

Parent's Wellbeing and Special Educational Needs and Disability (SEND) Support



Spotlight Report

March 2024

Context

We wanted to do some initial insight gathering to understand the mental health and wellbeing impacts for parents and carers of children with special educational needs (SEND) and what parents and carers were accessing to help support their mental health and wellbeing.

We also sought to understand, from their perspective, where improvements could be made to the services provided for their children.

What did we do?

The Healthwatch Kent team met with two different groups of parents and carers to speak to parents about their experiences of parental mental health and “SEND” support. We used a pre-designed, semi-structured questionnaire and advised all parents that they can answer as many or as few questions as they’d like.

In August 2023 we attended the Kent PACT summer picnic event and in October 2023 we visited the Faversham Community Gymnastics and Activity Centre. We spoke to a total of 26 parents and carers.



Participants and Demographics

The 11 parents we spoke to at the Kent PACT picnic each specifically discussed only one of their children, therefore, the combined total of children discussed during this engagement was 11. The children's ages ranged from: 4-16 and one parent wanted to include insights relating to their 24 year old son in this discussion.

The 15 parents we spoke to at Faversham Community Gymnastics and Activity Centre have a combined total of 23 children. The children's ages ranged from 1-10 years old.

The total cohort of 34 children within this report are:

- 22 Male
- 11 Female
- 1 child identified as transgender
- 6 children have a diagnosis of autism.
- 4 children have a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD).
- 3 children have speech difficulties.
- 3 children have dyspraxia.
- 2 are believed to have autism but have not been diagnosed.
- 1 child has special educational needs (parent did not specify).
- 3 children have attention deficit disorder (ADD).
- 1 child is experiencing signs of early anxiety.
- 1 child has global development delay
- 4 children had multiple diagnosed conditions

Parents at the Kent PACT summer picnic event told us...

What impacts your confidence whilst caring for your child?

- **36% (4)** of parents told us that long waits for access to health and social care services has negatively affected their confidence in caring for their children.
- **36% (4)** of parents told us that they were experiencing long waits for referrals or a diagnosis for their child.
 - “I went to the GP but in the end had to go privately to get help for my children as we were waiting such a long time.”
 - “My child has long covid and we have had no support, we went to the GP who referred us to a paediatrician, however the referral was rejected and nobody told us. We did eventually manage to get a referral but it took a long time.”
 - “I’m not actually sure what my child has as we have been waiting so long for a diagnosis. We have been struggling, we have been to the school and health visitor. We have been waiting since 2021 and have not had any support.”
- **18% (2)** of parents emphasised the positive effects that attending playgroups, meeting other parents and spending time with family had on their confidence.
 - “Play groups, meeting new parents, myself and my child socialising”
 - “We have a great family support.”
 - 9% (1) of parents told us that they believe families could use more guidance to make them aware of services and support that’s available. This will enable parents and carers to find sources of help more readily without relying solely on GP services.
 - “[I don’t know] what services we can access and [I don’t understand] who provides services, I have no idea what is available to support us or how we can access support. It’s also difficult to access reliable carers.”

What support helps to build your confidence ?

- **36% (4)** of families praised the support they had received from “Beams”, “Mind” and “Scope” charities. “Beams” being mentioned three times and “Scope” and “Mind” mentioned once. These charities have provided the parents with vital support in caring for their children.
 - “Beams have been really supportive.”
 - “Mind have been really good! Scope have provided really good therapy.”
- **36% (4)** of parents advised that their social support network has been the most valuable source of help for them. Friends, families and meeting other SEN parents have made a positive impact on the parent’s experience of raising their children.
 - “My family and friends are a great support. I've found online Facebook groups of SEN mums to be really supportive.”
- **27% (3)** of families identified their social workers as “brilliant”, “amazing” and “wonderful”. One family identified their speech therapist as extremely helpful. Children’s centres and teachers had also had a very positive impact on another family.
 - “The children's centre has been great and really welcoming and supportive. The teachers are also really good.”



What has been your experience of having a neurodiverse child?

- **27% (3)** of families reiterated the challenges and negative impact of long waiting times to receive a neurodivergence diagnosis and relevant support for their child. One parent told us that they were expecting a long wait to get support for their child with ADHD, but their social worker was able to speed up the access to the help they needed.
- “The other child we think may have ADHD and it was going to be a 12-15 month wait but the social worker called someone and they managed to get it moved to August this year, which is great for us but what does that say about the system! It makes a mockery of it to others who are waiting!”
- **One** of the parents highlighted a gap in support for the siblings of SEN children, suggesting that this would be a valuable service for the whole family. Access to SEN support for siblings would benefit the entire family as they will have a greater understanding of how the child can be supported to thrive in their family environment.
- “What we have noticed is that there is a lack of support for siblings of children who are neurodiverse, there is very little out there.”



Parents at the Faversham Community Gymnastics and Activity Centre told us...

What has impacted on your own mental health whilst caring for your child?

- **67% (10)** of parents told us that they felt they had faced challenges relating to raising their children that had negatively impacted their mental health.
- **20% (3)** of parents told us that they experienced anxiety, loneliness, isolation and a loss of independence whilst caring for their child.
 - Yes, I've found many things a challenge whilst looking after my child. I've lost a lot of my independence, which has caused me to become isolated."
 - "My kids are a handful, but I'm lucky that my partner can stay at home and help look after them."
 - "I often worry and feel anxious."
- **13% (2)** of people identified that balancing work and parenthood was a big challenge for them.
- **33% (5)** of parents told us that they hadn't experienced challenges or anything that impacted their mental health.



What helps most to support you with your mental health as a parent?

- **85% (11)** of respondents identified that spending time with friends, family or neighbours was their most effective support function.
 - “I meet with my sister who has two little ones and she is a great support”
 - “Our family were far away but are now closer and that makes a big difference having the grandparents near.”
- **69% (9)** of people said walks, green spaces and exercise had a positive impact on their mental health.
 - “We get out to green spaces a lot for walks and play.”
- **46% (6)** of parents said spending time with other families was a big support.
 - “I go to baby groups, they have a baby gym here and a craft group at the community centre”
- **31% (4)** of parents described “self-care” as a contributing factor in maintaining their mental health.
- **23% (3)** said support within their child’s educational settings had helped them.
- **15% (2)** said support from other organisations had a positive effect on their mental health.
 - “We got the support from ADHD services and support with getting school places, so we were very lucky.”



What else would have been helpful that you didn't have access to or weren't offered?

- **60% (9)** of parents advised that they did not need additional support beyond social interaction, enjoying green spaces and exercise and self-care practices.
- **15% (2)** of parents said that access to SEND sessions and services specific to their child's behaviour needs would have been beneficial.
 - "SEND specific activities, groups and support would've been helpful for me."
 - "Better provision of services would help. Everything to do with family support, for example "Sure Start", they are so good."

What support your child has received from the NHS, local authority children's services, or education providers such as schools, could be improved?

- **27% (4)** of parents told us that they couldn't think of anything that needed to be improved.
- **15% (2)** of parents emphasised the struggles they face when accessing GPs.
 - "GP appointments are a luxury which is a bit different from what I grew up with."
- **15% (2)** of parents told us that the process of accessing school places needed improvement.

Other suggestions were:

- "Child mental health services needs to be improved. More consultants are much needed as waiting times are way too long."
- "There doesn't seem to be a full plan for care and we always receive mixed messages"
- "I had a really nice health visitor, but it would be good if there was more follow up after the two year check, something between then and school to fill the gap."
- "There should be more knowledge about the 'ELSA' program (Emotional Literacy Support Assistant)"

Next Steps

- We will liaise with KentPACT to enable them to raise the concerns of parents and carers evidenced within this report.
- We will share this report with Public Health and Mental Health services as insights of the positive impact of social networks and open spaces on managing mental health and wellbeing.

If you would like to chat with us about the report, you can reach us through the following routes:



Online:

www.healthwatchkent.co.uk



By Telephone:

Healthwatch Kent Freephone
0808 801 01 02



By Email:

info@healthwatchkent.co.uk



By Text:

Text us on 07525 861 639. By texting 'NEED BSL', Healthwatch's British Sign Language interpreter will make contact and arrange a time to meet face-to-face

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