

**Autism
Spectrum
Disorder
Services
Parent and carer
experiences
2017**



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Case Studies

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Introduction

Healthwatch Wakefield was created as part of the Health and Social Care Act 2012 and started in April 2013. It provides an opportunity for local people to have a stronger voice to influence and challenge how health and social care services are provided.

Young Healthwatch in particular gives a voice to children and young people. It is open to those aged 8-18 years, and up to 25 years for those that are vulnerable and those with disabilities. It gives the individuals an opportunity to identify issues and gaps in services and to help shape and develop future services.

Healthwatch Wakefield had heard concerns from various sources, including parents, regarding their experiences of assessment and treatment for Autistic Spectrum Disorder (ASD). There were specific concerns that an increased investment in ASD services and assessment had resulted in minimal impact on waiting times.

Healthwatch Wakefield decided to investigate service provision and the experiences of children and young people and their parents and carers of ASD services. The work was split into two parts, the experiences of parents and carers and the experiences of children.

This report details the findings from the work with parents and carers of young people with ASD. A separate report is available detailing the findings from the work with children and young people.

Aim and Outcome

Healthwatch Wakefield wanted to engage with parents and carers of children with ASD to find out their experiences of ASD services including:

- Waiting times
- Support whilst waiting
- Assessment
- Support after assessment

And the transition from children's to adult's ASD services, including:

- What works well
- What doesn't work well
- What could be improved

The desired objectives were to have a good understanding of current experiences during 2016-2017 covering all the areas outlined above.

Methodology

The method chosen was the collection of case studies in the form of stories from parents and carers of children and young people who have neuro-diverse conditions including Autism Spectrum Disorder in Wakefield District. During May through to July 2017 staff met with parents from voluntary and community sector groups which included the Beat Autism group, the Fusion Youth Club and Kidz Aware. Some parents and carers were also contacted through other mechanisms such as word of mouth.

Stories were collected through informal semi structured interviews with the following prompt questions:

1. Experience of
 - Children's autism services
 - Transition from children's to adults services
2. Waiting times
 - Support while waiting and what impact this had
3. Assessment
 - Efforts made to help parents/carers understand the condition
 - Expectations of the assessment
4. What happened after the assessment and what impact this had
5. Any suggestions on how this service could be improved

Points to Consider

The numbers of parents and carers interviewed were relatively small, with a total of nine interviewees. The data collected was qualitative in nature and the data was analysed and sorted into key themes which are detailed in the main body of the report. All feedback was from White British parents and carers.

Survey Findings

This section goes through the responses from parents and carers and highlights the key messages that became clear from the work.

Waiting and Assessment

Parents and carers said:

- Waiting times for assessment and diagnosis were too long;
- The option of home visits for assessments would help staff to understand the family and the patient better;
- Services for assessments could be based together (geographically) which would improve things;
- Processes need to be better explained to parents and carers, particularly at times of transition for example house moves, changing waiting lists;
- There was one case of a patient getting "lost in the system" following a geographical move;
- Letters and reports that are produced following diagnosis need to be understandable for parent and carers. A lay person's summary was felt to be a useful way to do this.

Following Diagnosis

Parents/carers said:

- More regular reviews by a paediatrician would have been useful rather than being reviewed by support staff e.g. communication nurse;
- There was not enough access to support services such as Speech and Language Therapy (SALT) and Occupational Therapy following diagnosis.

Support

- There was a lack of support for parents, carers, and patients both while patients were on the waiting list and also following a diagnosis;
- The Beat Autism group offered support for several families;
- More empathy and compassion could be displayed towards both parent and child throughout the services;
- Some parents and carers found that they did not know where to go for support because they were having trouble navigating the system.

Transition from Children to Adult Services

- Periods of major change can be difficult for patients with additional needs and the lack of continuity between children and adult services can be particularly problematic. One patient disengaged from services completely due to difficulties at this point;
- There was evidence that during this transition period the role of the main carer changed and they were no longer included in assessments, contact with services, or if they were they were asked to remain silent. This was distressing for both carer and patient as they were unprepared for this change in role and the carer still felt they needed to be included.

Other

There was a general sense that staff working with these patients need more training in how to manage patients with ASD. This was particularly highlighted in relation to GPs and staff working at Pinderfields Hospital.

Some changes were suggested to the service provided at Gate 15, the Children's Centre (ward), at Pinderfields Hospital. These included ensuring all patients are made aware of the Sensory Room that can be used whilst waiting for appointments and consideration being given to the employment of a play worker to meet and greet children as they have at Leeds General Infirmary.

Conclusion

This work describes experiences of ASD services in 2016-2017 from a parent and carer perspective. The findings also offer suggestions for improvements in services that could be implemented to improve the experience of those accessing these services. In addition to some specific suggestions for change, such as the employment of a play worker at Gate 15; whilst some general themes cut across the key messages that came from this work.

Lack of resource

Overall, there was a feeling of lack of resource for the service which was displayed by the long waiting times for assessment, lack of support for parents and carers prior to and following diagnosis and access to specialist staff and the therapy support following a diagnosis. In addition to an increase in the support services available for parents and carers and their children there was also felt to be a need for training for staff working in autism services, both directly and indirectly, to be better able to manage interactions with patients, parents and carers and specifically around empathy and compassion being displayed by staff at all levels.

Communication

Communication is another key issue arising from the case studies, this ranges from better communication about processes and procedures and clearer communication in reports through to specific information regarding local support services and facilities being provided.

Transition period

Finally, it is also very clear from these case studies that the transition period between child and adult services is a particularly challenging time for parents and carers who have to negotiate a change in their role and relationship with services in addition to supporting their child. Specifically, parents still need to feel involved in the adult assessment process and feel that their views and experiences are being taken into account.

Healthwatch Wakefield is aware that there is a broader review of ASD services taking place and hopes that this work will be of use and feed into that review.

**Autism
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June 2017**



Case Study 1

Meeting with Beat Autism 5 May 2017

Experience of Children's Service

Waiting and assessment

At age two her son was being seen by his GP on a regular basis and mum raised concerns. Mum was made to do a parenting course by the Health Visitor. Mum knew something was wrong since the child was a baby and told the Health Visitor. Child was offered a place at the Sure Centre nursery for two days a week.

At age three the son was referred to CAMHS was seen by four different staff; was also seen by a speech therapist. At age five was added to the ASD waiting list following a referral by the community paediatrician due to the child's behaviour. Age six child held a knife to another child's throat at school. He was then given a learning mentor every day for two years, which was great as they worked on child's behaviour and feelings. Mum felt health services should have helped with this. At age eight the child was offered occupational therapy, which mum felt should have been offered sooner. After the assessment the doctor informed mum that the child needed to be seen in an ADHD clinic and asked the psychologist to refer back to CAMHS. This was never done and the clinical staff who agreed the plan were no longer working at the centre. Mum had to then go back to the GP several times and made frequent phone calls to CAMHS to get the appointment. Son is eight years old now and had ADHD assessment August 2016.

Impact

Mum did not agree with the speech therapist's assessment that the child did not have communication issues for his age. Mum felt that no support was given. Mum now suffers from mental health issues. Mum felt that she could have quite easily given him away. She felt no effort was made for her child. During the appointments mum expected to spend more time with the clinical staff in order to fully explain what was going on. At the age of 10 the child has not been diagnosed with ADHD although at age five was confirmed that he did not have ADHD. Mum's feedback on the CAMHS service was that when her son was age eight it was "crap".

Suggestions for improving the service

Mum felt that if her child had been diagnosed with ADHD earlier then they would have had something in place before ASD.

Case Study 2

Meeting with Beat Autism 5 May 2017

Experience of Children's Service

Waiting and assessment

After referral the child was put on the fast track waiting list. When he got near to being seen he was taken off the fast track. No explanation of why this occurred was provided. Mum said this was a hard start. They have now been waiting for 2 years for the appointment, and at present the child is expected to be seen in June 2017. The child was referred for ASD assessment aged three. Child is now five years old.

Impact

The communication nurse has seen the child every three months. A sensory profile has been done but the child still cannot access occupational therapy as he is too young. Speech therapy: seen every six months but mum feels that this is not enough as at school teachers are unable to understand the child. Bowel Management Clinic: seen every three months. Mum thinks that is connected to ASD. Dental: child had two teeth removed at hospital aged four.

Suggestions for improving the service

It would be preferable that the child is reviewed by the paediatrician not just by the communication nurse.

Parents need better explanation of actual processes.

Case Study 3

Meeting with Beat Autism 12 May 2017

Experience of Hospital Services

Waiting and assessment

Teenager aged 13 years who is still waiting for an assessment after grandma sought second opinion when discharged by CAMHS. Child was referred to CAMHS but was only seen once and discharged in 2015. Child has Tourette's syndrome and dyspraxia. Although he is aged 13, has cognitive development of a 6 year old. Has set the house on fire, tried to kill the dog and hit sibling. The child is under community paediatrician who refused to send the child for an ASD assessment. The referral only occurred following a second review after the family sought a second opinion. The carer described feeling like they are in battle as the education authorities say its health issue and the health services say it's an education issue, "You're made to feel like a yoyo". The child did have occupational health involvement but this has been stopped as the child developed some skills such as cutting food, but the carers still feel he cannot do several things such as tying shoe laces, which they feel they need further support with. No speech therapy has been offered but the carer feels this would really help him with communication especially though the teenage years. Kings Medical Centre have been very supportive but it is hard to get an appointment with the regular doctor who is dealing with their case.

Impact

While waiting for further review the carer is very worried as this boy is physically getting bigger and she doesn't know how she will cope. The grandmother is currently unable to cope too and now her other daughter is having to take unpaid leave to help.

Suggestions for improving the service

Make it easier to access an early assessment.

Reduce the waiting list.

More input from speech therapist and occupational therapists would be invaluable.

Services need to listen to parents.

More training for GPs in this area of mental health.

Case Study 4

Meeting with Beat Autism 12 May 2017

Experience of Hospital Services

Waiting and assessment

Been seen by the paediatrician since four years of age and was put on the MDT list. Was only reviewed 18 months after being put on the MDT list. Parent was told waiting list would be for 3 years. No support was provided for the parent and they were told to contact WeSail for the child if needed. Had assessment January 2017 and the specialist had come from Ireland. The education psychologist went to see the child at school and mum spoke with the speech therapist at Pontefract. A telephone call at the end of February confirmed a diagnosis of ASD and a letter confirming this has just arrived now in May. When the letter arrived it was an 8-10 page document, which the parent was unable to understand. The parents were however very happy with the assessment process. Child is now aged seven.

Impact

Since having the diagnosis nothing much has change. However the parent were relieved to have a piece of paper, which confirms that something is not right and that the issue were not merely made up by the parents, which is how they had previously been made to feel. The child already had a special assistant at school, but said this was because the child was already in a very good school. They also struggled to access DLA.

Suggestions for improving the service

The waiting list of three years is too long, and the parents felt the child should have been assessed before commencing school. The assessment itself was really quick and simple.

Letters/report copies sent to parents need to be understandable lay summary would therefore be helpful.

Case Study 5

Meeting with Beat Autism 8 May 2017

Experience of Hospital Service

Waiting and assessment

Young boy who is now 10 years of age, and when attending hospital appointments at Pinderfields there is always an issue, but not at LGI Neurology ward where they are better. At Pinderfields they don't understand his needs and behaviours, also they are abrupt. At Gate 15 Paediatrics there is no play worker. It would be good if there was a play worker to meet and greet the child at the onset of the appointment. At a recent appointment he played with the fan in the waiting room. The nurse said it was a Health and Safety issue and he wasn't allowed to do that although he has played with the fan before. She took it off him and he kicked off. Parent complained to PALS about this to see what could be done. PALS asked the ward staff if the fan could be put away before his appointment, which was going to happen next time. Also PALS found out there was a Sensory Room on that ward which the parent didn't know about. None of the parents at the Beat Autism support group knew about it either. It's good to know so they can take him there before the appointment. There is a need for the child to go in first, but often they have to wait and a child with his type of disability doesn't understand so he then becomes disruptive.

Impact

When he was first assessed the parent wasn't satisfied with what they had been told and they didn't understand the condition. They expected to be told more and what to expect. The parent gets support from the Beat Autism group from parents who have had experiences of the system. The child goes to a special school and sees quite a lot of professionals at school but when they go to Pinderfields it's a nightmare. The parent dreads these appointments because none of the staff seem to have awareness of autism or even basic training in it.

Suggestions for Improving the Service

Need to have medical staff in Pinderfields trained in Autism Spectrum Disorder.

Need to have specialist play workers at Pinderfields Hospital on Gate 15, as they do at LGI in Leeds.

Case Study 6

Meeting with Beat Autism 15 May 2017

Experience of Services

Waiting and assessment

Grandparent has 15 year old Grandson who they care for and who lives with them in Wakefield District. They have had six appointments over six weeks in the last 12 months at CAMHS but then they were sent back to the Paediatrician. They are now awaiting a decision from the Multi Disciplinary Team. He has severe anxiety and suicidal tendencies. He is frustrated with how he is, knows he is different, not 'normal'. He can be disruptive in class because he makes loud noises. He doesn't make friends easily but those he does have understand his difficulties and do help him.

He is at a mainstream school, and the Grandparent has insisted on this throughout his school life. They visited OT in March and the report came through in two weeks. It was a good visit. They recommended a raised laptop and table in a specific position because his writing down in class is slow and he doesn't write everything down in time. He also finds exams difficult because of time constraints. It was recommended that the Grandparent make an appointment to see a SENCO teacher. He is meeting all his targets according to his teacher at the Academy so he is not offered one to one support for his writing. The Grandparent has requested a scribe to be in class with him but this has not been offered. His GCE's are coming up soon and even though he understands the work he won't be able to answer all the questions because of his slow writing. He has a 'One Page Profile' but not a 'My Support Plan' which sets out what support he should be getting. The Grandparent has requested the Support Plan to be put in place. His school have not done this yet and therefore he is not getting the support in class that he needs.

They went to Speech and Language on 19 April and the report from them is imminent. The Grandparent was told it would be two weeks. They are going back to Speech and Language this week and the following week will get feedback from them.

Impact

They have been waiting for a full diagnosis regarding ASD for three years. When the young person went to the Educational Psychologist three years ago she suggested he might have ASD but no one as followed it up. CAMHS really haven't helped him, they only offered the six weeks then it was back to the Consultant. The Grandparent says it is a constant battle to get their grandson what he needs in terms of support and is having an effect on their health. They have been treated for depression because of all the hassle. They have had to fight for paperwork from school regarding the report the Community Interaction Team (CIAT) did. It took them a year to get that.

They went on a parenting course through CIAT at County Hall. On the course they learnt that they should take time out for them self, but their Grandson's needs and the battles to get the right support is all consuming. They can't cope and have no support except for when they go to the Beat Autism group.

Suggestions for improving the service

The Grandson has been seeing the Paediatrician for three years and the process needs speeding up. It is only recently that the case has gone to a Multi-Disciplinary Team. They are still waiting for an official diagnosis of ASD. The waiting times need to be looked at as it takes too long.

If all services you need assessments for were together that would improve things.

Case Study 7

Meeting with Beat Autism 22 May 2017

Experience of Children's Service

Waiting and assessment

Diagnosis was confirmed at 10 years of age. The family waited for six years to get a diagnosis. Mum was shocked and upset when diagnosed and did not know what Autism was and what they should be doing as parents. After the diagnosis mum could see traits of autism in her ex-husband. As a mum she was worried about her child's future, especially how he would cope in school and socially. After the diagnosis came the Physiotherapy treatment came to an end. Mum was told that there was nothing more they could offer and discharged. Son is now 14 years old.

Impact

At the time of diagnosis, the diagnosis did not bother the child but now he is 14 and only able to play with younger children aged six years, and he is becoming increasingly worried about why he cannot play with children of the same age and make friends. Due to this he is getting picked on at school and doesn't like going to school.

Her son at the moment does talk about killing himself and has taken a knife and threatened to stab himself. At age of 14 her son is unable to hold a knife and fork and his writing illegible. He is still not getting any support with this and this worries mum about how her child will cope in life.

Suggestions for improving the service

I don't know what help to ask for but I know it is affecting my health.

Health professions should be trained more in how to manage children with autism for example the GP often says "can you stop him moving around" and you can wait too long in waiting rooms.

More compassion and empathy is required for both the parent and child.

Case Study 8

Telephone call to Healthwatch Wakefield 12 June 2017

Experience of Services

Waiting and assessment

Son was referred to CAMHS and the ADHD clinic when he was four years old. When he was six years old he had an ADHD assessment and the outcome was that he did not have ADHD but should be assessed for ASD. Since 2014 he has been on the ASD waiting list and has been seen regularly by the Pontefract Children Centre. However apart from this the family has not received any support.

In 2016 the family had to move from Wakefield as they could only afford to buy a house that was big enough in Batley. The family includes both parents and four children, including 18 month old twins. The son is now aged nine. Since the move the mother has been informed that the child will not be able to be assessed by the Children's Centre under Mid Yorkshire Hospitals NHS Trust.

Impact

The mother would like to know why this happened, especially as the child has been waiting for 18 months on the waiting list. Moreover, they still live in the catchment area under Mid Yorkshire Hospitals NHS Trust. Their GP from Kirklees has also tried to refer the child but has so far been unsuccessful.

As a parent the mother informs me that she is coping well and also has a diagnosis of ASD.

Suggestions for improving the service

The mother doesn't know where to go to seek help and contacted Healthwatch Wakefield after suggestion given by KidsWesail.

Case Study 9

Contact with Healthwatch Wakefield 19 June 2017

Experience of Services

Waiting and assessment

Son, who is now 20 years old, was diagnosed with ADHD when he was four years old, however has always been treated as someone with Asperger's Syndrome. Now mental health services would like to complete an ASD assessment, however the son has disengaged from mental health service and refuses to have the assessment.

Impact

Whilst the child was at school his mother felt she "could not have paid for better care", however from the age of 18 she felt "he might as well not exist". The mum is unable to have a break as her son has become housebound and will not allow anyone else into the house. Since he turned 18 years of age, mum feels the services have disappeared and the son has been discharged. In March 2016 an incident occurred when the child's OCD escalated. A friend advised the mum to take her son to the A&E department as the Crisis Team were considered to be really good at A&E. It was a struggle to get her son to A&E as he did not want to leave the house but she did manage to get him there. At A&E mum thought the team were brilliant, in particular they were given a quiet room and only waited about 10 minutes before the psychiatric nurse came and assessed him. After three hours the nurse arranged for another assessment with a psychologist at Fieldhead hospital. The patient became distressed as he did not want to go to hospital and the nurse was able to offer another appointment at Garden Street Clinic, which was preferable.

The parent stated that a professional called Claire had provided really good support to her son but when the family asked if Claire could do a home visit to observe the child's behaviour at home this was not possible. The mother felt a home visit would have been particularly useful to understand the issues affecting her son, and thought this would naturally be part of the care they would receive if her son was being managed by the community team.

The patient disengaged at this time and although his mum had suggested he needed a further OT assessment they were told by the service if the patient did not attend clinic appointments then he would be discharged as they would not do home visits. The mum felt that this was a threat and that a home visit by the CPN would have been valuable. The family have had considerable help and support from their GPs at Lupset Medical Centre who will do home visits when required.

When the child was 19 years old he deteriorated further and expressed a wish not to live anymore and asked the parent to help him in this regard. When the mum refused the child stopped eating and drinking. The GP then referred the patient through the single point of access scheme and the occupational health team came to review him.

In August 2016 the OT came and did four visits but would not always stay for the duration of the time booked out. The OT was a smoker which the patient did not like and put the patient off accessing help.

The mum felt the OT used too much jargon and the patient was unable to understand what was being said. After the fourth visit the OT returned and informed the patient that he had stopped smoking, however the patient and parent found this hard to believe as there remained a strong odour of tobacco smoke. At this point the parent informed the OT that he should not lie to the patient.

Services need to remember that although the patient is now an adult it is the parent who is still the sole carer for the patient. When staff speak to the patient they tend to block the parent out and do not enable the parent to contribute to assessments. The parent was told “as he is an adult you can stay but are not allowed to speak.” This does not help the parent or the patient. Also the parent did not like being spoken to in this manner in her own home, “I have been his sole carer for 18 years and do everything for him”.

Currently the patient is not receiving any support or help as he has disengaged from adult services. The services have said that the patient’s ADHD has settled down, but mum is not sure that this is the case. The mum is constantly worried about what will happen to her son as he is becoming increasingly isolated and just wants to stay at home all the time.

Suggestions for Improving the Service

To have the option of home visits especially from staff patients relate to well.

Parents to still be involved in patients care especially if they are still the main carer.

To have some overlap/continuity during the transition from child to adult services, as this major change is difficult for such patients and may result in disengagement from services.

To understand that even if the aim is for the patient to self-manage their illness, if they are in actual fact still wholly dependent on their main carer that this should be taken into account and not dismissed.

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