



**Healthwatch Kent** - August 2019

The reality of autism for young people  
and their families in Kent



# Purpose

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**We hear about the difficulties families face when accessing support for their children who may be autistic.**

We wanted to explore the issues in more detail and gather more feedback about services for children and young people who have autism.

# What were we trying to achieve?

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**We wanted to understand three key things:**

- **What did people expect from the service?**
- **What in reality was their experience?**
- **How in their view, could their experience have been improved?**

We recognised that issues about waiting times were well known so we wanted to ensure we heard about other concerns too.

We wanted to uncover positive stories as well as the not so positive.



# What did we find?



**Over half of the young people we spoke to felt that they didn't get enough information at the time of their diagnosis.** We heard that young people wanted "a follow up appointment after the diagnosis" and felt that they were "sent on their way with no information". People told us that follow up and ongoing support is critical to encourage young people and empower them following their diagnosis.

**Parents expressed a desire to have been offered training courses much earlier.** Currently courses are only available to parents once their child has been diagnosed but this can be some time down their journey.

**Most parents and carers felt that they wanted better access to services.** They told us that "a clear pathway to diagnosis and a clear pathway to educational and mental health support" should be offered.

**We spoke to parents who wanted to access help for themselves too,** "you have to keep fighting but it wears you down and your mental and emotional health is affected" and "I feel completely alone".

**80% of parents told us that they hadn't received any support.** Most parents said that they just wanted "adequate support", training courses, access to support groups, and access to the CAMHS service.

**Parents felt that high functioning autism wasn't addressed by schools well enough;** support staff did not believe that the student required an assessment because they were meeting their academic achievements, and therefore did not inform the relevant teaching staff that a student may have autism.



# What did we find?

**Parents talked to us about the lack of support in schools.**

Social problems were being ignored by the school and staff; parents told us that their child had problems maintaining friendships with their classmates and that they had no awareness of dangerous situations. Parents felt that school staff are only interested in exam results and performance and are not providing holistic support to children in need. We heard that “SENCO’s are not bothered about anything that happened outside of school”.

**There is much confusion regarding the referral process, and parents were unsure who to speak to regarding a referral.**

One family went to the GP, who asked them to speak to the school about a referral for autism. Other families told us that the SENCO at school said that it was not her responsibility to refer to assessment, but she suggested that they see the GP. Families did not know who to turn to for help.

**When referrals are made there is no response from the provider to acknowledge receipt of the paperwork.**

Families are left without any contact details or any understanding of the waiting times. Some families asked the contact person in the school, the Family Liaison Officer, who was unable to help as they were not given any acknowledgement of referrals made either. Parents described that they “felt lost in the system”.

**Parents were not signposted to local support groups or local activities to nurture their autistic child.**

Many of the parents that we spoke to expressed a desire to have more social groups, like the Home-Start group but for older children, ideally running after school hours or at weekends. Parents did not know how to access these groups as they were not informed by anyone but had to source support by themselves.





# What have we recommended?

## For Children & Young People:

Having heard from young people, listening to their experiences, and hearing what support they would have liked, we have made recommendations to improve the support and services at the point of diagnosis:

**1.**

More information regarding diagnosis, available therapies & treatments and management **must** be provided to young people at this critical stage.

**2.**

There should be a clear offer of CBT or alternative age-appropriate support therapy following a diagnosis.

**3.**

There should be a clear process to follow up with a young person from the point of diagnosis; including CBT, referral to local support groups and return appointments.



# What have we recommended?

## For Parents & Carers:

- 1.** Information and support must be made available for parents and carers when the child is referred for an assessment and not wait until the point of diagnosis.
- 2.** There should be better signposting to local support groups and the Kent Autistic Trust, following a referral for an autism assessment.
- 3.** At present, referrals to parent training courses such as Cygnet and Early Bird are made following confirmed diagnosis of ASD. If the initial screening process indicates a strong likelihood of ASD, earlier access to these courses should provide parents with more knowledge in dealing with ASD.
- 4.** Families told us that they wanted more support, advice and respite. Parents and siblings should be offered family support sessions to help understand and learn about how to deal with the diagnosis and the impact that it has on their lives.
- 5.** There must be clarity for parents and carers on how to refer into the neurodevelopmental pathway. Health and education must work together to refer young people; with supporting statements from any relevant agencies or parties (ie SENCO, Education Welfare Officer, Health Visitor, Youth Offending Service).
- 6.** The crisis line currently in operation should have dedicated staff available, who are experienced in supporting parents, carers and young people who are struggling.





# What have we recommended?

## For Schools:

1. Schools should aim to have a model support system in place that includes a partnership between the SENCO, the children's liaison officer and family liaison officer, to ensure that the academic and emotional needs of the young person are met, and that families are well supported.
2. Parents who have children with high-functioning autism told us that the school provided no support because of their academic abilities, but young people struggled with emotional issues that could have been better supported. Children and families should have a named member of staff, specialising in supporting the emotional needs of young people in the school setting.

## For Professionals:

1. When the referral is received by the CYPMHS service it should be acknowledged in writing and sent to the family, the GP and the SENCO, with a named contact person who can advise on referral progress. This will stop families feeling "lost" within the system.
2. There should be a single dedicated point of information, accessible to professional staff so that they can appropriately sign post young people and families to services in their local area, for example art therapy or Lego therapy. Many local groups have been established for years but are not mentioned on the Kent Local Offer page.

**We will be reviewing our recommendations to understand what progress has been made.**



# How did we go about it?

## We spoke to young people, families and professionals across Kent:

- We released an online survey and had **127 responses**.
- We spoke in-depth with **three families** at a local children's centre.
- We spoke to education staff who specialise in supporting young people with autism and other additional learning needs.







# What did people tell us?

## Children & Young People:

"I had no official help"

I wish I could have "follow up reviews over a period of years, to make sure that I'm coping"

It would have been helpful to have "recommendations for dealing with sensory difficulties, such as accessing tinted glasses and noise cancelling headphones"

We need to have "more support at school"

"My doctor is aware of my condition but my treatment and help is only in the form of a 6 week CBT course or antidepressants"

I would have liked "local support groups for children and young adults"



# What did people tell us?

## Parents & Carers:

- “I’ve asked for help, reviews of behaviours and actions to be put in place but it is always forgotten”
- “There is a lack of relevant and helpful clubs for autistic people and children in my area, especially during the holiday”
- “Mental health services should be seeing all children referred to them and have a pathway that all children follow”
- “The support and understanding is still very poor for someone with a hidden disability”
- “The services need to provide care to children and adults, and transition them between both”
- “When your child is diagnosed you are given leaflets and sent on your way. This is a life changing diagnosis”
- “We paid for a private diagnosis as the wait list was too long”
- “Services remain disjointed and focus upon a reactive approach. The quality of service provision is extremely poor and it is down to parental knowledge and resourcefulness to ensure children get care”
- “The system only works if your child shows behaviours within the school environment. Issues that are isolated to the home/community are invalid”
- “We only found courses are available during the day, that’s no good for working parents”
- “Every professional has declined to help as my son does not show behavioural issues at school”
- “My youngest child was left suicidal and self-harming at 6 years old”
- There needs to be “more understanding of autism in the mainstream setting”

Many of the support groups that were mentioned by families are locally run, as well as registered charities:

**Kent Autistic Trust, SNAAP, We Are Beams, Dandelion Time, Purple Octopus Project**



# The reality of autism

As part of our research to find feedback, we visited a children’s playgroup at a Children’s Centre and participated in a “Play and Learn Session”, which is run by the Home-Start organisation.

We spoke to families in-depth who are experiencing various stages of referral, diagnosis and assessment for ASD for their children, and we gathered a snapshot of feeling about the process. These three examples of families that we spoke to exemplify the struggles that parents in Kent are facing:





# The reality of autism

## Real Life: Story One

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"I first realised that my daughter was on the spectrum when she was around 2 years old. She had "certain traits" that didn't seem right. She's quite high functioning. The big thing we noticed was her social problems and she struggled to maintain friendships. I got quite worried before she finished her primary years, and she was saying strange things and had no awareness of danger. I found her standing on the window ledge once, and another time she said she wanted to walk out in front of a moving car.

When she was 10, I got the GP to refer her for an assessment. The SENCO said that she was fine because she was meeting all of her academic targets, she felt that a referral wasn't necessary. I really feel that the SENCO needs to be more proactive, and not just be concerned with academic performance. The social aspect was totally ignored in school. As long as my daughter was performing well, the SENCO had no concerns about her.

At her first parents evening in secondary school, half of her teachers knew about her diagnosis and the other half had no idea! There was no coordination of communication

between teaching staff. The SENCO at secondary school hadn't circulated it to all staff involved in her timetable. The school had no interest in helping her, because they didn't see the need for a referral in the first place.

When she was young and in preschool, I wish there was more support, some peer support would have been useful for me too. I wish that there was more coverage of autism, particularly in girls. It is assumed that it just affects boys. The SENCO said that too, she couldn't be autistic because she's a girl!

There should be more social groups locally, many of the social groups are aimed at younger kids but my pre-teen has nowhere to go to make friends. There are very few support groups in our area, and any support groups that I found were all during the day. This is useless for working parents!"



# The reality of autism

## Real Life: Story Two

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"I first knew that something was 'different' with my son when he was 3 years old. He taught himself to read and he has a photogenic memory, I didn't realise that this was unusual. The SENCO was aware of my son and she picked up on some of his unusual abilities and we discovered a lot of things that fit with autism.

I went to see the FLO (family liaison officer) at the school to discuss my son's "quirks". We discussed things and agreed that it sounded like he was autistic. The SENCO was there too and also agreed, but she wasn't keen to send the referral for assessment. She told me to see the GP and get him to do it. I felt that a referral was best coming from the school as they know him well. The SENCO eventually agreed to do the referral.

When the referral was sent for an assessment, I don't know who it went to. The school knew, but I wasn't given a contact number. If I wanted to chase it up I didn't know who to contact. I wasn't even sent an acknowledgement letter to say they had received it.

I was given no information from the SENCO, she didn't provide any leaflets or signpost me anywhere, no support offered! It seems that I can't get help from the school and they don't provide any information or support to me! Maybe once we have a diagnosis then I can ask how they can help my son or make changes to his routine in school to help him.

It's a very isolating position to be in; the school have given us very little information. In fact the only support I have is coming to the Home-Start group at the local Children's Centre, which happens to have a couple of other mums with autistic kids. That's not sufficient, you shouldn't just stumble across other people like this. There should be local groups and meet ups."



# The reality of autism

## Real Life: Story Three

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“I wasn’t aware that my daughter had autism, or that anything was different about her. Things all happened when she was at preschool and the SENCO from the school visited the nursery kids and she noticed my daughter’s speech wasn’t great. She was sent for Speech & Language Therapy and then referred to a paediatrician at a special needs school.

After seeing the paediatrician, he told me that he had sent a referral to CAMHS for an assessment for autism. I had no idea what it was but a SENCO at the special needs school told me a little bit about it, and she gave me some information for courses in the area that might help me. I felt so much better after going on the courses, I felt that I understood autism and what to do when my daughter has a meltdown. I never would have known where to go for information.

I don’t know exactly how it all came about, but I had a meeting with someone, a wellbeing officer. It was just for me! I was so happy, it was as if someone wanted to speak to me about everything that was going on, and how I felt. It was very emotional and I just cried. I got everything out and just talked. It was so good to have that experience.

It would have been good if the people doing the assessment on my daughter had contacted me to suggest local groups or activities, during our wait for the assessment. I am on a few Facebook pages for autism and parents. Sometimes it helps, but sometimes it can be overwhelming. I wish that there was a local group for kids my daughter’s age who have autism. It would be great if a local group was run that parents of autistic kids can attend. Sometimes for advice, sometimes if a professional was there to discuss meltdowns and stuff: that would be good. There doesn’t seem to be a professional that keeps in contact with parents. SENCO’s certainly don’t, they just keep saying that everything is fine at school. They’re not bothered about home life, meltdowns, or anything that happens outside of school.

If it wasn’t for Home-Start then I don’t think that I would leave the house. The groups they have are great for me to get out, but they were also great when I needed to get my daughter out the house (before she went to school). I’m quite isolated, and things get lonely for me, but I feel that Home-Start are my family unit, and I know that I can ask them for help.”



# Healthwatch Kent

**Healthwatch Kent is the independent voice for local people in Kent.**

We gather and represent people's views about any health and social care service in Kent.

Our role is to understand what matters most to people and to use that information to influence providers and commissioners to change the way services are designed and developed.

Our **FREE** Information and Signposting service can help you navigate Kent's complicated health and social care system to ensure you can find and access the services that are available for you. Call us on 0808 801 0102 or email [info@healthwatchkent.co.uk](mailto:info@healthwatchkent.co.uk)



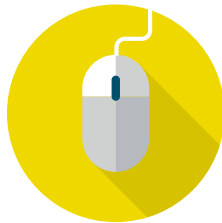
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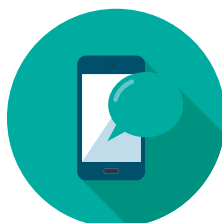
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