

AUTISM PATHWAY REPORT

An Exploration of the Parent Carer Experience, of the Multi-Agency Pathway, that identifies and supports children and young people with Autism Spectrum Disorders in Derbyshire.

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Prefix

This is a response from a participant who fed back to Healthwatch Derbyshire on reading the report:

“The report is appreciated and I only hope it may bring about a review of how things are carried out and that it will prompt change to much more appropriate services.

Educating people about autism is key. If people can REALLY understand the challenges that a young person on the autistic spectrum faces, the day to day difficulties, and put in place ways to reduce stress and anxieties for the young person (and their families) then the world will move towards being more ASD friendly.

I would just like to add that for us, the most useful thing in the whole process was receiving a detailed Clinical Psychologist’s report which included and explained a breakdown of (named child’s) cognitive functioning, his strengths and difficulties. This enabled me to develop a deeper understanding of (named child), his emotions, his frustrations etc, so that I knew him even better and could support him more appropriately. I was also able to tell him why he was finding somethings challenging, explain that it wasn’t his fault and give him strategies to cope. I could also feed this sort of information through to schools etc. Consequently this has been the most beneficial thing for (named child) too!

Prompt diagnosis is definitely necessary and, more than that, a full and detailed assessment of what that diagnosis actually means for the individual child.”

1. Acknowledgement

Healthwatch Derbyshire (HWD) would like to thank all 26 families who participated in this Service Evaluation. We would like to express our gratitude to the Autism Coordination Group for their support, and also to the providers that helped to publicise the project to support the recruitment of participants.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all parent carers who have experienced the Autism Pathway, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that parent carers conveyed to HWD. The data should be used in conjunction with, and to compliment, other sources of data that are available.

3. Background

HWD is the local consumer champion for health and social care. The Healthwatch network is made up of 148 local Healthwatch organisations and Healthwatch England, the national body.

Healthwatch has a common purpose - to ensure the voices of people who use services are listened to and responded to. The network shares a brand, has common values and comes together to work on priority areas and campaigns.

Local Healthwatch work to provide unique insight into people's experiences of health and social care issues in their local area; HWD is the eyes and ears on the ground finding out what matters to our local community.

Autism Spectrum Disorder (ASD)

"Autism is a lifelong developmental disability that effects how a person communicates and relates to other people. It also effects how they make sense of the world around them." (National Autism Society).

ASD is characterised by a triad of impairments in social interaction, imaginative thought and communication, it includes Asperger's Syndrome and childhood autism. No child presents the same traits and there are no medical tests that can diagnose ASD, clinicians have to observe an individual's behaviour and development to make a diagnosis.

An early diagnosis and the provision of support services are considered essential for a child's development, future progress and general quality of life, as is support for parents and carers in providing guidance on how to monitor and cope with a child who has ASD.

It is expected that 700,000 people have ASD in the UK, which is more than 1 in 100. In Derbyshire there is estimated to be 1,915 young people who may have ASD. (National Autism Society, Statistics).

Derbyshire County Council has a Multi-Agency Pathway for identifying and supporting children and young people with ASD for school age children and pre-school children in maintained early years setting that was produced in 2012. A summary of this pathway can be found in Appendix 1.

4. Purpose of the Report

Anecdotal evidence obtained by HWD during general engagement activity suggested that although there was some good practice across the county, other parents were not entirely happy with how certain parts of the referral pathway operated, including delays in diagnosis and lack of support. This resulted in parent carers feeling isolated and reaching crisis point.

The purpose of this Service Evaluation, therefore, was to give parents and carers the opportunity to talk in more detail about their experiences of the Autism Pathway in Derbyshire.

It is important to note that we looked at the experiences of the pathway, not at particular professionals, departments or issues.

As the pathway operates differently in the North and South of Derbyshire, due to how services are organised, we conducted the study countywide, but also compared experiences between the North and South.

The Autism Co-ordination Group was also very supportive of the Service Evaluation and HWD worked in collaboration with Derbyshire County Council and all relevant stakeholders.

5. Methodology

This Service Evaluation gathered qualitative accounts of parent carer's experiences of Derbyshire County Council's Autism Pathway over a 12 month period.

Although qualitative studies such as this one have a smaller sample size than quantitative studies, it is acknowledged that:

- There will come a point where there is no new themes emerging, if the sample size increases it will no longer contribute to new evidence.
- There is no need to provide a sufficient sample size to estimate or determine statistical information.
- The type of information obtained in qualitative research is rich information. There will be many different parts of information in each narrative collected on interview. It would be near on impossible to transcribe a hundred narratives.

(Ritchie, Lewis pg 83).

5.1 Recruitment of Participants

Recruiting participants for this Service Evaluation was done by disseminating posters and flyers throughout the county via the HWD network, voluntary organisations, schools (including specialist schools and children's centres).

Parent carers were asked to get in touch with HWD if they have a child who has recently received an ASD Diagnosis and wished to share their experiences of this process. During this conversation Engagement Officers discussed the Service Evaluation, and went through the selection criteria.

5.2 Criteria for Recruitment

- Inclusion criteria
 - Parent carer of a child or young person aged 3-18 years who has been through the Autism Pathway in the last 12 months and;
 - Parent carer of a child who is in or has been in a Derbyshire school and;
 - Parent carer willing to provide informed consent to participate in the Service Evaluation.
- Exclusion criteria
 - Person diagnosed with ASD less than 3 years old or over 19 years of age.
 - Child or young person with an ASD diagnosis over 1 year ago.
 - Parent carer of a child or young person who has not been through the ASD Pathway.

All participants received HWD information, a participant information sheet and were asked to give their informed consent before interview dates and times were arranged. Parent carers were able to withdraw from the project at any stage if they wanted to.

5.3 Participants

A total of 26 families were interviewed.

- 14 families - 54% North Derbyshire
- 12 families - 46% South Derbyshire

The large majority of participants were mothers, whilst some fathers contributed in sharing their experience of the Autism Pathway. Two participants were Grandmothers.

Two interviews enabled us to speak to the young people about their experience.

Twenty families were interviewed who had boys going through the Autism Pathway with ages ranging from 3½ to 13 years old.

Six families had teenage girls going through the pathway.

Nineteen families had received a diagnosis, 5 were waiting for a diagnosis in North Derbyshire and 2 were deemed inappropriate for a diagnosis by their lead clinician.

5.4 The Interviews

HWD used an inductive approach which meant that the Engagement Officers didn't go into the Service Evaluation with pre-conceived ideas or theories.

Engagement Officers conducted open, un-structured, face to face interviews with parent carers. The interviews were digitally recorded and then transcribed.

Each interview lasted approximately 1.5 - 2 hours.

Parents were asked to talk about their experience in 3 broad areas:-

- Pre-diagnosis
- Diagnosis
- Post Diagnosis

To maintain some consistency, i.e. to ensure that both Engagement Officers were employing the same interviewing technique, the first few interviews were conducted jointly.

If/where participant's answers or recollections of their experiences were vague; the Engagement Officers used prompts where appropriate.

5.5 Data Analysis

This was a qualitative Service Evaluation, involving the interpretation of data.

Each transcription was examined in depth and a core category of themes emerged.

This technique basically involved breaking down the data that was gathered during the interviews into emerging themes (categories), e.g. communication, referrals, waiting times etc. It began soon after the collection of initial data, i.e. the first few interviews. This ensured that the Engagement Officers didn't go in with pre-conceived ideas, they let the data shape their thoughts. When it got to a point where no new themes were emerging, interviewing stopped.

The findings were recorded separately for both North and South Derbyshire.

6. Summary of Findings

Several overarching themes emerged during the Service Evaluation, these were:

- Education
- Impact on families
- Communication
- Waiting times
- General Practitioners
- CAMHS
- Diagnosis
- Support for parent carers during and after diagnosis

There wasn't a substantial difference between the experiences of parent carers in North Derbyshire compared to South Derbyshire.

6.1 Education

- All parent carers recalled experiences of education.
- Parent carers reported that there needs to be an improvement in support and recognition of the signs of Autism in Education.
- Parents felt that their child was not receiving adequate and/or sufficient support to meet their child's needs. This impacted on their child not wanting to go to school, being bullied and socially isolated, or even temporarily suspended due to teachers not being able to handle the child's behaviour.
- Parents also felt that they hadn't been listened to.
- Parents spoke about a reluctance of schools to make referrals to the educational psychologist.
- There were some examples of good proactive help given to parent carers by staff, but this was not consistent.

6.2 Impact on Families

- The impact on families was discussed in most interviews. With most parent carers expressing difficulties dealing with the situation, and feeling at crisis point.

6.3 Communication

- There seemed to be a lack of clarity amongst parent carers as to who was the first port of call to trigger a referral to the Autism Pathway.
- For the majority of parents it was stated that there was some form of communication breakdown at some point during the Autism Pathway. Issues in communication ranged from parent carers being unaware they were on the ASD pathway, causing a sense of confusion and frustration of what was going on, to errors and delays in the administration process.
- Parents stated that they had to repeatedly tell their experience to different professionals.

6.4 Waiting Times

- All parent carers stated that they had experienced significant waiting times to see various professionals.
- Some parent carers however understood the pressures that certain departments were under.

6.5 General Practitioners (GPs)

- Some parents felt that GPs were hesitant, or unaware, of who and where to make appropriate referrals to so that parents were quickly and efficiently being directed to the correct part of the system for help.
- Some parents spoke highly of their GP and found them very understanding.

- There was frustration amongst some parents that their GP has said that a referral would be made to a Paediatrician, but when appointments were chased up months down the line no referral had been made.

6.6 Child and Adolescent Mental Health Services (CAMHS)

- Some families also had contact with CAMHS.
- The majority of these experiences were recalled by participants in the North.
- When there had been CAMHS intervention with families, from the interviews it didn't seem to have been explained clearly to parents as to what the link is with the Autism Pathway.

6.7 Diagnosis

- There was an overwhelming sense that all parents wanted to know if their child was autistic because of the impact this would have on their child's future in terms of education, employment, relationships and if they would be able to live independently.
- Parents made positive comments regarding the autism diagnosis appointments.
- There were mixed feelings about the amount of information given. Some would have preferred detailed information where as others were happy with what they were given.
- Those families who received a diagnosis felt they could move forward in getting the right support and intervention for their child. They felt relieved.
- A large number of parents said that their initial instinct was right and wished that the professionals would have taken this on board much earlier in the process.
- Some stated that information was not given to them in plain English, some parents felt that it was meaningless because they didn't understand.

6.8 Support for parent carers during and after diagnosis

During diagnosis:

- Many parent carers said that they were offered some sort of support whilst they were going through the pathway.
- Others said they found great difficulty in getting appropriate support, or knowing where to get it from.
- Some parent carers stated that they were referred for inappropriate support.
- A large number of parents said they were unaware at which point the Autism Pathway had started.
- Parent carers interviewed found the pathway very difficult due to the amount of clinicians, professionals and assessments involved. There was a sense of confusion and lack of understanding as to where they were in the process.
- Parent carers felt they had to find out a lot of information themselves.
- All parents stated that they were the experts with their child and they knew them inside and out. There was a feeling that not all professionals listened to their views and some were quick to say that parents shouldn't want to label their child.
- It was stated that there was a lack of sibling support.

Post diagnosis:

- All the parent carers who had attended the Autism Workshop or an Understanding Autism Course (the details of which course or workshop was attended was not clarified with participant who tended to refer to them both as workshops) spoke very positively of them in North and South Derbyshire.
- Some parents shared their positive experience of getting support from a clinician at a support group.
- Parents commented on how great it was to be able to visit the clinician to get advice on different matters relating to their children on the Autism Spectrum.
- Only one parent carer spoke about being offered a follow up appointment after the diagnosis.
- Some parent carers didn't feel they received support post diagnosis, i.e. they weren't invited to attend the workshop/course, or weren't signposted to support.
- In South Derbyshire participants particularly stated that they had difficulty accessing support services as they weren't local to them. Most of the activity took place in Derby City, Matlock or Chesterfield. To parent carers the term 'local' meant within their district.
- Parents said that they really valued access to parent led support groups, they found that they could learn new coping strategies, meet new friends and share similar stories.

A large majority of experiences related to education which is technically beyond the remit of Healthwatch, however we would be willing to work with agencies to address this area.

Recommendations include:

- Increase awareness in education for teaching staff to recognise the signs of autism and to implement the appropriate support.
- Increase provision in appropriate support/advocacy for parent carers with children and the Autistic Spectrum and co-existing mental health problems.
- Increase provision of information to guide the parents through the pathway, to include the roles of the different professionals, what should happen at each assessment and local/national information.
- Ensure parent carers are aware that follow up appointments are available following diagnosis, when they are available and what their purpose is.
- A single point of contact, where the parent carer could communicate in order to be kept up to date with where they are in the process, and where they can access support to avoid getting to 'crisis point'.

More courses need to be offered to parents whilst they are going through the pathway to help them with coping strategies.

7. Findings

As the transcripts were examined the following themes emerged:-

- Education
- Impact on Family
- Communication
- Waiting Times

- GPs
- CAMHS
- Diagnosis
- Support during the Diagnosis
- Post Diagnosis Support

7.1 Theme 1: Education

All parent carers recalled experiences of education.

The majority of families interviewed across the County explained that there is a lack of autism awareness and training within teaching staff. Parents felt this had a direct impact as to whether staff in education were spotting or exploring the potential signs of autism as a cause of their child's behaviour even when parents were highlighting concerns.

"We didn't spot them and the teacher didn't spot them and the TA didn't spot them because there is not enough autism knowledge in education and I feel that that needs addressing because there is more diagnosis now of autistic children."

"When my child was in Year 5 the teacher said, 'Oh I don't think he is on the autistic spectrum.' I went away thinking maybe we're wrong, maybe we're being over anxious and I don't want to label the child with something ..."

Another parent spoke of the skills of teaching staff:

"Our problem was that the member of staff didn't have the skills. They hadn't got a clue to deal with my child's needs."

Some parents felt that their children were not receiving adequate and/or sufficient support and therefore the establishment was not meeting the needs of the child:

"I have mentioned getting some support from the Autism Outreach team; the school doesn't seem bothered in accessing that support. I don't feel like my child gets enough support because the SENCO only works for a couple of hours each week and she has to see other children."

Parents felt that the lack of support had a direct impact on the child not wanting to go to school:

"I struggled with the primary school, they let my son have unstructured playtime, they labelled him as a naughty child and he had three different teachers in one year. I had to move him because the thought of school in the morning caused him anxiety and made the morning routine very difficult."

Another parent said:

"My child's attendance is low because of the anxiety she faces because of the reluctance to go to school. Her worries start because of bullying, social isolation and the teacher's attitude."

Some parents discussed how they had tried to communicate with educational establishments in relation to their child's behaviour and didn't feel that they had been listened to:

“I highlighted all of concerns relating to my child two weeks before he was supposed to start, I told them all of his behavioural issues and explained how he interacted with other children. Despite my attempts to communicate with the school they couldn’t cope with him when he started.”

Another parent told us that the school had picked up on signs of autism but no referral was made because they wanted to wait until the child transitioned to secondary school:

“Problems were identified in Year 6 but nothing was done because my daughter was moving up to secondary school, no referrals, no information, nothing.”

Parents felt that professionals weren’t listening to them and that they were reluctant to refer the child:

“When I said this to the Head, she said, ‘He only comes every so often and we’ve got so many children on our books and, to be honest with you, we’re managing the [named child] fine, so I don’t think an assessment will be forthcoming But I can ask.’ I never heard any more about that and I wasn’t pushy enough to say I demand it because I’m sort of quite a humble person ... I don’t expect lots of support ... I thought I am the only advocate for my child.”

Some children were reported as having meltdowns within the educational environment, being labelled as naughty children they were isolated from other children, activities and, in some instances, they were punished. One parent gave an example of how a member of staff highlighted issues with how other members of staff were treating her child:

“I don’t think he’s treated very, fairly, I do believe he has some issues, he is singled out as a naughty child and there are certain nursery workers there who are only interested in the children who will behave. If he was the one to put his hand up to partake in an activity, he wouldn’t be chosen.

Another example was also highlighted:

“My child was strapped in his pushchair and left in a room on his own, a staff member was supposed to be rocking him asleep but she just left him.”

An example was given by a parent explaining how her child was isolated from other children:

“He just wasn’t coping well in the classroom situation. The first thing they did was move him away from the other children. They took his desk, put him on his own next to the teacher’s desk and right next to a massive radiator ... I had said to them he really struggles with his own temperature regulation ... I said if you are going to put him near the radiator, can you switch it off? So they did but then a couple of days later I came in and it was back on again. His seat was right up against it and he couldn’t see any of the other children from where he was ... he wasn’t allowed that same interaction ...”

A small number of parents explained that their children had been placed on part-time timetables. Quotes have not been inserted due to possible identification of the families.

A number of children were at the risk of suspension or were permanently excluded. Parents felt that establishments weren’t exploring the reasons of what could be causing the behaviour of the children and listening to the parents, this was a contributing factor as to why children were forced to move schools, and why some children were home schooled.

Parents recalled different experiences:

“My child has been moved from one school and excluded from another, both schools did not support him and I had a breakdown in relationships with professionals. My child now has input from the Intervention Pathway Team, I don’t have much confidence in them because they don’t seem to have much autism awareness. They also use centres that aren’t safe.”

One parent said, “... I was just beside myself. I thought a primary school aged child being excluded; I’d never heard nothing like it in my life.”

Parents spoke about the lack of ownership by the schools regarding referrals and assessments into the educational psychologist:

One parent said, “The school was unhelpful, they did not try to support my child, we never saw an educational psychologist even though we were on the autism pathway.”

Another parent said that teaching staff were arguing over who was going to pay for the educational psychology assessment.

A minority of parents had positive experiences with educational establishments. They valued the support from teaching staff and reporting that they helped parents to identify and implement the right strategies and/or make accurate referrals. This resulted in a positive impact on the child’s development. It also aided in building relationships with parents.

“... he just sort of says ‘oh well, I’ve been kicked and punched again today’ and when I find out about the incidents we go into school and the school deal with it brilliantly ...”

“The pre-school highlighted concerns to me but also recognised that my child was gifted and talented, they made all the appropriate referrals.”

“The private nursery has been brilliant from day one, they have gathered evidence right from the start and they have given me lots of support.”

“I can’t praise the school high enough to be honest; they are amazing they really are.”

“[Named school], are absolutely amazing.”

We found that experiences of education were consistent throughout the families in North and South Derbyshire.

7.2 Theme 2: Impact on Families

Most of the families interviewed explained the detrimental impact that arranging support for their children had on them. Some families were also trying to deal with other underlying worries as well as the autism.

“There is no support for me as the parent; I have struggled to get down to the secure unit and to understand what has been said.”

“[Named child] doesn’t always tell me. ... he just accepts some of it ‘oh well people hate me, people call me weird, they pick on me that’s what happens mum.’”

“When she got frustrated things were getting trashed like whatever came in her hand she just chucked ... four televisions have been smashed, doors, you name it and it was all frustration because she didn’t know how to express herself.”

“In some ways I think we’ve got this far because we’ve pushed.”

“I’ve done a lot of research and I’ve been reading books, so we’ve really geared ourselves up, but nobody outside recommended those things to us, we just did it.”

“It’s horrendous, it’s very stressful. We can’t go out, it’s difficult when you’ve got three children who are average children and they are doing what kids do but when you’ve got a child with autism it’s so unsafe when you’re out.”

“My son had enough of going to the assessments; he was frustrated because the clinicians kept asking us why we thought he had autism.”

“I thought why isn’t somebody listening to me, how loud am I going to have to scream before somebody says, ‘oh yes we need to help you’ ... getting to tipping point.”

“It’s definitely put a strain on our relationship.” And, “We’ve got no family, we haven’t even got a babysitter that could come and we never go out.”

“I want to be seen by a Psychologist because I’ve had enough of this.”

7.3 Theme 3: Communication

There was a general consensus from all the parents that there was some form of communication breakdown at some point during the Autism Pathway.

Issues in communication ranged from families being unaware they were on the ASD Pathway, causing a sense of confusing and frustration of what was going on, to errors and delays in administration processes.

“I missed an appointment because I always book, they’d apparently booked one for 11.30am that is not something I would do. I don’t remember ... we got there late, we never had a letter, they didn’t send us a confirmation letter or anything so ... we got there and we’d missed the appointment and then it took us another 2 months to get another one. This wasn’t very good.”

Some parents told us how they repeatedly had to tell their experiences to different professionals:

“I was getting a bit sick of how many times I had to tell this same information over and over again.”

“The Speech and Language Therapist referral was not successfully sent by [named establishment] as promised.”

“...we were calling a [named professional] for 2 weeks straight every day pretty much, and we were calling on the right days ... we were ringing and we got no answer... we were left in the dark a bit like nothing was happening.”

A number of parents were unaware of how they got onto the Autism Pathway:

“I don’t actually know who referred me.”

Numerous comments were made about the administration of appointments:

“There is no point in having good clinicians and good consultants if the admin is rubbish because the suffering is the same at the other end.”

A number of parents said they missed appointments because they didn't receive any correspondence:

"I had been waiting for an appointment for 10 months; I contacted the clinic when I didn't hear anything only to be told that I had missed my appointment months ago. I never had a letter or a telephone call informing me that I had an appointment."

"... they assessed him in school and I didn't know anything about it and they said he was fine. I had a letter to say he was fine and I said, 'excuse me, no he's not fine, you will re-assess him.'"

We found this consistent in both North and South Derbyshire.

7.4 Theme 4: Waiting Times

All families experienced significant waiting times to see various professionals.

Parents felt that the waiting times to see an Education Psychologist, Clinical Psychologist and Paediatrician were significant enough to raise.

A parent said, "... it took over 6 months for an Educational Psychologist to visit the school." The parent recognised that this delay was due to the cross border arrangements.

Another parent said:

"It's ridiculous ... I tell you why it's ridiculous. If you've got a child who's sort of age 14 or 15, 13 weeks of missed school is a whole term. It will mean they are down on their GCSE grades at the best. At the worse it means they have to drop certain GCSEs."

"...we were being told that there was a 12-18 months wait to see [named clinician], which seemed crazy ..."

"The continuity of a person would be good but the biggest problem is the time it all takes. It's such a shame ... if parents are lost or young or whatever you could be desperate, absolutely desperate and takes so long and if there is no support in place in the meantime it's very bleak, it could be a very bleak time. We are lucky we have each other for support."

"I was angry, and you see my son would have still been at day one," and "I was fighting for his rights."

To see a Clinical Psychologist a parent read out a letter which said, "We have placed [named child] on a waiting list. Unfortunately the waiting list is currently running over 14 months. If this situation becomes urgent we would ask parents to return to the person who's referred them to discuss the situation." Parent said, "I think it is a long time to wait."

"It took from June until September to even get on her waiting list ... there is a waiting list for a waiting list."

Parents told us that the waiting times were long. However they appeared to be slightly longer in South Derbyshire than in North Derbyshire. Some parents understood the reasons behind the waiting times causing frustration with the system.

7.5 Theme 5: General Practitioners (GPs)

Parents felt that some GPs were hesitant or unaware of who and where to make appropriate referrals to so that parents were quickly and efficiently being directed to the correct part of the system for help.

A parent said when they told the GP of what was going on with their child, he/she stated that more help was needed:

"This was another major problem in the system. The doctor didn't know where to refer to. She thought CAMHS."

"The GP was aware of my child due to a previous referral to CAMHS for Obsessive Compulsive Disorder, GP was aware of everything, he wanted to put my child on anti-depressants but this wasn't possible without consent from the Child Psychiatrist. The GP wrote numerous letters without a response which caused a delay in the prescription."

"Our Surgery has been fantastic with the children but I was recently told that my GP wasn't a specialist in this field and if I wasn't going to take the advice from CAMHS then I shouldn't waste their time." The parent carer said that the GP didn't know enough about the Autism Spectrum Disorder.

"I am constantly going back to see my GP with my child, he was reluctant to refer us to CAMHS but he did refer us to the paediatrician. GPs should be able to offer more advice on coping strategies or to signpost you to someone that can."

"The GP didn't think another referral to CAMHS would help us."

"I feel like I am going back and forth with my GP and passed from pillar to post, I feel like I am on a merry-go-round. We have many referrals into CAMHS but then my child doesn't fit the criteria and I have to go back to my GP to initiate a further referral."

A few negative comments were picked up which were around GPs not listening the parents:

"I have seen every GP in the building, there is a lack of continuity which doesn't help the situation."

"It was the doctor who was very patronising, said he's far too young shouldn't be referring him anyway ... it's not about labelling him, it's about getting the right intervention."

"I'm trying to see about having a [named] therapy to try and help him that way, and is there any way we can get any money through the PCT to help him? GP replied, 'No, no there's no funding,' so anyway it was a no-go area, everything I was fighting a losing battle so I just walked out."

Some parents spoke highly of their GP:

"My GP was great with us, I don't have any problem getting appointments, and my child was referred for Global Development Delay. She said that my child obviously needs support and help."

"My GP is great, I have no trouble getting an appointment and they seem to understand what I am going through."

GP is *"... a lovely lady, very caring, she was very supportive, very caring."*

Parent experiences of their GPs were similar in North and South Derbyshire.

7.6 Theme 6: Child and Adolescent Mental Health Services

Some families also had contact with CAMHS, the majority of these were based in the North of the County. They described their experiences below:

“CAMHS were slow, it took my child three overdoses before they would offer any help, my child was already known to CAMHS for OCD. My child had been self-harming for some time.”

“CAMHS said they would discharge my child because she didn’t have a mental health condition, but we didn’t have any support from anywhere else. Nothing else was mentioned.”

“My child had been under CAMHS for 1.5 years; we didn’t see any benefits or see how it had helped. It was just suggested that I attend an ADHD course. They couldn’t diagnose with ASD because that was another department’s responsibility. I got the impression that both departments kept separate patient records.”

“My child had 4 sessions with CAMHS, recommendations had been made to school and I was told that we would get passed onto another worker. I received a letter a week after stating that we had been discharged.”

“We are on the waiting list for a year but I don’t understand what CAMHS is.”

“CAMHS kept saying that my child had an attachment disorder, they don’t listen to me as a parent.”

One family said, *“We tried to get a referral to CAMHS, they wouldn’t take it. Just sent it back and said it wasn’t appropriate. Now I know it wasn’t appropriate because they didn’t have the staff and I get that.”* A second referral was made when the child was at secondary school, *“The school nurse there did a further referral to CAMHS ... CAMHS sent it back again.”*

One family explained. *“... CAMHS can be a blot on the young person’s record depending on which career path they may choose to follow when they are older”*

“We were getting nowhere and she was suicidal and I was having to sleep with her.”
Parent carer said, *“How can an hour a week make a big difference?”*

On one occasion family had to take child to Out of Hours. The member of staff said, *“Who is your crisis support?”* *“We said, CAMHS are closed, we have none. So she said, ‘well the only thing I can do it refer you to A&E.’”*

When one young person began to get better she said, *“CAMHS have done nothing for me.”*

“I don’t understand what CAMHS is and I don’t understand anything about the system.”

There doesn’t seem to be any clarity from the parent carer’s perspective as to how CAMHS fits in with the Autism Pathway.

There were some positive experiences of CAMHS:

“They came out to my house once a week to observe my child which I thought was really good. We got an appointment within weeks and our relationship worked really well. We

got help with issues and I can't praise them enough. We had great communication both by letters and over the phone."

"I thought that the Cognitive Behavioural Therapy was great, I saw a massive improvement with my child."

The majority of the experiences are from families in North Derbyshire.

7.7 Theme 7: Diagnosis

There was an overwhelming sense that all of the parents wanted to know if their child was autistic because of the impact this would have on the child's future in terms of education, employment, relationships and if they would be able to live independently.

Out of the families who received a diagnosis they felt they could move forward in getting the right support and intervention for their child.

"It is one of the hardest times because you don't want there to be anything wrong but you need to know if there is anything so you can access to help."

Parents made positive comments regarding the Autism Diagnosis appointments. There were mixed feeling on the amount of information given. Some would have preferred detailed information where as others were happy with what they were given.

"What does being autistic mean?"

"Diagnosis appointment needs a lot more details, e.g. test/assessment details."

Parents stated they were happy with the accuracy of the reports, although some said that they couldn't understand some aspects of the report because it was too jargonistic in parts.

A couple of parent carers told us how their lead clinician contacted them by telephone to go through the report, the parents were happy with this.

A few families were given information and a clear indication of where their child was on the Autism Spectrum and the others were given no indication. Parents spoke of being able to research specific information about the child on receipt of this information, others found it meaningless.

Other parent carers, with a confirmed diagnosis of autism, didn't mind that this information wasn't shared as they recognised and understood that the autism diagnosis is complicated.

"About his diagnosis, yes we got everything all in there, explained what autism is, that every child is different, there's different sections on the spectrum ... she even put me forward for a course ... which was fantastic."

Parent carers recalled feeling a sense of relief when the diagnosis was given. Comments were made of how the pathway should have been initiated at a much earlier stage in the child's life.

"She saw us all together and with the child outside the room. She said 'we've gathered lots of information' obviously from the whole history that we provided the Speech Therapist, Educational Psychologist and doctor and she, there and then on that day, said,

‘It’s Asperger’s Syndrome.’ You could have knocked me over, not from shock because as I say all this had bubbled under for years, just because I really wasn’t expecting a diagnosis. I thought here we go again, it’s another professional, we’re not going to have another 12 months of providing information ... I could have cried because, why could this little poor child not have had this years ago?’

There were a minority of parents who said they disagreed with the outcome of the diagnosis appointment: An Autism Diagnosis was not made. They were not advised what the next steps or options were from that point onwards, e.g. a second opinion could be sought.

A family felt that time was needed to process the fact their child had been diagnosed with ASD. A follow-up appointment would have been helpful to go back and discuss things further.

Most families spoke about the need to learn strategies that they could implement when needed. It was felt that this type of help and support was lacking. For example, wanting help with toilet training.

Parent carers spoke equally positively of how and when the diagnosis was given in North and South Derbyshire. However:

In South Derbyshire families said they were given a pack of information once they received a diagnosis. The families made the following comments about the packs:

“She gave me all these papers and they’re all mixed up ... I tried to sort them out.”

“The packs were not in an accessible format.”

“It took 5 telephone calls for the pack to arrive ... When the pack did arrive there was duplicate information in it ... one printed in portrait and one in landscape ... some other information was good, different websites ... The one thing we didn’t find useful was the parent support group telephone number. I rang it up and the lady I spoke to said that the group had not been running for the last two years.”

“We’ve found out now you can claim disability.”

7.8 Theme 8: Support during Diagnosis

Many families spoke about being offered some sort of support whilst they were going through the pathway. Others found great difficulty in getting appropriate support, or knowing where to get it from.

“Our problem is that we know that we need support but we don’t know what support we need and then the things that we do know we need, people don’t seem to be able to help us.”

“Still wasn’t getting any help and I was pretty much drowning on my own at this point but I was glad they didn’t close the case and I hadn’t had to fight to keep it open.”

“It was stressful going through the pathway, you don’t know who to contact for support because you don’t know if there is anyone out there. I haven’t been given any information about groups. I feel that the whole experience and the lack of support has caused me to develop depression.”

From A&E “... so we just went home and spent the rest of the Easter weekend just on constant suicide watch with no one to turn to. It was awful ...”

“... you know you’ve got to make yourself a nuisance basically to get the action that you want from them and I understand there’s only two Paediatricians but when you’ve got all these other people saying yes we are doing this but we are not doing the other and you’re expecting something to happen and nothing happens, again you’ve hit a brick wall, you know you’ve got to sort it really, really push to get that other appointment.”

“Social Services were supposed to offer me support because I was at a crisis point and I felt that I couldn’t cope. No one got back in touch with me.”

Children’s Centre worker, “ ... she was really good.”

MAT worker was found to be very supportive. “She was our life saver.”

Parents said they have had to find out a lot of information themselves.

Parent carers said they were told to look at websites to find information about local support groups and to try and understand what autism is.

Parent carers spoke about feeling frustrated that they were signposted to attend positive parenting courses, all of the parent carers didn’t feel that the course was appropriate for them as they couldn’t implement the coping strategies. However one parent found the peer support useful as she was able to learn other family strategies.

Parent carers said they found out about support groups through word of mouth or by the use of social media.

Parent carers that worked full time couldn’t access the support groups.

Some parent carers said that they really valued the support they received during the pathway as they were able to talk to parents that were experiencing similar difficulties.

Some parent carers stated that they received support from a carer support service, three of these parent carers said that they were able to help them fill out forms, one parent said that the carers support service couldn’t help her fill any forms in.

However they didn’t receive any direct support as parent carers with children potentially on the Autism Spectrum, and they thought of them as a signposting service. However, two parent carers were able to access the Carers Break Grant, but parent carers couldn’t leave their children.

Some parent carers experienced difficulties with their children who had co-existing mental health conditions, two of which were admitted into secure units. These parents reported that they received no support as parent carers with children with mental health problems and autism.

Some parent carers received support from MAT teams and children centre workers, they all were very grateful for the support. Two parent carers described being discharged when workers thought that they had all the right coping strategies in place.

There was concern expressed at the lack of support that siblings received, stating that they were not identified as young carers even though they provided a lot of support for the child with autism.

7.9 Theme 9: Post Diagnosis Support

All the parents who had attended the Autism Workshop/Understanding Autism Course (the details of which course or workshop that was attended was not clarified with participant who tended to refer to them both as workshops) spoke very positively of them in North and South Derbyshire. Parents greatly appreciated the opportunity to access the workshop/courses as it gave the parent and a family member the chance to understand what autism is and to learn about different coping strategies. Parents mentioned that the workshop/course provided an arena for them to meet other people from parent lead support groups and they developed friendships with other parent carers.

“The autism workshops were amazing; I was put on the waiting list as soon as my child got the diagnosis. It helped my husband to understand autism because he had been sceptical about the whole process as he was under the impression that our child had behavioural issues.”

“The clinician referred me to the autism workshops; I really valued the support because I had never come across autism before. It gave me an in-depth understanding.”

“Autism course was brilliant.”

Some parent carers shared their experiences of getting support from a clinician at a support group; they also mentioned that the clinician even visited parent lead support groups to offer advice on coping strategies and behaviour management. The parents commented on how great it was to be able to visit the clinician to gain advice on different matters relating to their children on the autism spectrum.

One parent carer was offered a follow up appointment after the diagnosis to see how the family was coping. However this was not consistent across all the parent carers interviewed.

Two parent carers were told that their name was on a waiting list but they haven't heard anything since, they did understand that this was because of the high demand due to the success of the workshops.

Parent carers stated that they weren't signposted anywhere when a diagnosis was made and nothing further was offered in terms of support from the professionals. .

“The support is non-existent, we just support each other the best we can.”

“If you're diagnosed with autism, the journey with the health service finishes ... effectively because they do not have any autism support.”

“Of all the numbers that I've got, I've had to find out myself basically. I thought that even when you're just first talking about it, even before the diagnosis, if you could have somebody say well if you've any concerns there are these numbers they'll get and just people's names what they do, a phone number and an email address and that's all, laminate it and put it into someone's letter. The school should have them, the nursery should have these things just to give somebody because you feel like you're on your own; you really do feel like you're fighting. Or just one local website that's local. I mean we've only just found out about the MAT Team.”

“Yes they signposted us to a lot of things. We haven't really taken up with anything. At the time he was really struggling to make friends in secondary school ... and the most

wonderful things have been some of the books that [named clinicians] recommended, for me and to leave around for the child."

One mother said that she was just given a print out about girls and Asperger's, while the other mum said that she wasn't given any information about group or coping strategies.

Not many families had heard about the Local Offer website.

Two parent carers did have extensive knowledge about the Support and Aspiration Agenda.

In South Derbyshire, parents commented that support services, courses, workshops were difficult to access due to not being local to them.

"The problem I am finding is that, at a local level, it's really difficult to find services and information and then, on a national level, when you look on the internet or the National Autistic Society you're bombarded with information that's not in your area."

"We're Southerners and with two other children they are saying they've got this little thing after school, well Matlock's an hour and half away from us ... there doesn't seem to be anything in this area."

"I would like to be notified of things going on in the area that would benefit [named child] or anything."

"... some of things are in Chesterfield and Worksop and not around [named district]."

"There's a lack of information to other families. To sit and talk, to go out, even just get a function room ... there's just that lack of it round here. It's like in Birmingham it is a big thing where there it's like, oh right, we do this but we'll have to keep it a bit more low key sort of thing ..."

"I really needed somebody to come to my house and check in on me."

"We have just found out about charities as well that can/may help."

"You know we are stretched, we haven't got £500.00 to just go and buy a harness. He also needs a buggy which is £400.00. I am hoping that the occupational therapy can help us with some equipment to help us with that."

"There should be leaflets in there with charities that can actually help with specialist equipment, especially if a kid has got sensory issues of meltdowns where they can just go into their room to use some sort of equipment ..."

"He's been diagnosed and nothing has happened since."

All the parents unanimously said that they greatly valued, or would value, peer support:

"I don't want to go somewhere that I don't know, a named person organised a few things late at night and there were about 15 people in a circle. You had a coffee and there was talking about the new system and that was great and that's how I knew a bit about the new thing."

"I've learned so much from my friends because I've got a couple of friends with autism."

"Everything's a battle, you have to fight for every single thing, there is no agency or person in my view unless you find them yourself, there's nobody coming up to you and saying, 'you can ring this number they're going to help you,' you have to find the information yourself and most information is on the internet or its been through another

parent who's at the school saying 'oh you know you can ring this' because they are going through the same thing, sort of like that Net Mums."

"I'm just a mother, working clerical person ... I'm asking for advice with this person who's got autism. I don't know how to deal with it. I want to talk to somebody who deals with it. I haven't spoken to anybody with a person who's got an autistic child who knows how to deal with it, so I don't know."

8. Recommendations

These recommendations for service improvement have all been made by the parent carers themselves during the course of the interviews.

- The worries and concerns of the parents need to be addressed and explored further when their child displays behaviour that parents struggle to rationalise; behaviour being subjective to individual families.
- Time should be taken to actively listen to parent carers about the possibility of autism. (This is after some parents felt that clinician's did not listen to them and made suggestions to the parents about not wanting to label their children).
- Parent carers called for local information, i.e. within a district area. They wanted information and support on:
 - Local and national support organisations such as peer support groups.
 - Local and national support organisations for siblings to access.
 - Local and national organisations that can provide advice on welfare, benefits, charities and grants.
 - Local organisations/groups that can help with form filling.
 - Information that helps parents and the child/young person to prepare for the future such as transition into adult services.
- Parent carers called for agencies and professionals to work in a more co-ordinated way so that parents do not have to repeat information over and over again.
- Parent carers would benefit from the contact details of a named professional through whom they can communicate with the rest of the Autism Team. It was envisaged that this named person would keep the parent carer, child/young person up-to-date with information about waiting times, sequences of assessments, what to expect etc.
- Parent carers wanted a choice about how (if appropriate) they would like the information regarding the pathway to be shared with them and their child during the assessment process. For example, should the child/young person be at the appointments with parents, what would be an appropriate and convenient time to have the appointments?
- Parent carers requested that once a diagnosis had been made, that the information was shared with other relevant professionals and agencies, with parental consent.

- As only one parent carer mentioned the follow up appointment taking place, and other parent carers said that they would have benefitted from a follow up appointment, there seems to be some confusion as to whether they were offered/took place or not. Hence we would recommend that it is made clear to parent carers that follow up appointments are available, when and what they are for. This is because families expressed a need to digest the information given and gather further questions they may have for the professionals. This would also allow exploration of the risk of autism in siblings too.
- It was felt that the provision of specialised support for parent carers should be available across the county, this could involve advocacy services for parent carers. Support for siblings should be increased, siblings may not provide direct personal care but the experience still has an impact on them.
- Many parent carers made requests for a booklet similar to the Child Health Record, to guide them through to pathway to include:
 - A flowchart of the pathway.
 - What to expect.
 - Explanations of clinicians' job roles.
 - Charts to record pertinent points of the family history.
 - Record medication and sleep patterns.
 - A list of coping strategies.
 - Support groups.
 - A tick box to guide them through the assessment processes to help them understand where they are in the pathway.
 - The ability for this to be used as a communication aid between the different professionals.
- Parent carers requested more Autism Workshops, but also other courses that could be offered to parents whilst they were navigating the Autism Pathway to help them with coping strategies and give them someone to talk to about the process.

9. Responses

Response from the Derbyshire Children's Autism Co-ordinating Group

The Derbyshire Children's Autism Co-ordinating Group brings together parents and carers of children and young people with autism with professionals from Education, Social Care, Health and the voluntary sector. The group works to improve support for children and young people with autism.

The Group welcomes this report by Healthwatch Derbyshire. The group welcomes feedback from families about their experience of the current Derbyshire autism "pathway". The findings will inform a review of the current pathway for children, young people and their families to access support. Members of the group will also discuss the findings with their services and teams, to make sure that we learn from families' experiences of services.

Families' experiences of education

Although none of the recommendations in the report relate to Education specifically, the group notes the strength of parent carer feedback about their experiences of Education. The group will consider what more can be done to support schools and other Education providers in recognising the signs of autism and providing support.

Listening to parents, and addressing and exploring their concerns

It is disappointing to receive feedback from parents and carers that this has not always been their experience. The current Derbyshire autism pathway states that:

“Parents and carers must be treated as equal partners at every stage; their concerns must be listened to and they must be treated with respect. It is important that all parents/carers understand the pathway; that they not only understand what strategies and support are being put in place to support their child but can inform and shape those strategies.”

All partner agencies will be asked to explore their own practice, and report back to the group on how they are improving parents' and carers' experience of services.

Parent carers called for better local information

A great deal of work has taken place to improve information about services and support. The Derbyshire 'Local Offer' website was launched in September 2014, and brings together a wide range of information about local and national services for children and young people with special educational needs and disabilities, including autism.

The Local Offer is at www.derbyshiresendlocaloffer.org

If families cannot find the information they need, or do not have access to the internet, they can ring Call Derbyshire on 01629 533190 and ask them to help.

The group will review the information on the Local Offer about services for children and young people with autism, to make sure that it is comprehensive and easy to find.

The Local Offer also needs to be publicised to families better. Information is being placed in libraries, GP surgeries, schools, children's centres and other settings. Details are also being sent directly to the parent carers of children and young people with statements of Special Educational Needs/Education Health and Care plans and to the Derbyshire Parent Forums.

Services need to work together in a more co-ordinated way. Families should have access to a named lead professional. Information should be shared with other relevant professionals once a diagnosis is made, with parental consent.

Parents/carers should have choice regarding how information about the pathway is shared with them and their child throughout the assessment process. Follow up appointments should be available following diagnosis

The group accepts these recommendations, many of which are already expected within the existing pathway. Services will review their current practice, and report back to the group on how they will make improvements.

Provision of specialised support for parent carers, including advocacy services

The Derbyshire Information, Advice and Support Service for Special Educational Needs and Disabilities (formerly Derbyshire Parent Partnership Service) is an information, advice and support service which supports parents and carers of children and young people (0-25 years) with special needs or disabilities. The service works closely with statutory and voluntary organisations.

Parent carers can also request to access disagreement resolution services if their child has a special educational need or disability, and they are not satisfied with the education, health or social care provision which is being made.

Support for siblings should be increased

More autism workshops and other courses should be offered to parents to help with coping strategies and give them someone to talk to in the process.

The group accepts that support for siblings is not consistently available, and that it would be desirable to increase support. The group welcomes the very positive feedback from parent carers who have attended workshops or training. Currently some parent carers may not be able to access these sessions, due to the age of their child and/or the service(s) they receive. The group agrees that it would be desirable to increase the provision of workshops and training. These recommendations will need to be considered in the context of the significant budget challenges facing both the Local Authority and NHS.

A booklet similar to the child health record to guide families through the pathway

The group welcomes this suggestion and will explore the possibility of developing a booklet.

Appendix I



Derbyshire Autism Pathways: Information for families

The Derbyshire Children's Trust has agreed how children and young people with autism in Derbyshire should be identified and supported. This information is a summary for parents/carers. The full pathways are on the Derbyshire County Council website at: www.derbyshire.gov.uk/autism

School-age children

If anyone has concerns about a child's development, they should raise them with the child's school - or with the local multi-agency team if the child is not attending school. You can find your local multi-agency team in the Derbyshire Family Information Directory (see Derbyshire County Council website or telephone Call Derbyshire 08456 058 058)

The school or multi-agency team will look at what is causing concern and identify what can be done differently to support the child. The school may be able to get advice and support from specialist services at this stage, for example an Educational Psychologist. The school will normally try out new ways to support the child for a term (around 13 weeks) to see how well these approaches work.

If there are still concerns at the end of the term, and it seems possible that the child may have autism or another developmental disorder, the school/multi-agency team will make a referral to a Community Paediatrician.

At this time, the school/multi-agency team will also identify someone to take the lead in working with the child and his/her family and to co-ordinate any support that may be needed. There may also be an assessment of the child and family's needs, carried out in partnership with the family (a "CAF"). The school will consider whether any extra educational support is needed, following the Special Educational Needs Code of Practice.

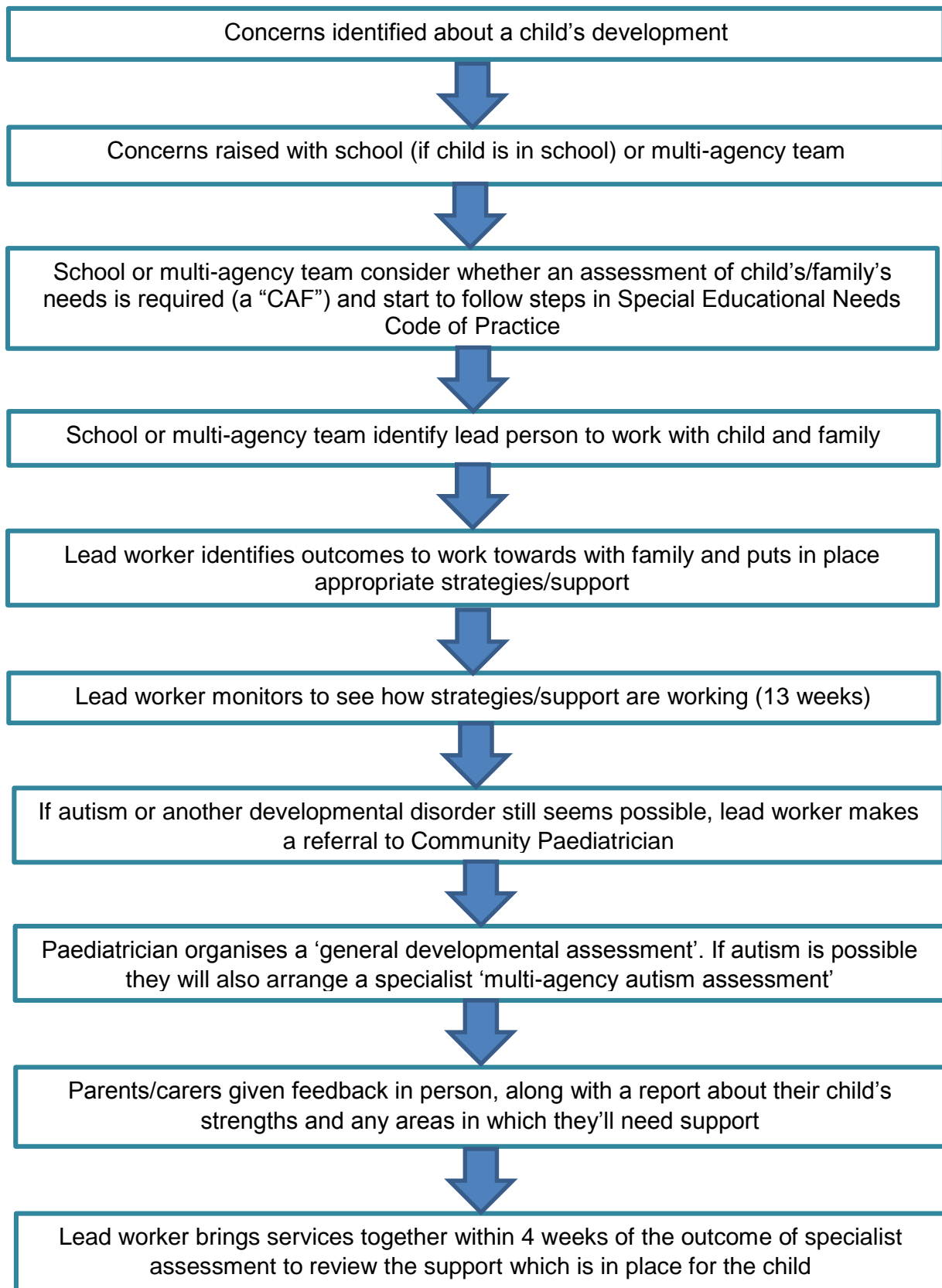
The Paediatrician will organise a developmental assessment. It's unlikely that a diagnosis will be made at this stage. If the Paediatrician thinks that autism or another developmental disorder is possible, they will arrange a more specialist assessment. This will always include professionals from different backgrounds with relevant experience and specialist training.

While the assessments are being carried out, any support which has been identified for the child will continue to be provided by the school and local services.

The outcome of the assessment will be communicated to parents/carers in person, along with a report which sets out their child's strengths and any areas in which they will need extra help. With parents' permission, the report will be shared with the school and with other services supporting their child.

Once the specialist assessment has been completed, the professional who is working most closely with the family will bring services together again (within four weeks) to review and update the plan for supporting the child. The child's plan will always include clear outcomes for the child and family, and will be regularly reviewed.

Flowchart: Pathway for school-age children



Pre-school children

Pre-school children who attend nurseries funded by the Council will be supported in the same way as children who are at school. There are a few small differences for children who attend private day nurseries, childminders and children's centres; and for children who don't attend any early years provision:

Children who don't attend any early years provision: If anyone has concerns about a child's development these should be raised with the local multi-agency team (or children's centre – children's centres are part of the local multi-agency teams). They will consider a CAF and make sure that the child is receiving appropriate support. If there continue to be concerns after 13 weeks, the multi-agency team will make a request to the 'Derbyshire Early Years Panel' for additional educational support and/or referral to a Paediatrician for a developmental assessment.

Children who attend a private day nursery, a childminder or a Children's Centre: If anyone has concerns about a child's development, these should be raised with the child's early years provider. The Special Educational Needs Code of Practice will be followed and the provider will consider a CAF. If there continue to be concerns after around 13 weeks the provider will make a request to the 'Derbyshire Early Years Panel' for additional educational support and/or referral to a Paediatrician for a developmental assessment.

Contact: Linda Dale – linda.dale@derbyshire.gov.uk. Tel 01629 532456.

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3) Since reading this report:

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