

Supporting children and families where ASD and ADHD is suspected

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Contents

Summary	3
Key findings	4
Recommendations	5
Response to recommendations	6
Background	10
Method	11
Limitations of the project	12
What people told us	13
1. Lack of knowledge and understanding of ASD and ADHD	13
2. Poor communication and co-ordination	14
3. Lack of information	16
4. Delays in the referral and assessment process	17
5. Issues with the pathway and assessment process	19
6. Lack of support, advice and practical help	21
Conclusion	24
Acknowledgements	24
Appendix 1 - Demographics of families interviewed	25
Appendix 2 - Guide for interviews with parents/carers	26
Appendix 3 - Guide for interviews with professionals	27
About Healthwatch Northamptonshire	28
Contact us	29



Summary

Healthwatch Northamptonshire talked to 12 families who had experience of the process of assessment for a diagnosis of autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD) in the previous 12 months. We also spoke to professionals who are involved in the assessment process or who provide support to families of children with ASD and ADHD. Sixteen interviews were carried out in total.

This project aimed to explore families' experiences of the current ASD/ADHD pathway in Northamptonshire and how effective it is. We also aimed to identify potential improvements and highlight good practice already taking place.

We found that the process of seeking a diagnosis of, and help for, ASD and ADHD often takes so long and is so fragmented that children and their families are struggling. There is often little or no support for the families to address the behavioural problems that lead them to seek professional help or a diagnosis. Delays in assessment can have a significant impact on a child's wellbeing and educational outcomes.

What people told us for this project also reflect the findings of a national briefing by Healthwatch England¹. This highlighted

- the lack of consistency in pathways for diagnosis and support for children with ASD and ADHD
- professionals not always knowing where to send families for support and guidance
- in many areas there is no single unified service available to cover autism services.

¹ Healthwatch England (2017) *Children and young people with autism: Findings from the Healthwatch network* - www.healthwatch.co.uk/resource/autism-services-children-and-young-people-findings-healthwatch-network, accessed 31.05.18



Key findings

- This project heard about experiences of good support (Portage², Sleep Solutions and some education professionals), especially for families of pre-school age children.
- Some relevant professionals have limited knowledge and understanding of ASD/ADHD and lack empathy for the child with possible ASD/ADHD and their parents. Some parents felt that their concerns were not listened to by professionals.
- Sometimes there was poor communication and co-ordination between professionals and services, and some professionals did not fully understand the process to refer a child for diagnosis and support.
- Parents lacked clear information on the process of the ASD/ADHD diagnostic pathway.
- There were often long delays in assessment, diagnosis and access to services, leaving families unsupported and unsure about what was going to happen next, how long to wait, who to contact etc.
- There were problems with the assessment process and a lack of consistency in the tools used and setting for carrying out a diagnosis of ASD or ADHD.
- Families lacked support, advice and practical help during and after the assessment process.
- Transitions from primary to secondary school are critical for children with ASD or ADHD and this presents particular issues for assessment and support.

² Portage is a home-visiting educational service for pre-school children with special educational needs and disabilities (SEND) and their families.



Recommendations

It is recommended that the relevant organisations and professionals in Northamptonshire work together to:

1. Instigate more staff training and development in education and primary healthcare to increase knowledge and understanding of autism and the needs of families.
2. Improve communication and co-ordination of all the services involved, with clearly defined responsibilities so that families know who to approach about the pathway.
3. Provide clear information on the pathway and what parents can expect, who needs to be involved and when, with realistic timescales.
4. Reduce delays in the referral and assessment process through employing more educational psychologists or equipping more staff to undertake the relevant assessments.
5. Provide support and practical help for families at an early stage, which should not be dependent on a positive diagnosis of ASD or ADHD.
6. Provide extra support and careful co-ordination at the time of transition to secondary school for children with ASD or ADHD.



Response to recommendations

Response from Northamptonshire Healthcare Foundation Trust

Northamptonshire Healthcare Foundation Trust (NHFT) would like to thank Healthwatch for taking the time to compile this report. We would like to recognise the significant challenges identified by the parents and carers interviewed and would like to reassure them that we are doing everything we can to ensure we provide the evidence based, holistic diagnostic service we are commissioned to provide.

Currently, the NHFT Team currently see all Secondary (11 +) children across the County, and share the care for Primary age children in the North with NHFT Community Paediatrics. Primary children in the South of the County are seen solely by Northampton General Hospital (NGH) Community Paediatrics. Referrals are accepted by from any professional (medical, education, social care) working with that child, and a ‘**Professionals**’ referral line is available daily for enquiries about whether a referral is appropriate/how to access the pathway. We currently receive over 200 referrals a month into our service, for children with suspected Autism, ADHD, or both.

We have noted the recommendations in your paper and would like to respond to each, in turn:

1. Staff and education training on autism awareness.

Our team undertake a wide range of third sector training with regard to autism and ADHD awareness, both for health professionals such as health visitors and school nurses, and also for teachers, SENCOs and other education staff. These can be arranged via the Team. Any training that we provide is always fully booked and attended well.

2. Improving communication and coordination of services, with clearly defined responsibilities.

Currently there are two commissioned diagnostic providers - ourselves (NHFT) and Northampton General Hospital. Our Referral Management Centre, a central point of access for all referrals into NHFT manages all referrals into our service and will swiftly redirect any incorrect referrals. We are working hard to improve communication between ourselves and NGH. We have launched a Consultation line for any professional working with a family, who want advice about how to refer, whether to refer, or any information about the pathway or what support is available.

3. Provide clear information on the pathway and what parents are to expect, with realistic timescales.



All families are sent a comprehensive leaflet upon referral to our service with clear information about each step on the pathway and likely timeframes. Parents are also provided with a contact number for the team and can ring for further information if this is needed. However, the pathway is not always linear: as with any holistic process not all children undertake all steps on the pathway, and therefore it is difficult to give anything beyond an approximate length of time for each stage. In addition, waiting times can vary over periods of time depending on demand and capacity.

4. Reduce delays in the referral and assessment process.

Currently approximately 50% of referrals are rejected during stage 1 of the screening process, for being incomplete or not providing enough information. This lengthens the process as we go back to referrers to ask for additional information. We then send out referrers a pack of questionnaires to be returned before we will offer a face to face appointment. We have been reviewing our referral packs to try and help referrers to understand what sort of information we need and to streamline the process, and from September 2018 we will be launching a new referral pack. This sets out very clearly what information is needed from referrers, including a questionnaire for the child or young person to complete if they wish, and this also includes all the questionnaires for families and schools. This means that a face to face appointment should be able to be offered within 13 weeks from receipt of the completed referral pack, significantly reducing Step 1 of the referral process.

We are working hard with our partners in Northamptonshire County Council (NCC) and the Clinical Commissioning Group (CCG) to overcome issues and delays in other parts of the assessment process, and this work remains ongoing.

5. Offer support to families irrespective of diagnosis.

All families are offered a post diagnosis workshop, for support and strategies to use to support their child or young person. We also offer workshops to parents and carers of children who do not receive a diagnosis, to explore other avenues of support for their child or young person. Alongside this, we offer workshops to young people who go on to receive a diagnosis of ADHD and/ or ASD.

For children with behavioural issues, whether they have a diagnosis or not, we offer two evidence based behavioural intervention programmes called 'Positive Behaviour Support' (PBS) and The 'Incredible Years'. We encourage parents of children who demonstrate challenging behavior to undertake either of these courses whilst waiting for the assessment process as the strategies taught will benefit families irrespective of whether a diagnosis is given or not.



We also strongly encourage families to seek support from other services outside of NHFT, which are commissioned locally to offer support and help to families, irrespective of a diagnosis. We encourage families to engage in the Early Help Assessment (EHA) process which should allow them to access a variety of support and intervention and is needs led, rather than led by diagnosis.

It is our experience that families state that they are unable to access support via such mechanisms because services ‘just aren’t there’. We also find that parents tell us that they cannot access extra help in school for their children ‘without a diagnosis’, often stating that they do not necessarily want a diagnosis for their children, but that it ‘opens doors’ for their children to get extra help, especially in schools. This suggests that there appears to be a lack of resource or support in universal and targeted services that leads to pressures on families to seek a diagnosis to access help and support.

Anecdotally it is our experience from what parents tell us, that many services inform them that they cannot offer any help ‘until they know what a child’s diagnosis is’, which again goes against the philosophy or principle of children being able to access help and support based on individual need, rather than an individual diagnosis.

We sometimes experience resistance from parents to engage in support offered either via our service or the 3rd sector because they believe the interventions will not be applicable to their child, if there is an underlying ASD or ADHD present, which is not an accurate perception.

It is important to note that there is a multi-agency responsibility for a wide range of services and professionals to provide intervention and support to young people who are either diagnosed with ASD/ADHD, or suspected of a diagnosis. Many children referred will not meet the threshold for a diagnosis. This places a large responsibility on universal and targeted services to be able to provide support that is available for children in a much wider context.

There has also been a recent **Autism Strategy** review commissioned and undertaken in the county, that looks at all the services for Autism, including assessment pathways, collaboration, intervention and the lifelong help and support that is available. The strategy is currently in draft format and will be implemented shortly. Many of the items raised in the Healthwatch report are identified and addressed in the strategy.

Sharon Robson
Head of Specialist Children's Services
Northamptonshire Healthcare Foundation Trust



Response from Northamptonshire County Council

Thank you for forwarding your survey to NCC for comment. We are assuming that the report will be presented to the Disabled Children and Young Peoples Delivery Group (DCYPDG) for a full discussion.

We are pleased to note the feedback regarding positive support from Portage, Sleep Solutions and Education Professionals. However, we acknowledge the difficulties and frustrations the families interviewed expressed regarding aspects of diagnoses and service provision.

We acknowledge the recommendations and would like to place on record our thanks to the parents for taking part and sharing their experiences.

The draft all age Autism Strategy, currently out for consultation, does highlight similar issues to those your project has identified and will be seeking, with the support of parents and young people, to focus on solutions.

The strategy identifies the need to:

- directly address staff training and development
- improve communication and coordination
- provide a swift and transparent diagnoses process, provision of support pre and post diagnoses and advice and guidance for when children do not receive a diagnosis.

A detailed, co-produced action plan will be drawn up to identify how solutions will be progressed.

We would comment that the opening summary appears overly emotive. This is in contrast to the key findings and recommendations which are clearly evidenced and geographically based. We would agree with the identified limitations and think it is essential, in order to validate the study, that a much larger sample group is consulted. Notwithstanding the fact that this piece of work gives us a valuable insight into the views and experience of 12 families, the data base is very small.

Bob Fletcher
Commissioning Manager (Autism)
Northamptonshire County Council



Background

Autism is defined by the National Autistic Society as ‘a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.’³ It is a spectrum condition and autism affects people in different ways. Asperger’s is a form of autism on the spectrum. Autism is not a mental illness, but the difficulties experienced by autistic people may lead to anxiety, depression or other mental health conditions. It is estimated that there are around 700,000 people with autism in the UK and the number is rising, as is demand for diagnosis and support services. Attention deficit hyperactivity disorder (ADHD) is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness. ADHD is common in people with autism⁴.

Following the Autism Act 2009 all local authorities were required to take steps to make services accessible to adults with autism and develop an all-age autism strategy. In 2015, the government published *Future in Mind*, a report that sets out the case for change in delivery of mental health services for children and young people, including children and young people with autism spectrum disorder.

‘At the heart of any good local system should be cross-sector agreement to ensure clarity in respect of how services are accessed.’⁵

To achieve the improvements set out in *Future in Mind*, organisations working in this sector in Northamptonshire came together to develop a local action plan, known as the Local Transformation Plan (LTP), which was published in 2015. The LTP set out the actions that need to be taken in the next five years, including making improvements to the ASD and ADHD diagnostic pathway (the route a referral takes through assessment to diagnosis).

In the absence of a clear autism strategy in Northamptonshire, and responding to concerns from members of the public, this project aimed to investigate the experience and effectiveness of the current ASD/ADHD pathway. The project aimed to understand the way in which families experienced this diagnostic process; identify potential improvements for the benefit of all involved; and highlight good practice already taking place in Northamptonshire.

³ National Autistic Society <http://www.autism.org.uk/about/what-is.aspx>, accessed 23.03.2018

⁴ National Autistic Society <http://www.autism.org.uk/ADHD>, accessed 23.03.2018

⁵ Department of Health/NHS England (2015) *Future in Mind*, p39



Method

This project used qualitative methods to engage with families who had concerns about their child having ASD or ADHD and had sought professional help for their child. Families were recruited via local networks and recruitment posters displayed in local children's centres and at local community events.

The children about whom the families were concerned ranged in age from 3 to 14 years at the time of the interview. All the families we spoke to had concerns about their child's or children's development or behaviour and had experience of the assessment process for ASD and/or ADHD in their child or children. Some had recently received a positive ASD or ADHD diagnosis. Some had not received a diagnosis but had been referred for assessment and were at some stage of the diagnostic pathway, although as is clear from the findings below, many families did not understand what the pathway was or what stage they were at in the process. Each family's situation is unique and their child's behaviour and developmental concerns are also specific to that child, but after talking to 12 families we felt we had gathered sufficient data to tell us that the system was difficult to navigate and clearly not working for many families.

A total of 12 families were interviewed, talking about 17 children. See Appendix 1 for demographic details of this group. In this project the voice of parents is the main focus, and this is reflected in the report. Parents and carers were interviewed in their own home using a semi-structured interview guide (i.e. a list of key questions and prompts). The interview guide is included as Appendix 2 of this report.

Four interviews were carried out with professionals who worked in child and adolescent mental health, education and the voluntary sector. One was a special educational needs co-ordinator (SENCo) in a primary school, one was an educational psychologist. We also spoke to an autism consultant working in education and two staff members working for an autism charity (who were interviewed together). The purpose of interviewing professionals was to understand local processes and policies, and to gain professionals' perspective on how the ASD/ADHD pathway is working. Professionals were interviewed in a range of settings, including one by telephone, also using a semi-structured interview guide (see Appendix 3).

The interviews were carried out between April and November 2017. All interviews were recorded using contemporaneous notes or a voice recorder and the interview was transcribed soon afterwards. Key themes were identified through regular reviewing of the data and discussions among the project team. To maintain confidentiality, names and identifiable features have been removed from all quotations in this report.



Limitations of the project

A limitation of this project is that we did not speak to children and young people themselves. We also only spoke to a small number of parents, although the variation in age of children and location meant that we captured a range of experiences. The structure of services in Northamptonshire to assess and support children and young people with ASD and ADHD is changing, which makes it hard to capture how the pathway is working now. This report focuses on interviews with parents carried out in a six month period in 2017 about their experiences within the preceding 12 months.



What people told us

The findings of this study are framed around the difficult journey that many parents take in trying to get concerns about their child(ren) taken seriously and investigated fully.

The interviews carried out for this project show that the process of ASD and ADHD diagnosis takes so long and is so fragmented that children and their families are struggling. There is often little or no support for the families to address the behavioural problems that lead them to seek professional help or a diagnosis. For children who are given a diagnosis of ASD or ADHD, this can help in obtaining appropriate support and adjustment in home and educational settings. Delays in assessment can have a significant impact on a child's wellbeing and educational outcomes.

1. Lack of knowledge and understanding of ASD and ADHD

Many parents noticed signs in their child(ren) at a young age, such as language delay, mobility difficulties or repetitive behaviours, that made them concerned. For other families, their child's difficulties emerged later, in the form of anxiety and self-harm, often either at the time of starting school or during transition from primary to secondary school.

Some professionals were very quick to respond to parents' concerns, or picked up the concerns themselves, such as in a pre-school setting or at a developmental check by a health visitor. For example:

“Pre-school were alerted to the problems and agreed with what we had been observing... I called my health visitor, a two year check was done and the health visitor agreed to make a referral to hospital... Pre-school were very good, the SENCo is learning from the start how to respond.” (Parent of 4 year old)

More often it was the parents who had initial concerns and then sought professional help. For some parents, it was then a struggle to get professionals to listen to them or recognise the problems.

“There had been problems with this health visitor and with the GP from the day he was born. They wouldn't believe he had any problems ... the health visitor was no help. I was told I was a paranoid parent.... No one listens and they don't see what we live through on a daily basis.” (Parent of 4 year old)



“We spoke to the doctor - that didn’t go too well. They were like, “I don’t think it’s that” [Asperger’s]. They did a referral to the paediatrician, umming and ahing. They said they’d probably reject it.” (Parent of 9 year old)

“Trying to get school to understand that what we are dealing with is real. They don’t see any issues at school - I tell them their behaviour at home is affecting school stuff.” (Parent of 9 year old)

Some of this reluctance to respond among professionals in primary healthcare or education may be linked to them not having sufficient knowledge and understanding of ASD and ADHD.

“Pre-school haven’t been helpful - they think they’re just a naughty child who plays them up.” (Parent of 7 year old)

“People seem to think that ASD is something they will ‘get over’, get rid of it, like a bag on the back. They don’t view it as something that some people need to learn how to carry!” (Parent of 14 year old)

2. Poor communication and co-ordination

Although there were examples of individual professionals who supported, informed and advocated for families, parents told us that the communication and co-ordination between different services and professionals was often poor.

Sometimes parents were not informed of incidents involving their child or invited to multi-agency meetings.

“Unfortunately, the health visitor doesn’t really know what they are doing, they’re a bit disorganised. They only invite the doctors a few minutes before the meeting, you find yourself inviting the people you want there, even if it’s not your job.” (Parent of 4 year old)

“SEN [special educational needs] response varied from good to non-existent; schools did not inform us of meetings with professionals and visits from professionals; school ignored serious injuries that required subsequent hospital treatment; school ignored the fact that X spent much of their time in class underneath their desk. X was bounced between various medical professionals.” (Parent of 11 year old)



Families were passed from one professional or service to another, leaving parents uncertain what was happening. For one family, a lack of clarity among professionals about who is responsible for what led to confusion and significant delays:

“I phoned Autism Outreach⁶ after five months, explained that the educational psychologist had seen child and had made a referral and I had not heard. They couldn’t find them in the system: “Has a referral been made?” It says here on my paperwork, ‘referral to Autism Outreach’. Manager got in touch to say a referral hadn’t been made. ... and school has to make referral. I spoke to new SENCo who had started in September and they didn’t know they had to do it and felt the educational psychologist had done that. ... So what do I do and how do I get a diagnosis? I had thought that the educational psychologist had made the referral that was going to get a diagnosis! “You have to go to the GP and ask them to refer.” I did that. ... GP will refer to paediatrician.” (Parent of 10 year old)

Some parents’ experiences clearly indicate a need for a more co-ordinated, joined up approach:

“There was no main point of contact; there were so many agencies involved... The first multi-agency meeting we had was in March 2017; we were invited after a chance meeting with the SENCo, originally we had not been included. The purpose of the meeting was to get X back into school.” (Parent of 14 year old)

Parents told us that they often had to be proactive in ensuring that professionals responded or followed up on actions.

“School were not keen on getting an educational psychologist involved ... We only got the educational psychologist when I wrote a list of all the tests they would be doing. They were doing X a disservice denying them learning and the help X was being denied.” (Parent of 9 year old)

“You just get left to it - e.g. they wanted X to have blood tests and we had to push towards it. It was all forgotten.” (Parent of 7 year old)

⁶ The Autism Outreach team is part of the SEND Specialist Support Services for Northamptonshire and provides a needs-based service for children with Special Education Needs and/or Autism aged 0-19.



One parent, who had experienced a swift and co-ordinated response for his child, was very comfortable in the role of co-ordinating and being the main contact in the assessment process:

“There are good reasons for parents being the main point of contact: information stays the same and isn’t lost in ‘Chinese whispers’. We have been the central point of contact, the hub of the wheel. It is fine for us; we like to be in control of that.” (Parent of 3 year old)

Several parents said that they felt that they had to work hard in order to get their child’s needs looked into, but they were then seen by professionals as either over-protective or even aggressive.

“People think I’m being over-protective and finicky... teachers made me feel over-sensitive because X was my first [child]. I’ve been perceived as a fussy parent.” (Parent of 10 year old)

“If referral is turned down and you appeal you’re [seen as] aggressive - it’s not, I’m passionate, I want X to get the help. If they get it soon enough they can adapt and become a functioning adult but the longer you leave it the harder it is.” (Parent of 12 and 14 year old)

3. Lack of information

Parents spoke about a lack of clear information about what to do with their concerns about their child’s behaviour or development, how to make a referral and how the process for ASD or ADHD assessment and diagnosis works. Many parents did not use or understand the word ‘pathway’ at all. They were unclear what would happen next, how long they could expect to wait and who to contact about the process:

“Parents don’t know where they are in the system, or what the system is.” (Parent of 9 year old)

“I feel like I’m banging my head against a wall. I still don’t know how long or what the process will be.” (Parent of 10 year old)

“They need to change the process of diagnosis; parents are left in the wilderness with no support or advice.” (Parent of 14 year old)

Several parents, as well as professionals, spoke of the need for clear, accessible information to explain the process of referral and diagnosis:

“There’s a need for clear, easily accessible information for parents.” (Parent of 8 year old)



“There should be a diagram that someone can look at and understand - it feels like they’re making it up as they go along. Education has a role but they need guidance. Health needs to join up with education... It needs to be joined up and transparent.” (Parent of 12 and 14 year olds)

During the project we were given a copy of a flowchart that attempts to illustrate the local ASD/ADHD pathway, but this was for internal use only and was not a public document. It demonstrates how complex the process is, making it difficult to understand for parents and also other professionals.

One parent suggested that families need more information following a diagnosis:

“It would be helpful to have a coverall standard piece of information for parents to digest that says ‘my child has been identified as having social and communication difficulties - what does this mean?’, that sets out the possibilities and explains in plain English why you can’t be sure what’s going to happen and where you can get practical advice and emotional support.” (Parent of 3 year old)

4. Delays in the referral and assessment process

The majority of parents spoken to had experienced long delays and waiting times during the assessment process for ASD or ADHD. Only two families spoken to had not experienced any delays. Their children had progressed from referral for an assessment for ASD/ADHD to diagnosis in less than 18 months.

“In 2015 we saw paediatrician at the hospital, but it was decided X was very young and we should return in six months. March 2016 ADOS [Autism Diagnostic Observation Schedule] assessment. In April 2016 X had a two day assessment at the Child Development Centre, including speech and language therapy and physiotherapist, two to three weeks later, diagnosis of ASD received from paediatrician. We received the complete report and information about support groups.” (Parent of 4 year old)

“For us the process has been easy - it’s been about the right amount of time for us to be able to process what’s happening.” (Parent of 3 year old)

In both these families the child was young and there were additional developmental concerns. Among the families we spoke to, the system seems to be swifter and more joined up for early years, pre-school children.



For other families, waiting times of over two years (from the time of referral) were common, and several families were still waiting for an assessment. Some children and their families had been ‘in the system’ for much longer than two years, from initial concerns being first identified and parents getting their concerns taken seriously by professionals. The process had taken up to eight years for one family:

“The doctor completely agreed [with concerns about possible ASD] and got things moving, but it was summer holidays so everything took ages - 10 months before X got seen... While waiting for these to come, no one offered anything, no help, just told can’t rule out autism, Asperger’s or ADHD.”
(Parent of 4 year old)

“I got a letter saying they’d both been accepted on the pathway - that’s where I learnt the guidelines for the timescale, but I’ve heard nothing since. Date is now six months on - out of time frames.” (Parent of 12 and 14 year olds)

“School started ball rolling with the educational psychologist. We waited eight months, [then they] phoned and asked permission for assessment, would do observation in class then a few days later... We waited and waited, assuming referrals had been made. After eight months you get used to waiting.”
(Parent of 10 year old)

“In January 2017 I chased up the educational psychologist [referral]. The response was that there was a two-year waiting list, and that Year 6 children were being prioritised.” (Parent of 9 year old)

Sometimes delays were because professionals were slow to recognise and respond to parents’ concerns, and sometimes there was confusion about who was responsible for making a referral or following it up. There were incidents of referrals being sent to the wrong service or being lost. However, most of the delays seemed to be linked to a lack of resources to respond to a rise in numbers of referrals, in particular a shortage of educational psychologists.

“There are a large number of referrals that can be responded to at any point in time. There is always a long waiting list.” (Educational psychologist)

A SENCo working in a primary school told us that delays were caused by:

“An over-stretched team and service; we can’t get what’s needed.” (SEnCo)



One professional we spoke to explained that the commissioning process for educational psychologists had placed the burden of cost on the school. It was suggested that some schools may be reluctant to request educational psychologist resources to explore possible ASD or ADHD with a child as this incurs an extra cost.

“Five years ago educational psychologists became a commissioned service. Schools have to pay from their SEN budget. Schools are reticent to commission an educational psychologist ... their time for schools is valuable, it is more likely to be used for cognitive assessments.” (Autism education consultant).

Delays in the assessment process were frustrating for parents, but more significantly, delays had an impact on children’s wellbeing and education, as illustrated in the quotations below.

“There’s months of waiting. X is already going off school.” (Parent of 7 year old)

“I don’t want X delayed even longer as their chances of education are passing away.” (Parent of 13 year old)

“X had been bright at school but that is slipping now. We were trying to get some one-to-one support for X to halt that because they are now struggling.” (Parent of 9 year old)

“There was a long gap in the process. Nearly every day school rang home to ask me to pick X up from school. I decided that they should receive home education as they clearly were not coping at school.” (Parent of 14 year old)

5. Issues with the pathway and assessment process

The Northamptonshire Local Transformation Plan of 2015 referred to making improvements to the ASD and ADHD pathway by having a consistent process and tools for diagnosis. The evidence we have gathered suggests that there are ongoing issues with the pathway and the diagnostic process. Parents and professionals also pointed to inconsistencies in referral routes and timescales, as well as different processes in different parts of the county. The age of a child at the time of referral also affects the assessment process, with particular difficulties for older children (age 11 upwards).

Some families we spoke to struggled to get ‘on the pathway’, although many did not use that term, due to decisions being taken at the referral stage to not carry out an assessment for ASD or ADHD. Parents were frustrated that a decision had been made without seeing the child because certain criteria had not been met.



“They had said no, X is already in the system with their ADHD so can’t accept a referral [for autism]. ADHD nurse can’t deal with autism, and the paediatrician had closed X’s case without saying.” (Parent of 13 year old)

“School thought X had ADHD at primary, it kept coming back saying no. Never got to see consultant after school referrals as X didn’t meet the criteria, but no one would say what they were! Back and forth, referral by SENCo at school. This continued, the doctor referred. We’re still in system because no one assessed X.” (Parent of 14 year old)

In some families where an assessment had been carried out, professionals concluded that the child did not have ASD or ADHD without seeing the child in their home setting:

“I kept saying you’ve got to come to the house, but it was always about nursery, X is not there much ...they have health problems so rarely there and not really settled.” (Parent of 4 year old)

“Educational psychologist sat with a clipboard saying there was nothing wrong and I said, “Are you sure?” ... I was really upset, none of them believed us. I asked if they could come [to the] home and they said, “No”.” (Parent of 9 year old)

Another concern raised was the use of inappropriate tools in the diagnostic process, in particular introducing toys that were unfamiliar to the child.

“Dr X used the wrong equipment for X when they did the ADOS test. When [child] refused to play with an Action Man and a Barbie doll they refused to redo the test - that was the worst moment. At [another] clinic they used things that X was familiar with and enjoyed and that worked.” (Parent of 11 year old)

In the assessment process for ASD or ADHD, the main power seems to lie with the community paediatrician, who may consult with other professionals, but he or she has the final say in the diagnosis.

“When we went to the first [community paediatrician] we sat in a room for 15 minutes and they said, “No, they’ve got no ADHD or autism.” How can you tell in this time?” (Parent of 14 year old)

“We couldn’t get past paediatrician Dr X even though other professionals believed they could help. The diagnosis should not be down to one person - all the other professionals agreed, but we could not get Dr X’s agreement: as a



result we could not get the support that [child] needed.” (Parent of 11 year old)

Three families spoke of requesting a second assessment or asking for a second opinion, with varying success. The family quoted above resorted to an assessment at a private clinic, where their child was given a positive diagnosis:

“[Following] the diagnosis of ASD from the private clinic doors are open for [child] now; we need to find an appropriate place for X.” (Parent of 11 year old)

One family requested a second assessment but were disappointed:

“It was a waste of time because they had already decided there was nothing. They had to make out they were appearing to go through the process, do it and sign X off. ... So ADOS; same paediatrician and educational psychologist and as soon as we saw them we knew it was a waste of time.” (Parent of 9 year old)

It was particularly concerning that the paediatrician refused to share the assessment report with the parents. They subsequently received a single page letter informing them of that no diagnosis had been made, with no detailed explanation.

“We asked to see the [assessment] report but we were told we wouldn’t understand it, we would get a report later - anything on my child should be mine to see!” (Parent of 9 year old)

One professional we spoke to acknowledged that among professionals:

“There is a range of views about ASD from ‘everyone is on the ASD range’ to ‘it doesn’t exist’.” (Educational psychologist)

This helps to explain why parents sometimes struggled to get their concerns about possible ASD or ADHD taken seriously by professionals, and why the opinion of the community paediatrician can ‘make or break’ a diagnosis of ASD or ADHD.

6. Lack of support, advice and practical help

We were struck by the overall emotional impact that trying to access diagnostic and support services can have on parents:

“No one has an idea what we’re dealing with.” (Parent of 12 and 14 year old)



“They don’t know what life is like... It’s hell for all the family.” (Parent of 4 year old)

“It has been a struggle all the way.” (Parent of 11 year old)

Most of the families we spoke to were frustrated by the lack of support available, both during and after the assessment process. Parents needed practical help as well as advice and interventions for managing their child’s behaviour.

“I don’t know how to handle X, there’s no support when you’re in this half way stage.” (Parent of 4 year old)

“There’s no support at home for anything.” (Parent of 7 year old)

Some parents insisted that they did not necessarily want a diagnosis of ASD or ADHD - they just needed support and help for their child.

“I said I don’t want a diagnosis; I just want some help and support. I’d like an idea of what we’re dealing with. Can’t they do something to see which route to try and if it’s wrong we can try something else?” (Parent of 4 year old)

But some parents felt that they needed to get a diagnosis of ASD or ADHD before support would be offered and were concerned that a lack of diagnosis would mean no support.

“You have to do so much battling. Doctors think you want a diagnosis, a label, but they know that some schools don’t give any support without a diagnosis.” (Parent of 7 year old)

“Diagnosis opens a doorway - but that door shouldn’t be closed if there isn’t a diagnosis.” (Parent of 12 and 14 year old)

Some parents felt unsupported even after a positive diagnosis:

“We were given an ADHD diagnosis but no further support, no advice, just “off you go!”” (Parent of 9 year old)

Support was particularly lacking for children who had recently moved to secondary school. Even when information had been passed on, the transition to secondary school is a particularly vulnerable time for a young person with ASD or ADHD and extra support may be needed.

“Transfer to secondary school in September 2016 was a very anxious time for X, so they were withdrawn after a week to be home educated, at which all support was withdrawn.” (Parent of 11 year old)



Professionals told us that:

“At transition time children can get lost.” (Autism education consultant)

“This transition period in the ASD child’s life is “hideous”. Despite careful planning the majority of ASD transitions to secondary education fail, unless they are to a specialist setting.” (SENCo)

Parents also told us about positive experiences of support. Some parents got their main support from friends and other parents. Others cited specific services or professionals who had provided good advice and practical help:

“Nursery is very understanding and head on board is amazing, they do what they can. Without the school I’d have no one - they’ve been amazing.”
(Parent of 4 year old)

“Portage⁷ help with general advice and guidance. They are great with anxiety or behavioural issues.” (Parent of 3 year old)

“Sleep Solutions have been helpful - what they say works across the kids.”
(Parent of 10 year old)

⁷ Portage is a home-visiting educational service for pre-school children with SEND and their families.



Conclusion

From what people have told Healthwatch Northamptonshire it is clear that the local system of diagnosis and support is not working well for many families with children with ASD or ADHD.

When parents raise their child's developmental and behavioural problems with education or health professionals it is usually because they are serious and having a marked impact on the child and family life. Once parents have raised their concerns they can experience one of a range of responses. The best outcome for the parents and the child is that their concerns are recognised and acknowledged and the child is assessed appropriately and in a timely manner. Less satisfactory is where concerns are not acknowledged; or where they are recognised by some professionals but referral is delayed or impeded; or where assessment does not follow a systematic pathway.

Time is crucial to children and young people as they pass through the educational system and anything that delays access to interventions and support risks permanent harm to their educational achievement and their emotional wellbeing. These delays also impact on parental wellbeing and family life.

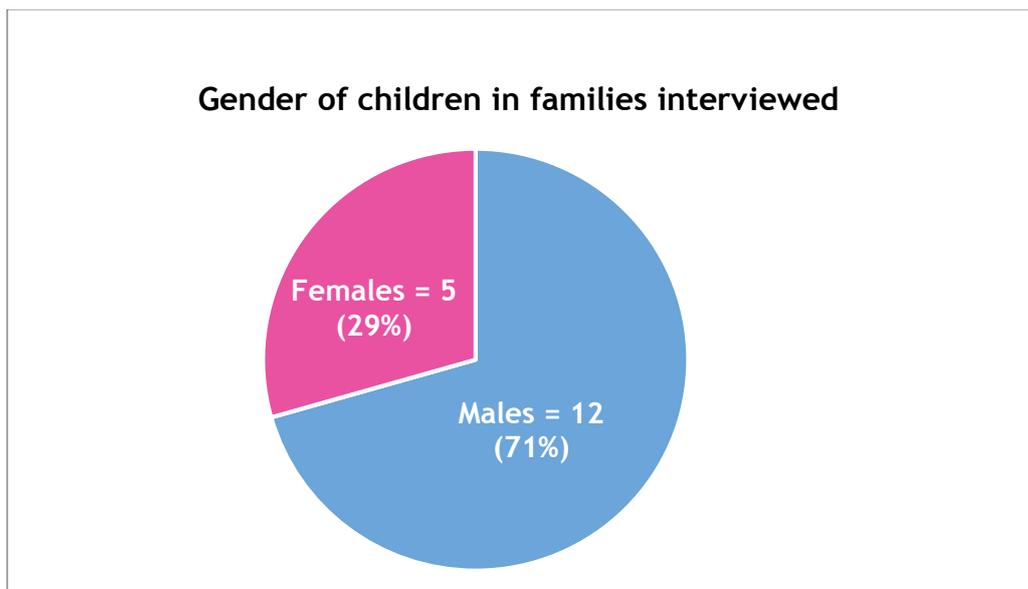
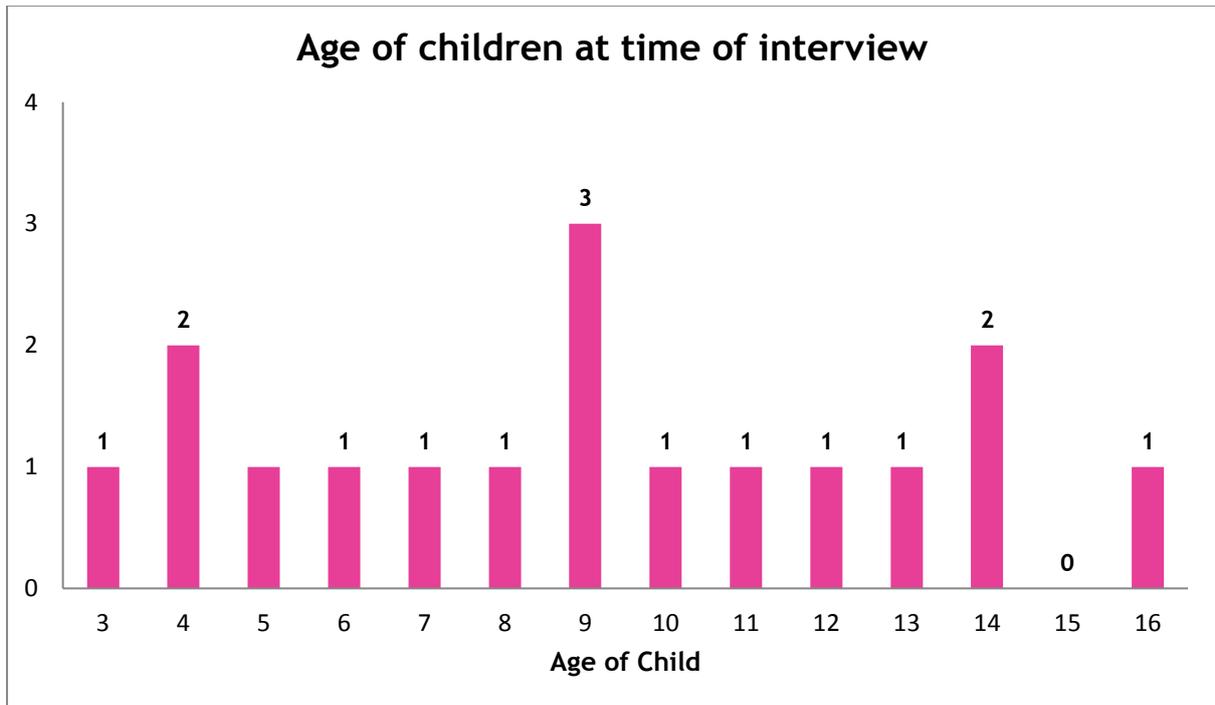
This project identified a number of situations where professionals and services work well together - mostly with pre-school children - and it is hoped that lessons can be learned from these areas of good practice to enable that children and young people of all ages, along with their families, get the support they need.

Acknowledgements

Healthwatch Northamptonshire would like to thank the families and professionals who agreed to be interviewed for this project. Thanks also goes to the Healthwatch Northamptonshire volunteers who carried out many of the interviews and who contributed to the analysis and final report.



Appendix 1 - Demographics of families interviewed





Appendix 2 - Guide for interviews with parents/carers

ASD/ADHD Pathway interview questions for parents/carers

1. Ask for basic information about child, DOB, other members of family.
2. Can you tell me what happened that first made you concerned about your child.
3. So what did you do? (List who was approached, who was seen, when and what happened at each step?)
4. How long did the/has the process taken from first informing a healthcare professional to the point that ASD/ ADHD is/was suspected to a confirmed diagnosis - of either yes or no?
5. What happened after you were told it is or it isn't ASD/ADHD (if got to that stage yet)?
 - a. Access to support, information?
 - b. How did you feel?
6. What have you found the most difficult aspect of the process? And what has been the easiest part of the process so far?
7. Have you had a main point/person of contact?
8. Who do you talk to if there is an issue/ problem/ questions?
9. What organisations have you had contact with?
10. Who do you think is responsible for ASD/ADHD in the Northamptonshire?
11. What changes would you make? How do you think the process could be made better for people in your situation in the future?



Appendix 3 - Guide for interviews with professionals

ASD/ADHD Pathway interview questions for professionals

1. Brief description of professional role, background, experience, area of county where they operate.
2. Can you tell me the process/pathway of ASD/ADHD diagnosis locally as you understand it? Can you outline who is approached, seen and when and what happens at each step, and how long this process would usually take? (Probe: Where has this knowledge come from - training, documents, experience?)
3. At what point in the process do you usually get involved? (Probe: how do you get to see a young person (route of referral), what information do you receive at this point, who does it come from?)
4. What is your specific contribution to the process? Where do you see CYP? Who do you work with (professional networks)? What information do you add and where/who do you send that on to/what happens next?
5. What gets in the way/what are the barriers to you doing what is expected of you?
6. In your experience, who/what is the best source of support for families going through the process of getting a diagnosis?
7. What works well (for you/for families) at the moment in the process?
8. What changes would you make/how do you think the process could be made better for families in the future?



About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.



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