# Update on Autism services in Kent. April 2020



## Autism services for children in Kent

#### A Healthwatch Kent update

In September 2019, Healthwatch Kent published feedback from 127 people detailing their experience of autism services in Kent.

We shared our findings with Kent County Council and made a number of formal recommendations about how the service could improve for young people with an autistic spectrum condition (ASC) and their families.

#### What did we recommend in 2019?

Our recommendations included:

- 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. At present, referrals to parent training courses such as Cygnet and Early Bird are made following confirmed diagnosis of ASC, 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 ASC.
- 3. Schools should aim to have a model support system in place that includes a partnership between the SENCO, the children's liaison officer and the family liaison officer, to ensure that the academic and emotional needs of the young person are met, and that families are well supported.
- 4. There should be a named member of staff at school, to support the emotional needs of the young person.

#### The Autism Awareness Project

Our report coincided with a report from OFSTED and the Care Quality Commission which raised serious concerns about children's services in Kent (not just autism services). Since then children's services have responded and are working with families to improve what is offered. As part of this work, a pilot began in Canterbury to try and reduce the numbers of young people on the waiting list for a diagnosis of autism. The pilot has involved organisations from across health, education and the voluntary and community sector coming together to work in partnership on a project called the Autism Awareness.

The pilot aims to support families while they are waiting for an assessment for their child. Families are currently waiting two years for an assessment for their child's possible autism, but the pilot aims to offer support and information to help alleviate some of the stress and frustration while they wait.

At Healthwatch Kent we wanted to understand how it has benefited young people.

#### What did we find?

We attended a session in Canterbury talking to nine families about their experience of the pilot so far.

#### **Dedicated support**

We asked families if they had been offered a named contact at the school or educational setting, and if there was someone that they were able to discuss any issues with.

- Over half the families told us that the SENCO was their point of contact, with others also telling us:
- "the class teacher and the family liaison officer, we have a close relationship" and "the school are good at communicating if we go to them"
- We also heard that people go to the class teacher, the family liaison officer and even the head teacher to get support.

• 2 people told us that there was:

"nobody specific, maybe the head of the year" and "head of form, but not sure", indicating that, in some cases, the school or educational setting had not made a clear connection with parents and have a set "go-to" point.

We asked parents if the pilot had helped them to feel more empowered to work with the SENCO (or their named contact) at school.

EVERYONE said YES, and that they felt more confident to work with schools to help them understand their child's needs:

"the SENCOs will have a better understanding"

"...it was good.... To familiarise ourselves with the SENCOs and professionals"

"very beneficial. The lecture has confirmed and given me understanding"

"very informative"

"it gives professionals a better understanding of supporting parent's and child's needs"

It was very beneficial. The lecture has confirmed what I thought and given me understanding.

### Has the pilot made a difference for families?

We asked parents and families what they felt was the most useful part of the day. They said;

- "good to reinforce the positives"
- "good to talk to people in various situations"
- "the whole thing was good, learning mannerisms and seeing my son's behaviours are normal for ASD"
- "I will be reconnecting with the college for ease of transition from the current form"
- "good for my child to experience/listen and understand autism"

ALL of the families that we spoke to told us the event was useful, informative and valuable.

The event was well attended, with 50 families invited and multiple stall holders present, which included Kooth, HeadStartKent, Kent Autistic Trust, IASK, SNAAP and other agencies. Representatives and commissioners from Kent County Council and NELFT (the service currently providing CAMHS) were in attendance and actively engaged with families.

This was the second pilot event that has been organised. The first, in October 2019, was oversubscribed showing a demonstrable need from parents to access support and information.



This pilot scheme has helped to act upon some of the recommendations we made in our report.

Based on the feedback we heard directly from families, we would recommend that similar events are rolled out throughout Kent, to engage and inform families who are waiting for an assessment. This shouldn't detract from the work needed to reduce the length of time people are waiting for an assessment.

Having attended the event, we would suggest that future events are tailored to specific age groups. Different age groups have different learning needs and varying emotional needs. For example the needs of a preschool child differs from a young adult transitioning into college.

We would be very happy to help promote future events and encourage families to attend.

#### We still want to hear your stories

Your experience of autism services in Kent is still really important to us. We want to hear the good and the not so good. We are actively involved in discussions with decision makers about autism services for children and young people so do please continue to share your feedback with us.

At the time of writing this we are living through the Coronavirus epidemic and so it is particularly important that we hear how services are supporting people with Autism.

To get in touch call our Helpline for free on 0808 801 0102 or email info@healthwatchkent.co.uk

You can also share feedback through our website on https://www.healthwatchkent.co.uk/have-your-say



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