

## Children with Special Educational Needs & Disabilities

### *Exploring the views of parents*

In Spring 2018 we attended a support event in East Surrey for parents of children with special educational needs and disabilities. At the event parents shared some of the challenges they face in accessing health, social services and education for their children.

While the group was small the same problems were repeated from family to family, and their voices provide a unique and valuable insight into the reality of their experience.

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### **“We waited two years for him to be assessed by an occupational therapist”**



We heard about **very slow or non-existent service provision** – cases of families waiting years for assessments, not being offered any help at all, or resorting to private services to make sure their children were able to progress.

*“...there was a huge wait...”*

*“We were told by the paediatrician we’d have plenty of time to get an EHCP but have come to realise this is far from the*

*case.”*

*“It comes down to [whether you have] money and that shouldn’t determine whether a child is being looked after or not.”*

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### **“We had a diagnosis of autism at the hospital and we didn’t know where to go next”**

We heard about **lack of signposting and poorly integrated services** – carers who had not been given information on what other services they could or should be accessing to take their child forwards.

*“The GP didn’t tell us about the health visitor, I wish she had, we didn’t know what she could do.”*

*“They assessed him then ran away.”*

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### **“They could have just listened to us when we told them our son has specific problems”**

We heard of cases where **services and professionals failed to take carer’s knowledge of their child’s condition into account**, instead relying on snapshot assessments or written reports from third parties. This resulted in inappropriate service offers leading to challenges, unnecessary rework, and wastage.

*“You know your child... so when you tell a professional that your child has repetitive behaviours and they aren't seen in an assessment there needs to be a follow-up.”*

*“...in the whole report they picked out 3 lines which said my son was beginning to speak...they failed to realise my son ... repeats phrases and says odd words.”*

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### **“The paediatrician made us feel we were overworrying”**

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We heard about **carers left feeling stressed, belittled or guilty**, either in their interactions with services or by the decisions they had been forced to make as a result of failures in the system.

*“How do they justify putting a family through that [challenging an assessment at tribunal] when we are already under immense stress and pressure.”*

*“It makes you feel like you are asking too much of them.”*

*“I feel so guilty for [family member paying privately for speech therapy] but my son needs it.”*

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### **“We are again having to fight...”**

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We heard about carers who felt **the system was working against their children, not for them**: that they have to fight every step of the way to get a fair deal for their child.

*“Children are assessed against their faults and if you so much as mention a strength you are worried they will be penalised for it.”*

*“SCC are so fiercely defensive and protective.”*

*“When you are on top form in ideal conditions you have the energy to take people on and make sure your child gets seen and heard, but when your child is ill and not sleeping properly... can cost you a couple of months.”*



With thanks to YMCA East Surrey.

Healthwatch Surrey exists to give the people of Surrey a voice to improve, shape and get the best from health and social care services.

If you have a story to share with us – good or bad – please contact us at 0303 303 0023, [enquiries@healthwatchesurrey.co.uk](mailto:enquiries@healthwatchesurrey.co.uk) or through SMS on 07592 787533.