they need. The terminology 'Access Pathway' appears to give the misconception to parents that by starting on the pathway, they will have a diagnosis that will then unlock a host of support available to them.

Further themes included interactions with schools, and the impact of these experiences should not be underestimated. Likewise, there is the impact that the whole journey has on parents themselves, which sometimes makes them feel devalued, disillusioned and on an uphill battle.

Whilst there was a low uptake of engagement from children and younger people themselves, the feedback that was received still produced the theme of services needing to be more accessible and inclusive, and sensitive to how they may perceive situations.

Finally with regards to the experiences of professionals, similar suggestions were made with regards to developing the pathway, including a more timely and easier to navigate process; to be more tailored to individual needs; and a key worker approach. Several also suggested having drop in provision for families. Professionals also reported the need for a more consistent approach and greater training and clarity provided to them on the process.

Recommendations

Based on the feedback and experiences of parents/carers, children and young people and professionals who have been directly involved in the Access Pathway, Healthwatch North East Lincolnshire makes the following recommendations to commissioners:

1. A 'directory of services' of prevention, early help and universal support should be widely promoted and be made readily available to all parents, and to professionals working with children. It should also be made clear how such services specifically support a child's development. This information/directory needs to go beyond promotion of the web based Local Offer, as this does not seem to be reaching the public's awareness. It should also be continuously promoted throughout a parent's journey through the pathway as a route to further support.
2. Systems or information should be established that ensures parents are fully aware of any statutory assessments that take place with their child across health, social and educational setting.
3. It would be beneficial to conduct a specific review of existing parenting programmes/courses looking at numbers attending, feedback that had been collected, as well as awareness, accessibility, relevance and practical application. This would assist in future co-production initiatives to help shape alternative programmes that parents are more receptive to and find of benefit.
4. The feedback within this report to be assessed alongside the results of the pilot of the newly adapted EHA form. In particular the development of the EHA moving forward should allow for adequate input from parents and for them not to feel so 'at arm's length'. To provide the clarity that parents and professionals are seeking, it would also be of benefit to have a defined point when an EHA would be instigated, and where 'ownership' of the completion of the EHA lies.
5. A mapping exercise should be conducted of all professionals who could potentially have responsibility for completing the EHA. Feedback should also be collected from professionals who have completed the new piloted form. Following this, training should be delivered to all relevant professionals, and measures put in place to enable future professionals to receive the relevant training.
6. The role and function of the Families First Access Point (FFAP) needs to be clearly defined and promoted so that it is more easy to understand and accessible for parents.
7. Due to the high variances in response times, it would be useful for the FFAP to be reviewed to determine how contacts are triaged and responded to, along with average response times and case filing approaches.

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8. Greater transparency of the Access Panel and its decision making needs to be made for parents. Furthermore, by having more regular communication, greater involvement of parents and a more timed approach during processes leading up to this stage, should provide parents with the necessary assurances that information being presented at Panel is as comprehensive as it can be for appropriate decisions to be made, and again for parents not to be made to feel at arm's length.
 9. It appears apparent that a centralised coordinator or case manager would make the overall process and experience of parents more improved. Whilst Healthwatch cannot determine at what stage this 'role' should come in to effect, it appears from the feedback received that this needs to be very early on, and linked to the professional who parents first contact when initial concerns are first identified. Due to there not currently being a single defined route that parents should access with initial concerns, it is significantly varying the parents' onward journey and outcome. Establishing an early entry pathway with a defined access route for referrals for early development concerns could help identify where such a case manager would sit. To prevent the reoccurrence of the problems experienced further down the pathway, such access point would need to be fully knowledgeable of all local early help services available, and keep record of the services that have been referred to and accessed, along with any additional strategies parents have undertaken.
 10. The requirement for a centralised coordinator continues as parents journey through the Access Pathway, with the initiation of the EHA being a trigger point of need for such coordinator. This coordinator should ensure timely and full completion of the EHA; adherence to the Pathway timelines; as well as being a central contact for both parents and professionals.
 11. Regardless of there being a central coordinator in place, communication needs to be improved at each stage of the process and as a minimum should include notification of EHA being initiated; anticipated timeframe of completion of the EHA; receipt from FFAP and intended Panel date; panel decision and reasoning for; details of onward referral and lead professional contact; and timeline for review if required. All such correspondence should be tailored to the individual; be clear and jargon free; be clear on who (including the child) should be in attendance at appointments and what else should be taken; to fully explain reasoning for decisions; advise of alternative support available during the assessment and decision process; and provide a contact point to access any queries regarding stage of process, support available or decisions made.
 12. To provide greater coherence of an individual's journey through the pathway, trigger points for each stage, along with a standard timeline and optimum response times should be identified and mapped.

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13. Clearer information for the public of what the Access Pathway is should be produced and include, what it aims to achieve; the purpose of each stage of the pathway; the timelines and responsible body for each stage of the pathway; and the potential outcomes for families from the pathway.
 14. Greater understanding is still needed with regards to the mixed perceptions of parents of either wanting a 'diagnosis' not wanting a diagnosis, or feeling the need for some kind of diagnosis or label in order to access support. As part of future co-production initiatives, explore further with parents, families and children their expectations post the Pathway journey; the types of after support they feel they need or is missing; and what they perceive to be a good 'outcome'.
 15. A lack of involvement of parents and the opportunity for face to face contact with professionals was repeatedly reported as a concern; and several professionals suggested having some kind of drop in clinics for parents. Such provision should be reviewed further as part of the Pathway developments.
 16. Despite commissioners previously undertaking initiatives with professionals to inform them of the Access Pathway process, greater clarity still appears to be needed. As the Pathway is revised and developed, previous communications should be reviewed and new routes to communication undertaken as the Pathway is revised and developed. This should include communications to schools, with the pathway clearly defined to them.

Next Steps

This report will be submitted to North East Lincolnshire Council and North East Lincolnshire CCG, as commissioners of this independent review. The findings of the review will be presented participants and stakeholders in partnership with commissioners at two feedback events to be held in May 2019.

Moving forwards, Healthwatch North East Lincolnshire will continue to contribute to the development of the Access Pathway, and ensure that the feedback and recommendations within this report and taken in to account in the co-production of service developments.

Acknowledgements

Healthwatch North East Lincolnshire would like to thank all the parent/carers, young people and professionals who took part in this research.