

Healthwatch Kent Spotlight Series

Listening to families of children with disabilities



December 2022

Estimates suggest that **6%** of people living in Kent are young people under the age of 15 who have a disability. All of these children, and their families, will use many health and social care services in Kent and we wanted to hear their experiences.

We listened to **19 families**. We've also spoken with professionals who talked to us about the challenges they face.

What did they tell us?

- Families talked about the barriers they faced to get support. Common issues were lack of GP appointments, challenges to see a dentist and delays in mental health referrals
- Speech and Language services were praised for the quality of their staff and their eagerness to include families in their patient care.

Suggestions for the future

Many families shared their ideas about what would make a difference to them. Ideas included:

- A greater understanding of mental health and sensory disorders amongst dentists
- A smoother transition to adult mental health services for young people

The feedback in more detail

GP services

- The link with a GP was very important to families whose children have disabilities. However, nine families told us that getting a GP appointment was a challenge. This then caused added delays getting referrals for specialist services.

“I work full time so cannot get an appointment. I can't call at 8am”

“We need more availability of appointments”

“More evening and weekend appointments”

“More people are needed to answer the phone at my GP surgery”

- Three families told us that once they are able to see their GP, they are really happy with the care and support they are given.

“My GP appointments are usually very good!”

“I've been able to access long-covid pathways and I was given tips to help me cope”

- GPs were also crucial for families to access mental health support for both their children and themselves.

Mental health services

- Eight families shared their concerns about long waiting lists for mental health services and the challenges they faced getting a referral to receive vital wellbeing support.

“It feels like the services are just passing the buck to each other”

- Two families talked about their challenges to get a learning disability diagnosis. Long waiting lists and lack of access to the right service had caused extra delays.

“I had a wobble and went to hospital and they said I wasn’t able to access help. I don’t know where to turn, I feel like I need an ADHD assessment.”

- One family explained how positive their transition into adult mental health team has been.

“Once the team are in place, they are so good! The learning disability team have been brilliant!”

- However, two families told us that reducing waiting times for mental health support was vital and that young people turning 18 need an easier transition into adult mental health services.

“We need shorter waiting times and more mental health professionals”

“The mental health teams need to get better at communicating with each other when a child is going to turn 18. The health department should know this for their transition services, it isn’t joined up enough”

Speech & Language services

- Speech and language services were praised by two families for their willingness to involve families in the child's care and how they personalise their care.

"The Speech and Language consultant is really good and listens to our needs!"

"I've been invited to be on a Speech and Language committee. I was able to give my own feedback which helped make important decisions"

Support for professionals

- Professionals told us that they don't always have the right information about where best to signpost families to

"We work well with commissioners, but what would help even more is understanding the 'in-between' people, knowing who else is out there to support the work we're doing"

"We already do a lot, but we believe there should be no limit to how much information you give to your client"

- They also reported that they need more training and alternative ways to communicate with young people who are non-verbal

What will we do with the feedback?

1

The feedback from families will be shared with organisations and decision makers who work with children and young people with disabilities.

2

We will share the findings with the new Pan Disability People's Voice group which is being established in Kent. Their focus will be raising issues on behalf of people with disabilities.

3

We will use the feedback in this report to help inform future engagement.

4

We will share the feedback about speech and language professionals with Canterbury Christchurch University who will use it to help inform the education of future practitioners.

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



Online:

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By Telephone:

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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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