



Living with Autism in Cheshire East

October 2015

This report highlights the
experiences of carers of children
and adults with autism in
Cheshire East





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About Healthwatch

Healthwatch Cheshire East is here to make health and social care better for people. We believe that the best way to do this is by designing local services around people's needs and experiences.

Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience. We are the only body looking solely at people's experience across all health and social care.

As a statutory watchdog our role is to ensure that local health and social care services, and the local decision makers, put people's experiences at the heart of their strategies.

Our vision

Healthwatch Cheshire East as "Consumer Champion" will give everyone in our community a powerful voice enabling them to get the best out of their local health and social care services and help to shape and improve these services for the future.

Engaging with people who use health and social care services

Our Engagement Team's goal this year has been to increase the number of people we interact with.

Our priority was to listen to seldom heard groups and make sure their voice was represented. At the beginning of the year we analysed the stories gathered so far and undertook a 'gap-analysis' to find out who we hadn't yet listened to.

Our key target groups for the year were identified as:

- Carers
- Older people
- Young people
- Young mothers

'Seldom heard' is a term used to describe groups who may experience barriers to accessing services or are under-represented in healthcare decision making.

[NHSinvolvement.co.uk](https://www.nhs.uk/nhsinvolvement)

The following report details the issues and recommendations that were identified through our engagement work with carers



Summary of Issues

As one of our priorities in 2015 Healthwatch Cheshire East listened to carers across the Borough.

We defined a 'carer' as anyone who thought of themselves as a 'carer' for another person.

We listened to over 200 carers at groups and events over five months in 2015.

Within this group, most people were telling us about their experiences of caring for their children (some of whom were over 18) who were on the Autistic Spectrum (including Asperger's Syndrome and ADHD).

Our conversations with carers identified the following concerns which are highlighted here:

- There seemed to be a disparity across the region in relation to the timescales for diagnosis of autism and asperger's in children. In particular there were significantly longer delays in diagnosis of autism and asperger's in Eastern Cheshire, with some families waiting for over 5 years for assessment appointments.
- A disparity in schools' approach to children with autism and asperger's
- Lack of crisis care and support for families
- A feeling of a 'blame culture' from the professionals by parents
- Problems with appointments and everyday life

- Lack of knowledge of the support available to families
- Lack of support for adults living with autism and asperger's

To identify if the providers and commissioners were aware of the disparity faced by carers in Eastern Cheshire we listened to professionals working in the Children and Adolescent Mental Health Services (CAMHS) and Eastern Cheshire Clinical Commissioning Group (CCG).

Following this it was clear that there was recognition by both the Commissioner and the provider that there were current problems within the system and that there was a desire to make improvements for the carers and their children.

During the production of this report we have been working with the Commissioning Manager at Eastern Cheshire CCG to support them with their planned redesign of the service. Once implemented this will potentially address many of the concerns highlighted, particularly around waiting times.

We will also be sharing this report with other commissioners and providers as we want to share the stories with all parties to make sure people's voices are heard.

Although the majority of stories in this report are from people who are accessing services in Eastern Cheshire, many of the concerns highlighted after diagnosis are valid in South Cheshire and this report will be shared with all parties.



Current situation - Autism in Childhood

The borough of Cheshire East is covered by two Clinical Commissioning Groups (CCGs) - Eastern Cheshire CCG (which covers the northern part of the region from Poynton to Congleton) and South Cheshire CCG (which covers the South including Middlewich, Crewe and Nantwich).

In Eastern Cheshire a diagnosis of autism (for children) is made by the Child and Adolescent Mental Health Service (CAMHS). CAMHS are also commissioned to provide treatment and support post-diagnosis as well as treatment and support for other mental health disorders in children and adolescents.

In South Cheshire the diagnosis pathway does not involve CAMHS and we understand (from South Cheshire CCG) that waiting time for diagnosis (from referral) is a matter of weeks (under 10). This is in stark contrast to what we hear from people in Eastern Cheshire where people are routinely waiting years for appointments.

The diagnosis and treatment pathways differ across the region depending on where you live, but some of the key concerns from carers are true across the region.

Long waiting time for diagnosis

One of the most significant aspects of our findings in this area is that the vast majority of people that we listened to

have not received any type of formal diagnosis [for their children]. They may be in the system - referred by a GP or Paediatrician - to receive counselling or therapy services but have not had a diagnosis appointment.

This means that schooling and everyday life can be doubly difficult because without an official diagnosis the adjustments that can be made to support a person living on the autism spectrum might not be.

People in Eastern Cheshire are waiting *years* for appointments to help their children.

In the meantime people told us they are expected to cope alone, with little or no support. Below are some examples of how this affects families.

“We need an appointment desperately - my child is harming us and his sibling and we have exhausted all strategies that we know”

“We are still waiting for an appointment for my daughter to see CAMHS. She is very distressed. We have been waiting for 1 year and 11 months.”



“My son has been waiting for over 3 years for a CAMHS assessment. I think 3 years is far too long for vulnerable children to wait and I can’t understand why these things are taking so long.”

“We have never got as far as CAMHS, which is a shame given my child’s current levels of anxiety, lack of self-esteem and confidence. I think if we had had access to some help, she would not be as bad.”

“My daughter has complex medical conditions including epilepsy, dyspraxia and hypermobility. She has started displaying challenging behaviour at home. We were referred to CAMHS for help. We are still waiting 25 weeks later. We desperately need help and there is none to be had.”

Disparity in schools’ approach

Although education is not part of Healthwatch Cheshire East’s official remit, schooling affects young people’s (and their family’s) health and well-being. When we listened to people about their experiences of living with autism, it was clear we couldn’t separate schooling issues from health.

Some carers mentioned to us that some schools didn’t seem trained or experienced with supporting children with autism and aspergers.

It was also raised that some schools would support children and families without

diagnosis and some schools would not. Whether a child had received a diagnosis or not, the carers expressed that support from the school was vital.

Below are some examples of how support at school is critical to families:

“My son stopped talking at 2 and still has communication difficulties now (he’s nearly 10). He was bullied at school from Year 1 (age 6) onwards. The school denies there is any problem without anything official and so he has no support. I have just discovered that his reading age is still age 6-7 and so clearly he (and they) are not coping.”

“I had to take my son out of education for 9 months until a space opened up at a school that was able to support him. The mainstream school he attended made things worse and he (and they) couldn’t cope.”

“My son was bullied at school from Year 6 - Year 9 (when I removed him from the school) because he was ‘different’.”

“We are desperate for a diagnosis before we have to apply for secondary school. We see counsellors at CAMHS and they agree that my daughter will not cope at a mainstream school.”



“After months of hearing ‘there’s no problem with your son’ I self-referred for a school support assessment. The panel allocated him a support worker for 31 hours and we changed schools. Previously he couldn’t use the toilet independently (at 7) and now he can. He can also write his own name and knows his alphabet. I can’t understand how the first school thought he was fine.”

“My daughter is able to cope at school and gets good grades. It takes it out of her though and she falls apart at home. I’m convinced some additional support would help her but the school refuse to acknowledge there is a problem because her grades are good.”

“Not having a diagnosis is affecting my son’s whole life because the school are very unsupportive and refuse to acknowledge that they need help.”

“My daughter was referred to CAMHS by a private psychologist in order for her to get an action plan in place before moving to high school to enable all of us to prepare for the new changes. We waited for months before we could get an appointment. We did get the action plan in place but she is now in high school and struggling. We are waiting for a new appointment to update the plan. We have been told it will be 5-6

months. All the time my daughter is struggling.”

“We were told that it would be a three year wait for an autism assessment - this meant that my son would not have been assessed in time to apply for secondary school. We went private, but have since been told that private assessments are not accepted now. How does this help people at the back of the 3 year queue?”



Lack of crisis support

Where do families with children on the spectrum (whether diagnosed or not) turn when there is a crisis at home?
They don't know.

Through our conversations with commissioners and providers there didn't seem to be a clear pathway of support for families that are experiencing a crisis at home. Carers told us that the lack of immediate support at crisis points has a significant effect on them and their families.

Below are some stories that illustrate this:

“My son has severe autism and gets violent when distressed. One day I couldn't cope and called the social work team. They told me they couldn't help and that I should call the police.”

“My son is 5 and is autistic. He was having anxiety attacks that were affecting all of us and so I took him to the GP. The GP was lovely and referred us to CAMHS. They took days to get back to me and when they eventually called, they didn't explain the delay.”

“My daughter is 11 and has Autism. She started cutting herself. Once she cut herself so badly I thought she would bleed to death. I took her to the GP. I didn't take her to A&E because I didn't think they would give her the care she needed because of the Autism. My GP referred us to CAMHS but they didn't get back to us, even though it was a crisis. It took 3-4 days for anyone to contact us.”

“My daughter recently started to hear voices and this is very distressing for her (and us). We do not know how to deal with this at all. We phoned an emergency help line [to CAMHS] and we were told to distract our daughter with the TV.”

“Our son has started to self-harm and his OCD is very chronic. We have been referred to CAMHS. They continually fail him and us, and he has been passed from pillar to post with very little positive support.”



Understanding and compassion

Carers who we listened to believe there is a 'blame culture' from professionals. They said they are made to feel that they are the problem first, and support given a distant second. Having listened to various professionals in the region, we know that they are concerned and dedicated, but perhaps sometimes some thought could be given to the very vulnerable emotional position that families are communicating from.

Here are some stories that show what carers think.

“Why is it such a battle to get these professionals to believe you and acknowledge your concerns?”

“I wish the professionals could live a week in our world. Things might change then.”

“We listened to a very patronising lady at CAMHS. Not very helpful at all.”

“With a physical problem like cancer there is help almost immediately. With something more intangible it feels like you are blamed first and then helped a very distant second.”

“I was told by my daughter’s school that they didn’t recognise the child I was describing at all. I felt like they were telling me it was my fault she behaved badly at home.”

“I could see our daughter needed help, but I was ignored. The specialists started saying that it was all my fault. I was causing all this anxiety and poor behaviour that they didn’t see. I felt the implication was that our daughter only acted ‘differently’ when I was there.”



After diagnosis - everyday life

We have listened to some people who have received a diagnosis of autism. They told us that sometimes things don't get any easier living with this complicated syndrome.

Appointments

Children on the autistic spectrum go to various appointments with professionals as a matter of course. Carers highlighted that:

- There are sometimes long waiting lists for appointments.
- The appointments often lead to the children missing school.
- There is a need for ongoing training on autism for all health and social care professionals. (Particularly how to communicate with someone on the spectrum).

The stories below illustrate the difficulties people face on a daily basis.

“We didn't have a family therapy appointment for 9 months because of the waiting list. Our therapist then left and we didn't get a replacement for [another] 9 months.”

“Autism and associated co-morbidities are treated separately. So a child with Autism and associated ADHD or Dyspraxia must attend at least two separate appointments. One with the Autism team and then one with ADHD and/or Dyspraxia. This means that the children have to miss school on lots of different occasions and parents/carers

have to miss work or arrange childcare for siblings.”

“My daughter has Autism and needs to go to appointments with various consultants and specialists. I would prefer some of these appointments to be outside of school hours so she didn't have to miss school all the time.”

“We are treated differently every time we visit Macclesfield Hospital. Considering that they have all been trained in Autism it really depends on who you speak to. We have been to A&E three times this year. The first time, the receptionist listened when I explained that my son was Autistic and couldn't wait and we were seen very quickly. The second time we were told that we would have to wait like everyone else, and the third we were asked for the patient passport before being seen quickly. Some continuity and understanding would be nice.”

“We have to have the first appointments at the doctors because he can't sit and wait without getting agitated. At the dentist we always have a 2pm appointment, these things are paramount for us, and sometimes they do run late which causes problems. No one seems to understand the stress, high anxiety and routine we have to live



by. We are also the ones who get the backlash from the changes or because we have to take them to appointments.”

“People don’t know how to speak to my son. He can’t ‘do’ small talk. The GP thinks he’s rude, but my son doesn’t want to talk about the weather, he wants to talk about his health.”

“The physio who came to help my son insisted that he look at her when she was speaking to him. He hasn’t maintained eye contact with anyone since he was a baby. He’s 25 now. Couldn’t she have tried to make him feel comfortable about the situation?”



Confusing environment

Support available

The good news is that there is a lot of support around in Cheshire East for parents of children with autism. The bad news is that it's quite hard to hear about them. GPs (usually a family's first port of call) don't have a very full picture.

At Healthwatch Cheshire East, through our months of listening to people's stories, we have built up a very confusing picture of what's available for families. It also seems that things change quite often - team names change and personnel change frequently. It doesn't help that some groups are voluntary, some are commissioned by the CCG and some are run by the Council.

No big picture

What comes out strikingly in all our discussions with people (both public and professional) is that there is no overall picture of the support available to families in Cheshire East.

Care Act changes

To further complicate matters for parents, autism is not solely a healthcare condition. It can impact on a child's education too. This means that families not only have to navigate through the healthcare jungle; they also have to become experts in the education system. Healthcare professionals (including Healthwatch Cheshire East) often have little or no knowledge of the education systems and can give confusing or simply incorrect advice.

The Care Act 2014 aimed to simplify things for parents by bringing in Education

Health & Care (EHC) plans. These mean to combine all information about the child in one place, but at the moment they are in transition from existing plans and are not well understood by parents and professionals alike.



Adults with Autism and Aspergers

The majority of stories that we have gathered are from parents with young children who are still at school. Their major concerns are being able to access help in a crisis situation and transition from Early Years education to Primary and from Primary to Secondary education.

What happens when children leave school?

In some cases life gets better. We listened to one mum who said that;

“When my son left school he was finally able to be himself. Without timetables and so many rules he flourished. He has a job now and is able to support himself.”

We have listened to some parents who acknowledge that the reason they haven't complained about services is because there aren't any services to complain about.

“My son left college last year. He couldn't cope with yet more bullying. He now sits at home every day looking at the computer. The social workers don't know what to suggest. They say they don't know where to start looking for support. If they don't, how can we?”

Some groups who started opening up for children in the school holidays now open their doors to adults who are too old to officially come to the groups but who don't know where else to go. These groups have told us **“IF WE DON'T LOOK AFTER THEM, WHO WILL?”**

We haven't really started to scratch the surface of the difficulties of transition from children's services to adult services in Cheshire East (as a whole), but both CCGs believe there are problems.

This is an area that Healthwatch Cheshire East will be reviewing and we aim to work with all partners in this



Professional experiences

We listened to some of the team at CAMHS to find out what it's like to work there. Although they find the job rewarding, they are also feeling the strain when they simply can't help people because of a lack of resource.

Professionals are telling the public to complain to the CCG directly so that CAMHS resource is not spent on dealing with complaints.

We are working closely with Eastern Cheshire CCG, who wants to change the way people who are living with autism are treated. They have been very open and have heard all our stories. They have also listened to parents and carers and have

tried to take on board the suggestions that people have given them. They have listened very closely to our recommendations too.

We are delighted that the CCG is so open to listening to the public voice and we hope that by working together we can all make things better for people living with Autism and Asperger's in Eastern Cheshire.

South Cheshire CCG is also very open to discuss pathways with us, and have asked us to look into services available for Adults with Autism in their area. We are currently expanding our work in this area and are delighted to be working with them too, to improve services for local people.



Recommendations

After spending time listening to people who are in or who want to be in the system we can give the following recommendations for consideration. We recognise that the diagnosis process is being revised at in Eastern Cheshire and urge that future treatment pathways give consideration to the following:

1. To providing crisis care for families whether or not they are on the treatment pathway.
2. How any future crisis care will be accessed by families.
3. Review the treatment pathway to simplify and join up healthcare professional teams.
4. Produce (or commission) a directory of services available to families and keep it up to date.
5. Ensure professionals have and use the directory.
6. Train professionals in all processes and procedures relating to autism (treatment pathways and care plans included).
7. Train (or re-train) all health and education professionals as to what living with autism and asperger's means for individuals and their families.
8. Review the provision of Adult services available to people on the autism spectrum.
9. Review 'transition' stage support (from Early Years to School, from Primary to Secondary school and from CAMHS to Adult services).
10. Encourage all providers to see services as part of a 'one child' scenario (i.e. that health doesn't stop with healthcare services). All services need to be more joined up.



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- Space4Autism
- Cheshire and Warrington Carers Centre
- National Autistic Society
- Eastern Cheshire CCG
- South Cheshire CCG
- Autism Inclusive
- Cheshire East Parent Carers Forum
- Finally, everyone who spoke to us or told us their story.



Appendices

Impact case study: Autism in childhood - diagnosis pathway

A difficult start

Our daughter has had health problems all her life. She didn't have an easy start, being diagnosed with liver cancer at nine months old. She's a fighter though and got through that, including having a liver transplant. It means she has always had to go to hospital for regular check ups, and still does.

It's complicated

Life in the healthcare system is very complicated for us. When our daughter was diagnosed with cancer, all her treatment was done in Manchester (we live in Cheshire East though) but all the treatment to do with her transplant was done in Leeds. This obviously meant a lot of travelling to and from various hospitals for us, which was fine because the treatment was working. We still have to go backwards and forwards to Leeds for the check ups.

Distressing

Check-ups for our daughter's transplant treatment are always distressing. She hates having her blood taken and gets really distraught whenever this happens. She needs blood taken a lot - to check whether or not her liver is functioning properly.

“Every time we have an appointment coming up we all dread it.”

I dread it because I know that my daughter has to endure something that traumatises her and there is nothing I can do about it.

“We thought these appointments would get easier as our daughter got older. She would know that they were unpleasant but she needed them for her own good. This has not been the case. It's always been difficult to communicate with our daughter.”

School begins

When our daughter started school we started noticing how she played differently to the other children. She was much more interested in her own games. She seemed happy but was not communicating or interacting with the others.

“I started talking to our GP about Asperger's and Autism. It seemed clear to me that something was wrong.”

I talked and talked and talked for 18 months. Eventually we were seen by a play specialist at the Child and Adolescent Mental Health Service (CAMHS). The outcome of that was that our daughter was happy and so there was no underlying issue with her and so we were discharged.

I disagreed with this.



“I could see our daughter needed help, but I was ignored. The specialists started saying that it was all my fault.”

I was causing all this anxiety and poor behaviour that they didn't see. I felt the implication was that our daughter only acted 'differently' when I was there. I was persuaded to go onto a parenting course for six months which I agreed to because I believed that my daughter was on the waiting list for CAMHS once again. At the end of the course we discovered that we hadn't been put on the list but we were now.

“This means that I've been asking for help for 2.5 years and we are now at the end of a 3 year waiting list.”

All this time our daughter and our family are suffering. Our daughter finds it difficult at school and we find it difficult watching her struggle. We feel that we are told what we are doing wrong all the time, without any support to try and put it right. How can children who are struggling be made to wait nearly 6 years before getting any help?

“With a physical problem like cancer there is help almost immediately. With something more intangible it feels like you are blamed first and then helped a very distant second.”



Impact case study: Autism in childhood - diagnosis pathway

Why did you ask for your child to be referred to CAMHS?

We had concerns about our daughter's behaviour from a very young age.

Describe the referral process

Initially we were referred by the GP, but heard nothing (from CAMHS). A new (trainee) health visitor came to see us and got us back into the system, but we have had lots of appointments where the outcome is "come back in six months".

"Our overall experience of the diagnosis process has been horrendous and frustrating."

Continually waiting

Over 3.5 years we have had numerous referrals between paediatricians, all of whom have left after we saw them so no continuity. We have just been informed (by our speech therapist) that we will be referred for an ADOS (Autism Diagnosis Observation Schedule). This comes after 3.5 years of waiting...

Other comments

"Why is it such a battle to get health professionals (speech and language therapists excepted) to believe you and acknowledge your concerns?"

In brief:

- How long have you been waiting for a face to face appointment with CAMHS?
 - Over 18 weeks
- How long did it take to receive a formal diagnosis from the point of referral?
 - We are still waiting for an appointment.
- Which professionals did you and your child meet with as part of the diagnosis process?
 - Paediatrician
 - Occupational therapist
 - Speech and language therapist
- Did your child have a named person who dealt with their diagnosis?
 - No
- What information were you asked for as part of the diagnosis process?
 - Detailed questions about your concerns and child's concerns
 - Details of your child's experiences of home life and education
 - Details of developmental history
 - Medical history
 - Physical examination

NOTE: MOST OF THE INFORMATION ABOVE WAS PROVIDED IN WRITTEN FORM AT THE INITIAL APPOINTMENT WITH THE PAEDIATRICIAN - SHE HAD NOT LOOKED AT MY CHILD'S NOTES BEFORE THE APPOINTMENT.



Impact case study: Autism in childhood - diagnosis pathway

Why did you ask for your child to be referred to CAMHS?

Our daughter has always been anxious, but recently has started hearing voices in her head that tell her to do things. This is very distressing for all of us and none of us know how to cope with this.

Describe the referral process

We were referred by the GP, school nurse and paediatrician.

We are desperate for a diagnosis so that our daughter can go to an SEN school.

Waiting time

Our initial referral resulted in an appointment with CAMHS within 2 weeks. This appointment was very disappointing resulting in us having to be referred again. This time it took 2 months to get an appointment and we are just starting CBT.

HOWEVER, we have not been assessed for autism (or any other problems) and have not received a formal diagnosis of anything. We have waited for over 2 years for a diagnosis appointment because we weren't officially put on the waiting list for 6 months.

Other comments

CAMHS are just as desperate as we are for our daughter to get a diagnosis, because we are all worried about her mental state when she starts secondary school shortly.

We struggle significantly for family support too. Our daughter's psychosis is very distressing for all of us (including and especially her) and we do not know how to deal with this at all.

In brief:

- How long did you wait for a face to face appointment with CAMHS?
 - Over 18 weeks
- How long did it take to receive a formal diagnosis from the point of referral?
 - We are still waiting (over two years)
- Has your child been referred to CAHMS for mental health support?
 - Yes for anxiety and psychosis



Impact case study: Autism in childhood - diagnosis pathway

Why did you ask for your child to be referred to CAMHS?

He displays very challenging behaviour including violence in the home towards the family. Our child has multiple health complaints including dyspraxia and epilepsy and is displaying severe distress which manifests itself in violent outbursts towards us.

Describe the referral process

We were referred by a paediatrician.

Waiting time

We have not been seen after 6 months.

We have been told by CAMHS that they have no budget and therefore no appointments and so we must wait for many more months.

Other comments

We are desperate. My child is harming us and his siblings and we do not know what to do and cannot cope.

In brief:

- How long did you wait for a face to face appointment with CAMHS?
 - Over 18 weeks
- How long did it take to receive a formal diagnosis from the point of referral?
 - We are still waiting
- Has your child been referred to CAHMS for mental health support?
 - No



Impact case study: Autism in childhood - schooling

Suspected trouble

My son was a very quiet baby and toddler who initially had slow speech but stopped talking altogether at two and a half.

We were referred to Speech Therapy and then their chatter cats sessions. We noticed other concerns including balance problems and slow information processing speeds and so we were referred to a Paediatric Consultant and a Physiotherapist at Macclesfield hospital. The Consultant was fantastic and we were confident in my son's care with him.

The best years of your life?

Problems started again at nursery when my son was put on the naughty mat for not getting dressed quickly enough. I would be told by staff when I collected him that he had been so quiet they hadn't engaged with him all day. Fortunately we moved him to a pre-school which interacted with the children's play.

All too soon school started. Things were OK in to start with because in the reception class it was the child led play approach.

But in Year 1 (age 6) as the teacher's expectations raised and the reading got a bit harder things started to go wrong for my son.

He found the work difficult and had problems with his motor skills and focusing on the work and daydreamed a lot. We discovered he was suffering from stress stomach-aches after bullying and negative comments from another pupil, which wasn't addressed by the teachers.

How come the quiet well behaved children with special needs blend into the background, while the loud disruptive children get the attention?

No help

After a frustrating year, I applied for a parental request for educational funding in the hope of my son would get help. Unfortunately this was rejected by the education authority due to lack of support from the school and because there was no Educational Psychologist involvement.

How can a child be seen by an educational psychologist when only schools can refer the children to the service? If schools are not supporting some quiet children with special needs, how can parents access educational professionals for support and guidance for their child?

I went to the school nearly as much as the children in the end! Meeting after meeting after meeting. All to discuss the support that my son wasn't getting that I thought he should have been getting.

The school did not acknowledge he had a problem and with no educational psychologist involvement, we were denied funding for support.

I tried to help him at home, even paid for extra lessons, but I'm not a teacher and it's hard when they're tired after the day at school.



Dyslexia and Autism

Finally we had some fantastic support and help from Parent Partnership and we managed to get an appointment with the Cheshire East Autism Team because we wondered whether his communication difficulties might stem from Autism.

The school still didn't properly acknowledge that my son had problems. They had started to give him some support, but told me 'he's coping'.

Without an official diagnosis from an East Cheshire approved organisation they would not accept he had problems. This means it is impossible to get any help for him.

Eventually after an independent dyslexic assessment, he was diagnosed (by Dyslexia Action) as being dyslexic and dyspraxic. It was this assessment which highlighted that my son is three years behind his peers in reading, spelling, phonics and writing.

It's a waiting game

We are eventually on the waiting list for assessment with the Children and Adolescent Mental Health Service (CAMHS).

To even get on the list has taken four years. We were denied a space initially because the waiting list was closed we applied again but then were denied a space because my son did not have self harm issues, and finally we are accepted by towards the end of a very long waiting list. We understand that CAMHS only has

funding to assess 12 children per year in the Cheshire East area. No-one seems to be able to tell us when we might get the magic appointment, as there are over 160 children on the waiting list.

This means that after waiting for four years we may have years yet to wait for an assessment. With little support in the meantime.

We are already worried about applying to secondary school.

And now?

My turning point was meetings with the school head teacher, halfway through the last academic year. I cannot understand why I have been told for years that there is no problem, when clearly there was and is.

I don't understand what difference the 'official' diagnosis makes - why are struggling children not supported as a matter of course?

We need more professionals who can guide, assess, help and support our vulnerable children to properly access and receive educational support.

And if an official diagnosis is so important, why on earth have we and so many other people been waiting so many years for it?



Impact case study: Autism as an adult

School days

My son was diagnosed with Asperger's in Year 2 (age 7) of mainstream school. The school were telling us that he wasn't mixing very well with the other children, and we'd already noticed his lack of eye contact.

Consequently, my son found mainstream school very difficult to cope with and so we moved him to a special school for the rest of his primary education.

Secondary schooling was a nightmare.

The special schools were too 'special' for him and the mainstream schools weren't special enough. He got bullied constantly and ended up being set upon by a group of 5 other boys. Enough was enough so we removed him from the school - to protect him really.

Eventually, a special school managed to find him a space and he did three days a week until his was 18.

What next?

My son is great at music particularly drumming and so he started at college to study music. It didn't take long for the bullying to start again. He had a support worker, but sadly she wasn't much support. She wouldn't sit next to him in class saying that 'it would make the other students feel uncomfortable'. What about my son? Doesn't it make him feel uncomfortable that even his support worker won't sit next to him?

My son couldn't cope with the bullying and left college.

He has just finished a year at a local college doing evening classes to get his GCSE Maths. He has passed with a good grade, which I think is a huge achievement and just goes to show what he could achieve with some understanding and support.

Nothing doing

He's currently doing nothing. There is nothing for him to do. He can't get a job. No-one is interested in helping him get a job. I don't know how to help him get a job.

He has no support. We do occasionally get visits from social workers. I ask them where to get some help and support. They tell me they don't know. If they don't know, where do I even start?

We get benefits. I believe the benefits system is changing but no-one has explained what we are entitled to or how any changes will affect us. I called the Council to ask about a Carers budget but I was told that I didn't qualify because my son was too old and anyway there wasn't any money and so I couldn't be assessed.

The future isn't bright

I have no idea what to do next. I'm worried for the future. What happens if something happens to me? I can't get any support for my son how will he manage?

I can't understand why we are being denied any sort of support when we are struggling.



Knowledge and consideration

In all honesty people on the autistic spectrum need professionals who have an understanding of the condition.

We have had physiotherapists come to the house and refuse to speak to my son unless he maintains eye contact. He has never maintained eye contact from a baby. Why would he start now? If even the professionals can't accept him, what hope is there?

We also have a lack of understanding on the other end of the scale. Some professionals think my son understands what they are telling him. I know that he can work out what they want to hear and so he says that to them. Whether he understands or not.

Why bother?

No one seems to understand the stress, high anxiety and routine we have to live by.

I really wish the professionals would live a week in our world, things may change then.

Our world is very isolated, we go out and get abused because no one can see their disabilities but see them acting inappropriately, *we can hear the loud laughs, comments and see the nudges.*

I once tried to explain to the doctor about this and was told 'if your son doesn't see it why do you bother', I bother because it hurts deeply to see my son being laughed at and tormented.

It was easier when he was a child. At least there was some support. Now there's nothing. No-one cares about us.