Healthwatch Kent - August 2019

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

Background

In 2016 Healthwatch Kent released a report on the Children & Adolescent Mental Health Services (CAMHS) service in Kent. Many families and carers told us about the particular difficulties and complications they experienced when trying to get an assessment for a clinical diagnosis or for mental health support for a child who already has a diagnosis of ASD. One person summarised this by telling us "We need a comprehensive pathway for young people with autism, as many families in our situation feel abandoned'.

As part of our recommendations, we agreed to undertake a piece of work to explore some of these issues in more detail. In December 2018 Healthwatch Kent set out to understand the challenges that people on the spectrum and their carers face, and to understand what will be most helpful or needed when someone first becomes aware that they or their family member is on the spectrum, when they are diagnosed and when they have a crisis. At the time of the 2016 Healthwatch Kent report the CAMHS service was provided by Sussex Partnership NHS Foundation Trust however the service is now provided by North East London Foundation Trust (NELFT). Healthwatch Kent regularly meet with NELFT, since they took over in September 2017, to discuss changes in performance relating to our recommendations from that report

According to the National Autistic Society, more than 1 in 100 people in the UK are on the autistic spectrum. Including their families, autism is part of daily life for 2.8 million people.

National prevalence rates indicate that in Kent (2015) over 17,000 people have autism with 3,700 being under 18 years of age[1].

NELFT told us that when they took over the contract for CAMHS, they had 7000 young people within the neurodevelopmental service. The name of the service has changed from CAMHS to Children and Young People's Mental Health Service (CYPMHS).

The prevalence of young people age 19 and under with an autistic spectrum condition (ASC) is 45.1 per 10,000[2] however according to the SEN register the incidence is 124.9. This suggests that not every individual diagnosed with ASC and on the SEN register has their medical details accurately recorded against their NHS number.

To have a greater understanding of the challenges that people on the spectrum and their carers face, this research used four key methodologies to provide a comprehensive picture of the user experience.

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[1] "Autism Spectrum Conditions" June 2017, Kent Public Health Observatory

[2] Kent Integrated Dataset, "Autism Spectrum Conditions" June 2017, Kent Public Health Observatory

Method	Total responses
Online Survey	122
Postal Survey	5
Face-to-face engagement interviews	3
Education Professionals	4

CQC & Ofsted Inspection: Phil Minns (Lead Inspector) Published 29/03/2019

At the time of researching autism services and our survey being live, there was a joint local area SEND inspection in Kent. The findings were published and appear to concur with our discoveries:

- Although we never asked about waiting times, many parents expressed their frustration at the length of time from initial referral to the 1st appointment. We were told by one parent, "it would have helped to actually get an assessment in a timely manner. My son was eventually diagnosed at 13 years old having waited 18 months. My other son was 10 years old and waited nearly 2 years". Another parent said "we need quicker referrals; children are being left for so long in a poor system". Furthermore, we heard that families went through multiple assessments and waited for years before getting a confirmed diagnosis. This was also mentioned in the CQC report: "the unacceptable waiting times for children and young people to be seen by some health services, particularly CAMHS"

- We heard that parents were frustrated when the schools did not provide support or put measures in place to help pupils, because they did not have an EHCP, something that was also noted in the CQC report ("there is a mistaken belief that an EHCP is essential to ensure their child's needs are met"). One parent told us "EHCPs are too hard to get for high-functioning children which means they go without support".

- The CQC report said that the system was fragmented. One parent in our findings said, **"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 CQC report found that "some parents had to secure additional support for their children using private assessments". This was something that our surveys also found, with parents paying for ASD assessments and speech & language therapy privately because they could not access the services within Kent within a reasonable time. We heard, "the consultant diagnosed…there was a big waiting list on the NHS…we paid for it". Also, "it has taken 1 year to even get access to the right service. We went private to get an appointment, but we are still not diagnosed". Another parent said, "we paid for speech & occupational therapist for 2 years" and another parent said, "we paid for a private diagnosis as well as private speech therapy and occupational therapy as the wait list was too long".

What were we trying to achieve?

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?

Audience One: Young people who have been diagnosed with autism

We had 10 responses from young people (0-25 years) who had a diagnosis of autism, all from the online survey which was circulated on social media sites within Kent that would target young people with ASC.

We asked, "was there enough information given to you at diagnosis to understand what autism was?", with four choices of responses:

Answer choice	Response
Yes, I had all the information I needed	10%
No, there was not enough	60%
No, there was too much	10%
The information I had was not much use	20%

This suggests that over half of the young people engaging with us felt that they never had enough information given to them at the point of 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".

What did we find?

We asked, "what kind of help did you have when you were diagnosed with autism?".

- "I had CBT for several months with a CAMHS therapist"
- "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 had no official help"

Four other responses indicated that they had received no help following diagnosis.

We asked, "what kind of help would have been useful to someone just finding out that they have autism?"

- "support groups"
- "a 1-2-1 session to answer questions"
- "mentoring"
- "explanations to tell me how to cope with it"
- "agreement for follow up appointments"
- "recommendations for dealing with sensory difficulties, such as accessing tinted glasses and noise cancelling headphones"

Many of the responses indicate that continuous and follow up support is critical to encourage young people and empower them following diagnosis.

We asked, "what kind of extra help would be useful now?"

- "local support groups for children and young adults"
- "more support at school"
- "follow up reviews over a period of years, to make sure that I'm coping"
- "group sessions for young people to help them understand autism"
- "1-2-1 sessions with a psychologist"

Four of our respondents would like to have 1-2-1 sessions with a psychologist, suggesting that they have not had this support, or have had minimal support.

What did we find?

Our recommendations

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 diagnosis

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

Audience Two: Families and carers of young people diagnosed with autism

The majority of responses from our online and postal survey came from families and carers. We are keen to find out what their experiences are of the services that are in place for them and their young person, and what they think could be improved.

From the 117 responses to this section of the survey, we have been able to understand what families and carers already have in place to support them and what they believe is lacking.

We asked, "When did you first realise that your cared for person might be on the spectrum? Was it around a particular event?" Many of the responses indicated that educational establishments, such as nursery placements or reception classes at school picked up on the possibility of autistic traits. Other responses told us that detection was noticed much earlier, from the health visitor checks on toddlers.
(We had 72 responses)

- "both my boys had it picked up in their reception class in school"
- "around 18months old, there was a lack of eye contact"
- starting school, significant concerns were raised"
- "just after the 2-year check from the health visitor"

What did we find?

- “as an infant, we thought he was deaf because he was unresponsive”
- “around 3 years because of speech delays and social skills not developing”
- “the health visitor noticed his lack of attention during his 1-year check”

Although it was something that we did not ask, many of the responses also told us when their child was actually diagnosed, highlighting the length of time between being made aware of symptoms, and having a confirmed diagnosis:

- “20 months but not diagnosed until 11 years”
- “I had a feeling at 18 months, but diagnosed at 9 years”
- “since about 2 but took another 15 years to get diagnosed”
- “4 or 5 but not diagnosed until age of 13”

We asked, “How did you find out where to look for more information?”
Our most common responses to this were support groups and self-research. (We had 71 responses)

26 people said that they found information online after conducting their own research. One person said that “the internet provided information, as health services laughed at us”. We also heard, “I had to be proactive myself, I went to a conference and done a lot of research online”

Ten people told us that they went to the GP for advice:

- “went to the GP, they referred me to early help”
- “I went to the GP to get things started with referrals”
- “the GP, then he done a referral”

Other services that were mentioned as a reliable source of information were health visitors.
The Kent Autistic Trust was mentioned repeatedly as a reliable place to find more information.

What did we find?

We asked, “What information do you wish had been available back then?”
(We had 71 responses)

We wanted to know in retrospect, what parents would have found useful at the time surrounding referrals for assessments. We had a varied response to this question, but by far the most responses were around educational support:

- “learning techniques at school”
- “teachers need more training in ASD, especially with females”
- “more 1:1 support”
- “if teachers were geared up to deal with high functioning autism”

We also heard that 1-2-1 sessions would have been valuable, with one parent commenting, “1-2-1-sessions; the ones that the service is trying to reduce to reduce costs”

Parents expressed a desire to have been on training courses, which at present, are available to parents whose child has received a diagnosis:

- “courses and training”
- “understanding the ASD child courses”

Other responses we received were more diverse:

- “support for parents, somewhere to turn to”
- “I live in the Kent/Medway border and I was told I could not access certain services”
- “having a GP who would take the concerns more seriously”
- “access to a social worker”
- “more support groups”

We asked, “What support did you have?”
(We had 71 responses)

The largest response that we had to this question, was 34 people who said “none”; and parents telling us that “referral to CAMHS was a waste of time” and that they “found out what they needed to from other parents”:

- “none”
- “very little”
- “nothing”
- “none at present”
- “here is your diagnosis, goodbye”

What did we find?

Parents told us about what they had done themselves to get support:

- “we paid for speech and occupational therapist for 2 years”
- “we paid for a private diagnosis as the wait list was too long”
- “we went privately to get an appointment”

Some parents had more positive experiences of finding support:

- “a monthly appointment with the GP”
- Local, own sourced, support groups
- “Kent Portage”
- “I had a key worker”

We asked, “What do you wish had been available but wasn’t?”
(We had 69 responses)

We wanted to know what parents felt would have been adequate support, and this question inspired a wide assortment of suggestions:

- “education on the basics of autism and how we can support our child”
- “continuing care in transition to adulthood”
- “just someone to talk to”
- “better support in school to identify issues and support students”
- “more understanding of autism in the mainstream setting”
- “help with behaviour at home”

Most parents and carers identified 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 had many responses wishing that support for families was better:

- “advice for parents”
- “support for us as a family”
- “support for parents”
- “behaviour support for the parents and siblings”

What did we find?

We wanted to know, "What were the challenges in helping your cared for person?"
(We had 69 responses)

This was important for us to find out the challenges that parents face in Kent, and to see what services could better support families. The most mentioned subjects included problems with school, challenges with emotional support, and more practical issues.

Many of the responses came from people struggling with the education system:

- "exclusions from school"
- "fighting for a school place"
- "keeping my son in education, he is 4 years old and already had 2 exclusions and is now on a part time timetable"
- "trying to get school support"
- "the school placement broke down and spent months being home schooled"
- "trying to get support in school even though they are academically able"

Other responses focused on emotional issues:

- "my youngest child was left suicidal and self-harming at 6 years old"
- "physical aggression and low self-esteem"
- "managing the challenging behaviour, especially the lashing out and biting"
- "anxiety and suicidal ideation"
- "self-harm"
- "mainly behaviour"
- "extreme anger"

Other issues we heard about include:

- "lack of sleep"
- "acceptance and ostracism"
- "constant friendship issues and bullying"
- "trying to differentiate between reasonable adjustment for their autism and what is naughty behaviour"
- "toileting"
- "no awareness of danger"

What did we find? Continued.

We asked, "What help was available for each of the challenges?"

Over half of the parents and carers who answered this question said that they had received no support to help with the challenges. (We had 69 responses)

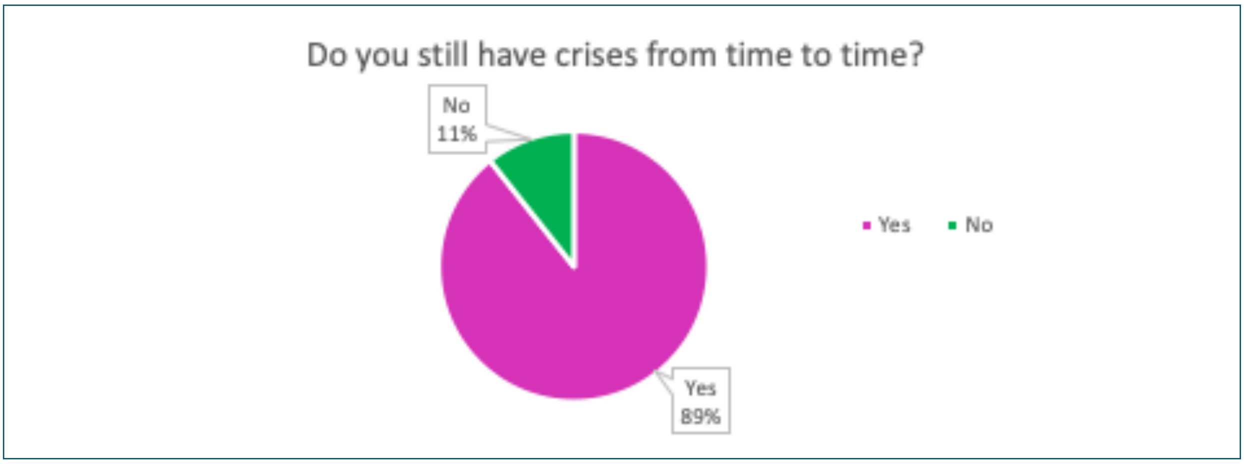
55 people told us that they did not receive any support and said that they struggled to get help:

- "no help pre-diagnosis"
- "every professional has declined to help as my son does not show behavioural issues at school"
- "the help was just signposting to websites and other organisations, but no actual help"
- "there is no phone line for support"
- "I just need someone to talk with who can provide practical strategies"
- "I need someone to help advocate in school"

Other parents had some positive experiences:

- "the early help support worker would try to help as best she could"
- "help was available from a pre-school specialist in nursery and then the transition to school"
- "without my key worker, I couldn't have done it"
- "he does have more support at his special school with trained staff"
- "Kent Autistic Trust and SNAAP helped"
- "the early bird course was very helpful"

We asked, "Do you still have crises from time to time?"
(We had 70 responses)



What did we find?

We wanted to know, "Do you have support that you can access during those times? If not, what do you need help with during a crisis?"
(We had 70 responses)

Some parents and carers found that they did have access to support:

- "yes, we have a CAMHS worker"
- "because my son is in a special school, we go to them for advice. Had he been in a mainstream school, things would be very different"
- "I attended the National Autistic Society's 10-week course, I developed an understanding of the difficulties and triggers that can arise and how to prevent"

Other parents and carers told us:

- "I manage, but not always"
- "only from other parents. I would like to have access to a health advocate who has my daughter's interests as her top priority"
- "I have family but no professional support"
- "I've been able to access some support but most of them end up shrugging their shoulders"
- "some sort of phone line to someone who cares would be good"
- "I would like to know how to handle these crises better"

Most of the answers we received said that they had received no help during a crisis:

- "I tried to get a disability social worker and was turned down"
- "I have no support, I have to ring 999 for police attendance"
- "no support, NELFT do not have the capacity to support the volume of patients in the area"
- "my child is 9 years old, CAMHS just said to ring the police or take her to A&E which is not a positive support system"
- "no, I am unsure what support is available"
- "I need help with avoiding self-harm, suicidal thoughts and anxiety management"
- "I've asked for help, reviews of behaviours and actions to be put in place for it always to be forgotten"

What did we find?

We asked parents and carers, "What additional help would you have liked?"

(We had 70 responses)

Most parents said that they just wanted "adequate support", training courses, access to support groups, and access to CAMHS.

- "we only found courses are available during the day, that's no good for working parents"
- "Better CAMHS support, my son at the age of 6 sat in front of them saying he wanted to kill himself. Never heard from them again"
- "support with meltdowns and social skills"
- "more support in the home"
- "support groups that take place outside of working hours"
- "respite care"

It isn't just support for the autistic young person that is required, we heard from parents that want to access help for themselves too:

- "I ended up in hospital really physically unwell"
- "I feel completely alone"
- "I need support to not feel so isolated and alone"
- "you have to keep fighting but it wears you down and your mental and emotional health is affected"
- "I had to give up my income, the emotional resources of the parent are drained"
- "there is no appreciation that some parents work and most have to give up work, I have"
- "the emotional toll of it all, I went to the doctor and had CBT and counselling. I'm on antidepressants"

We wanted to know if any parents had comments of their own

- the support and understanding is still very poor for someone with a hidden disability"
- health and education need to join up more"
- schools must be more inclusive and ensure if timetables are reduced then there must be alternative educational provision to ensure children are not disadvantaged"

What did we find?

- “mental health services should be seeing all children referred to them and have a pathway that all children follow”
- “staff at schools as well as health visitors should have intensive training on autism”
- “the services need to provide care to children and adults, and transition them between both”
- “there is a lack of relevant and helpful clubs for autistic people and children in my area, especially during the holiday”
- “when your child is diagnosed you are given leaflets and sent on your way. This is a life changing diagnosis”
- “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”

Our recommendations

1. Many parents and carers expressed that they did not know where to turn for support and information. There should better signposting to local support groups and the Kent Autistic trust, following a referral for an autism assessment.
Families are provided with a pack of information, which signposts to services following the diagnosis of autism. The signposting should be in place earlier in the process.

2. 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 ASC, earlier access to these courses should provide parents with more knowledge in dealing with ASD.

3. 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.

4. 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.

5. The crisis line currently in operation should have dedicated staff available, who are experienced in supporting parents, carers and young people who are struggling

6. There should be a clear offer of support provided to the parents and carers, with the ability to refer to adult mental health services when appropriate.

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

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

Case studies

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 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 3 examples of families that we spoke to exemplify the struggles that parents in Kent are facing:

Case studies

Case Study 1:

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; 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 1st 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. 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!

Case studies

Case Study 2:

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 know, but I wasn't given a contact number. If I want to chase it up then I don'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 we 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.

Case studies

Case Study 3:

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 visits 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 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.

School SENCO's

We felt that it was important not only to speak to parents who have experience of dealing with the assessment, referral and support process, but also the teaching staff who are in place to oversee and implement the Special Educational Need provision in schools.

We spoke with a Special Educational Needs Coordinator (SENCO) from an Ofsted-rated "Outstanding" school in Kent, to understand their interpretation of the services provided by Kent County Council and CAMHS. The school employ a Family Liaison Officer (FLO) and Children's Liaison Officer (CLO), both on a part time basis.

The school feel that they have benefited by having these recognised roles within the school, and that has been reflected by the comments in their Ofsted report: **"Pupils with special educational needs and/or disabilities (SEND) are exceptionally well supported"**. The SENCO's role works alongside the class teacher to identify those children who have specific needs and she will develop strategies to support these children. The children's liaison officer is a dedicated role to support and encourage the social and emotional needs of the children. The family liaison officer provides support and information to parents and carers; she helps parents to respond to the needs of their family.

Together, this established support unit within the school ensures that children's academic needs are met, their social and emotional wellbeing is looked after, and their parents and families are well supported. The Ofsted report supported this by saying **"they have purposely employed extra staff to provide considered and very effective support to pupils and their families when needed"**. There is an **"extensive range of very effective 'wrap-around' support for pupils and families"**.

The effective partnership in this support unit should be used as an example for other schools, to improve the quality of teaching, learning & assessment and also pupil's personal development, behaviour & welfare.

When we spoke to this school it was clear that they have the same frustrations navigating the neurodevelopmental pathways that many families do. If parents have concerns about their child's progress then they are encouraged to discuss this with the class teacher and the SENCO, who can then observe the child in the classroom. Unfortunately, many parents have assumed that a referral for ASD assessment comes from the SENCO. The SENCO has directed the parents to the GP, who is the primary medical contact, responsible for referring for medical services.

In some instances, we heard that families are being advised by the GP that he does not know the child well enough to support a referral, and that the family should return to the school for referral instead. This creates confusion and emotional distress to the young person and their family, who depend on professions to guide them during the difficult time.

School SENCO's

In addition to this, the SENCO found that some pupils had already been referred for ASD assessment prior to joining the school, and the family had asked her to "chase up" the paperwork; the SENCO was unaware of where the referral had gone and there was no indication of who to contact. It is assumed by many families that both the school and the GP are kept informed of the progress of a referral when in fact, sometimes the SENCO is unaware that a diagnosis has even been confirmed, until parents ask the school to support them in getting an Education, Health & Care Plan (EHC Plan).

The FLO has a noticeboard in the school reception area which signposts parents to local activities and support groups which they might be useful. Unfortunately, there is no single dedicated point of information for professional staff to access that will filter actives to local areas. The FLO spends much of her time resourcing local amenities and support groups herself, time that she feels would be better spent otherwise.

Our findings

1. 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 had autism.

2. 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 hear that "SENCO's are not bothered about anything that happened outside of school".

3. 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 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.

4. 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".

Our findings

5. Parents are 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.

Our recommendations

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. 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 (i.e. SENCO, Education Welfare Officer, Health Visitor, Youth Offending Service).

3. 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.

4. 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 therapy. Many local groups have been established for years but are not mentioned on the Kent Local Offer page.

Methodology

To have a greater understanding of the challenges that people on the spectrum and their carers face, this research used four key methodologies to provide a comprehensive picture of the user experience.

Method	Total responses
Online Survey	122
Postal Survey	5
Face-to-face engagement interviews	3
Education Professionals	4

As well as these responses, we also spoke with clinical psychologists within NELFT, school SENCOs, Additional Learning Support teams at local educational establishments and local support groups at Children's Centres.

The survey was our key method of gaining insightful user feedback on services, so the questions were broken down into two target audiences:

- Young people who had been diagnosed with autism
- Families and carers of young people diagnosed with autism

The online survey link was circulated on social media, for six weeks, to pages that were local to the Kent area and specifically targeted young people who were on the spectrum and the parents and carers of young people on the spectrum. These pages included carer groups, schools & colleges and support groups. Social media pages included: "ASD Ashford Autism Support Group", "NAS Dartford & Gravesham", "Kent UK Autism Support", "Thanet Autistic Parent Support", and "ADD, ADHD, Autism, Aspergers, ASD, FASD, FAS, GDD Kent".

Although we gathered feedback from the area of Kent, we received responses from families in Medway who use Kent services, and some neighbouring counties.

The questions were designed following consultation with additional learning support teachers at a local college; the wording and layout of the questions were carefully considered to ensure that there was no ambiguity. Most of the questions were multiple choice, with the option of having an "other" response, allowing respondents the opportunity to express their own opinion.

In addition to this, the online survey was designed with dark blue text in a large and clear font. This ensured that the survey was user-friendly to anyone with an additional need, such as dyslexia.

Methodology

With figures from KCC, the estimated population of Kent in 2018 was 1,554,600[3]. The prevalence of autism per 10,000 using Kent Integrated Data (KID) is 16.58. This ranges from 3.66 in Dartford, Gravesham and Swanley CCG to 46.19 in Thanet CCG[4]. Using these statistics, we calculated that our sample gives us a confidence level of 90% with a 7% margin of error.

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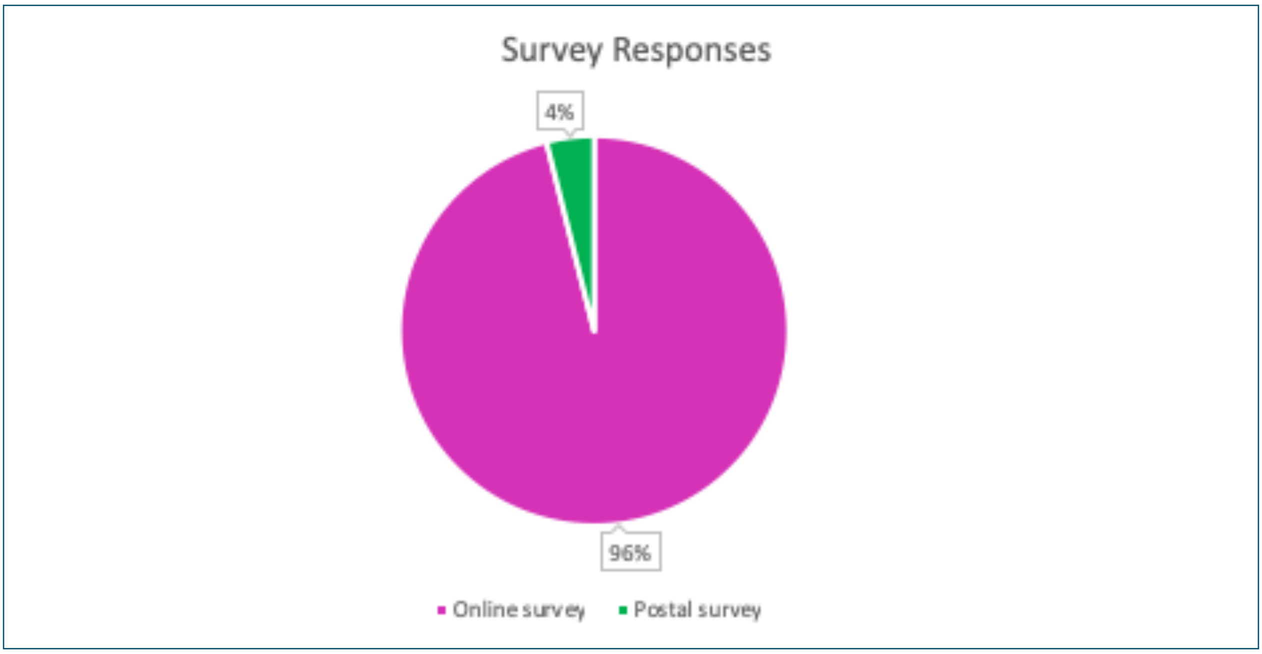
[3] https://www.kent.gov.uk/about-the-council/information-and-data/Facts-and-figures-about-Kent/population-and-census#tab-1 2018 census figures

[4] "Autism Spectrum Conditions" June 2017, Kent Public Health Observatory

Appendix 1: Our demographics

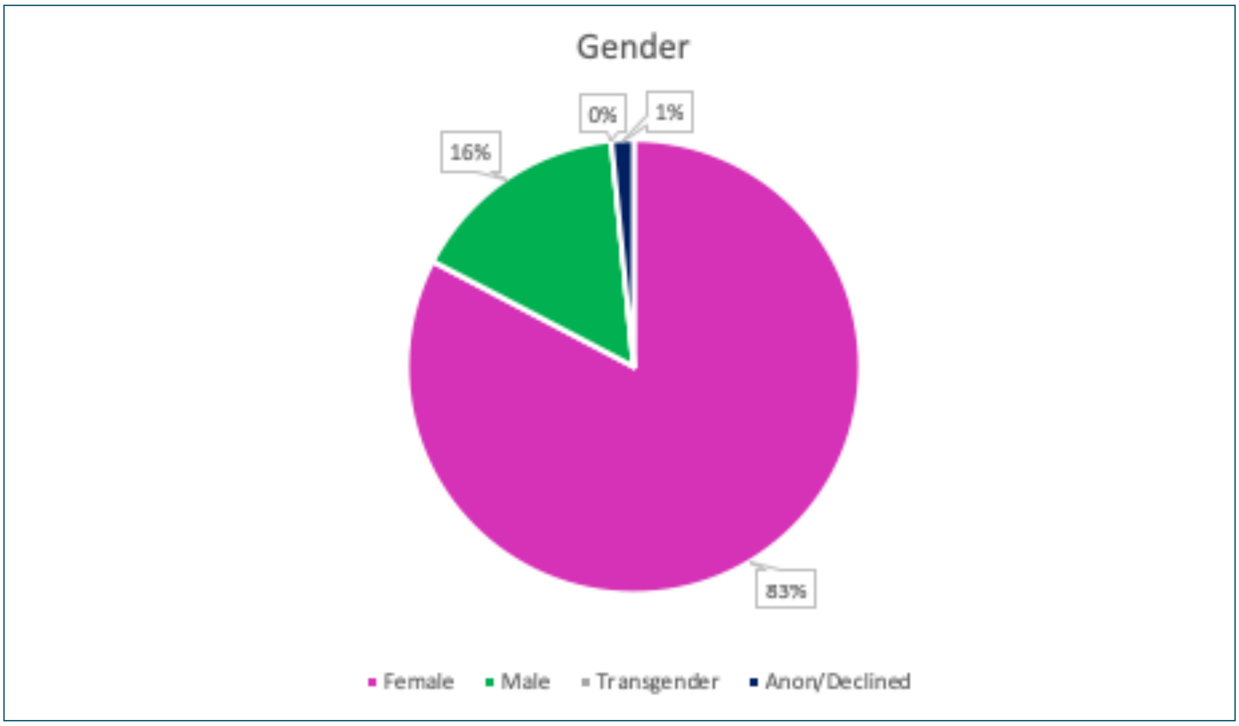
We conducted our research by generating a survey; on paper and online.

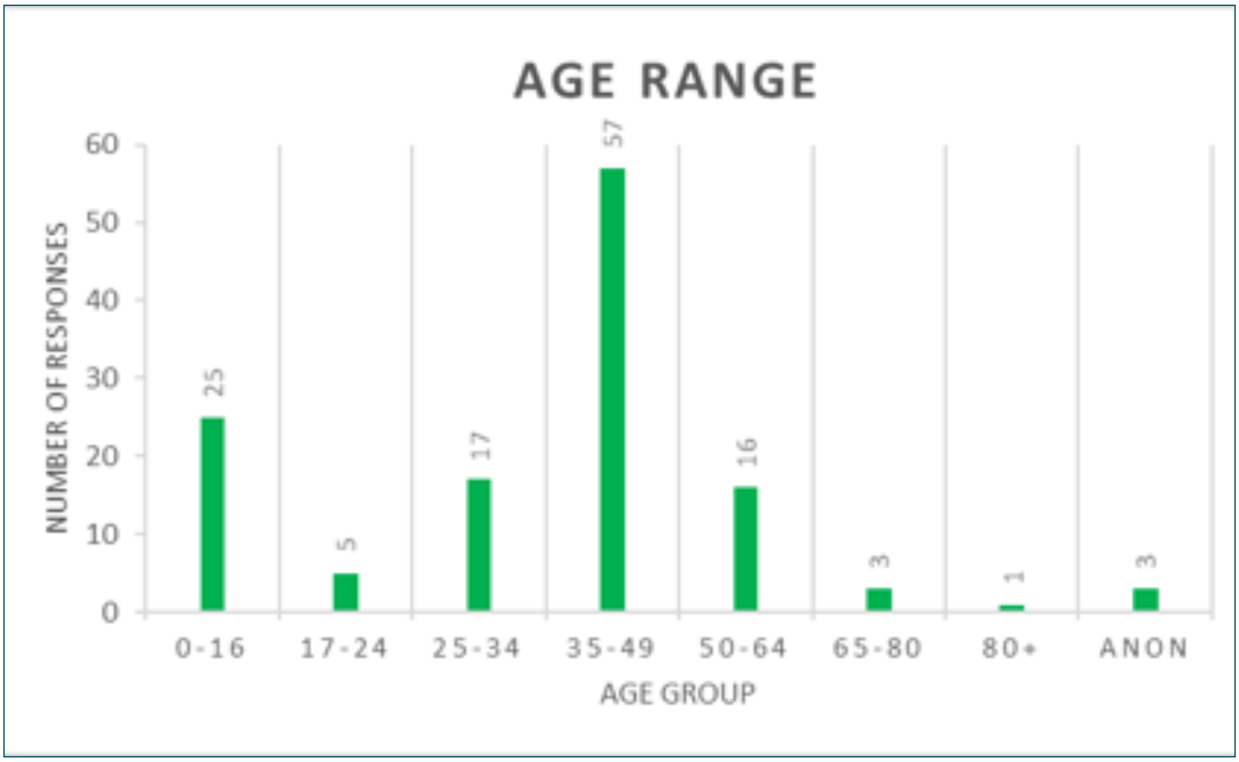


Most of the responses were completed online, as our survey was circulated on various social media platforms specifically targeting groups within Kent.

We had 127 responses from the survey; 122 online and 5 postal responses.

Appendix 1: Our demographics





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