

18 March 2024, Quadrant Court Woking.

Cllr Jeremy Webster, Cllr Jonathan Essex, Cllr Bob Hughes, Julie Armstrong (Scrutiny Officer)

4 participants

<p>A. I have a 9-year-old boy. Surrey came back and said we recognise he has SEN, you should work with the school and the school have turned round and said we can't support him. Our SENCo said take him out and put him in a state school. He's in a class of 13 and struggling. If I put him in a state school where there are 36 kids, what are you going to do to my child? Give us an EHCP.</p>	<p>No to issue EHCP Primary school says can't meet need</p>
<p>C. My son has Down's Syndrome and is registered visually impaired. Surrey missed the legal deadline for naming school. The evidence suggests that children with Down's Syndrome do better with clever children because they copy. It all went really wrong at secondary school because the new head wanted to up standards. He became so stressed he lost his hair. Eventually he had to go to special school. He had to stop doing things he liked like history and French because you don't teach special needs children French. We went to tribunal again because he wanted to go to a residential college which has a working hotel. They were late finalising the EHCP, again missed legal deadline. They missed the deadline for every single transfer. The only person that was actually helpful was Surrey's lawyer. The process nearly killed me. It coincided with lockdown and, I did a training course for mental health first aid. When someone's depressed and has suicidal thoughts the key thing to do is ask, do you have a plan? And when you have a thought coming into you head saying oh if I rush now I can get in front of that train, that's when you know you've got a problem. That is what this process drives you to. They now say they're not going to pay for his final term of college. Children's Services believe they should be educated in Surrey.</p>	<p>Timeliness, to name school School focus on grades Emotional/health impact (CYP) Special school not meeting academic need Not listened to Timeliness, to issue Plan + Solicitor Emotional/health impact (P/C)</p>
<p>Have you read the Code of Practice? The Code of Practice came out of the Children's Act in 2012. It is the guide for all local authorities, anybody dealing with children saying what must happen and it's what parents read to learn their rights. Now the first thing it says about assessing is that local authorities must work in a way that seeks to assess need. The fact that they've got so many tribunals queuing up for refusal to assess, when you've got professionals have told them this child's autistic and they said we don't need to assess and the school has said we can't teach this child, somebody in an education department who isn't a teacher and who has never met that child is saying we don't need to assess it because we know that that will put it on for another year.</p>	<p>Tribunals perceived as unjustified No personalisation Lack of trust - Delay perceived to be deliberate</p>

You lost 93% of tribunals last year. How much did that cost you? Do you know? I don't think you measure it. I'm told you give statement writers one and a half hours to write a statement; you could not read the evidence in that time, so don't refuse to assess is the first thing. Sorry, years of pent-up fury.

D. I've got two girls, one turning 15 next month and the other one is 12. Two very, very different journeys, I'll focus on the first one really and that's the most serious, I think. At a young age it was a bit obvious she was different. It takes three years to get assessed. The advice and suggestions things like star charts and structure and giving plenty of warnings before change, none of that worked. And as she progressed through school, it just got harder and harder. Primary it kind of depended on the year. Some years were good, some were bad and I think that just came down to the teachers.

Secondary, it all went to pot and not helped by lockdown. She fell out of mainstream in the first month of year eight. It just got to a sort of crisis family point where in between what I later came to understand were meltdowns, panic attacks where she would, you know hit her mum, twist her mum's arm, there was like a moment of clarity, an eye in the storm, where she just turned to me and said Dad, I hate myself, I hate my brain, why do I do this to you and to Mum especially? And my heart literally just cracked at that point and I just thought this isn't working. Traditional parenting wasn't working. So I just threw it all out the window and started again. Everyone always says you have to be a parent, not friend, so I reversed it, OK I'm going to be a friend, but also as a parent. And then just think what would a friend say, what would a friend do? It's radically different. And one of the most annoying things coming from professionals who, 'oh I know autism I've got 35 years experience', it's a spectrum, we're still learning about it so you really need to have a lot more humbleness about that really. And without realising it, I started to do all these sorts of things, picking my battles, reducing demands, managing anxiety, negotiating, collaborating. These kids don't see authority. They believe in trust and relationship, so it suddenly it's no longer like they're your pet and you just tell them to sit and if they don't sit, then you tell them off or you give them a punishment and when they do sit you give them a treat, that doesn't work. It's more like they work. It's more like they're a stakeholder and everything has to be a business case, you have to explain everything and suddenly there's a lot more talking to do, but once I started to do this, things got better at home.

And then when I discovered this charity and it sort of filled out my knowledge a bit, things got a lot better at home.

Unfortunately then at school, whether that interfered with her

Unnecessary cost to taxpayer
Under-resourced (case officers have inadequate time)
Don't refuse to assess

Timeliness, assessment

+some primary years
(dependent on teachers)
-some primary years
(dependent on teachers)

Lack of SEND knowledge

Third sector (knowledgeable)
Parental knowledge improved
home situation

ability to mask or whatever, it just collapsed at school. So she was she was in a mainstream and frankly, trying to teach 2 girls 13 subjects at home in a second lockdown nearly destroyed the entire family. And the pressure, like drama teacher telling me we haven't had any work you for a week. And I said, expletive I haven't, I'm just trying to get maths, English and science out of these two, you know, without any help. It was insane. And then, of course, she only lasted a month of year eight.

They just didn't get it. I could see, and I don't say this lightly, but I could see casual labelism. I could see the teachers were quoting her with, like the naughty child. You can see it with a look in their eyes and see it when they're sort of scowling, they're like, yeah, you can tell they haven't an iota of understanding of what it is to have special needs.

A. That's probably what we have is that they recognise he's autistic, but then I get the phone calls saying oh well you know he stood up and said X, Y and Z. **You're dealing with an autistic child, why are you responding that way?**

D. This is a yeah, entire country entirely. **Not everyone sees it as a disability;** it's a disability because of how the system and society is. I could see that they were treating them differently, I could see she got injured quite severely, a head injury, and they just downplayed it. They gave her an exclusion and I fought that and **they don't listen.**

Cllr Webster: So what's your interface been with Surrey?

D. I guess it's going through CAMHS and **getting the paperwork lost three times.** They did get a paediatrician to finally prescribe some melatonin, but other than that, **they're pretty much hopeless.** They eventually just discharged us, I stupidly thought fine, they were useless anyway I'll try MindWorks and then I got the discharge letter titled MindWorks and realised it was the same thing, they just keep renaming everything. It's no longer EOTIS, it's EOTAS. Stop renaming everything and just improve something.

Cllr Hughes: Did you encounter that these people knew what they were talking about?

C. **Not for Down's Syndrome.** And the training's there, it costs £600 a day from Down Syndrome Education International. You can only do it on Saturday for staff because the headteacher wouldn't release them. They were very reluctant to tell the staff it was going as they didn't want to ask their staff to work on a Saturday so you have to do it through parents. Nothing they taught was not relevant to all children. If you've met one person

Lack of SEND knowledge (teachers)
Labelling (teachers)

Lack of SEND knowledge (teachers)

Fight/battle
Not listened to

CAMHS error (lost paperwork)

Unsupported by CAMHS

Lack of SEND knowledge (teachers)

with Down's Syndrome, you've met one person with Down's Syndrome.

Cllr Webster: Would you say that this is a new thing or has it always been a thing in terms of this lack of knowledge?

B. I happened to choose special needs as a focus when I was training as a teacher, but I think we maybe had one or two lectures on special needs. As a member of staff, the TAs are the ones that go to the training because they're the ones dealing with the children, which doesn't work because you need that implemented in your day to day.

And I can't go down the education because there are so many simple basic things that can be done within a classroom within a teacher's day that would make, my eldest probably could have accessed mainstream.

The EPs themselves don't have the knowledge, certainly not for PDA. That sounds quite a big statement I know, but I have had the same EP twice assessing my two youngest. The first time in 2020 her report was OK, she admitted PDA isn't her area of expertise and her needs were extremely complex. The second report she wrote for my second child 18 months ago was not worth the paper it was written on, it was diabolical. The same EP, similar diagnosis, different needs I admit, but her report four years ago and her report one-and-a-half years ago is hugely vastly different in quality, and I'm sure that's down to pressure.

She waited seven months and the only reason she assessed was because my lawyer put in a Judicial Review because Surrey refused, they just kept saying we haven't got an EP. We got all the reports, they'd agreed to assess, and Surrey said no, we're not accepting any of those reports and they've done that twice now and both children Surrey have said we're not going to take any professional reports it's not worth anything, we're going to do our own reports and we will ignore them until you take us to tribunal, which we had to do.

Cllr Webster: Was that said directly to you or implied, we won't do X until Y?

B. I've got it written from a case worker saying we don't look at your reports.

Seven years go the EHCP process pretty much followed 20 weeks. A reasonable timeframe compared to now, when you're looking at a child that's four years in the system and still doesn't have a Plan. This child has been out of school 18 months. They don't talk, the case worker has had zero communication with me. She's lost in the system. We don't know who her case

Lack of SEND knowledge (teachers)

Mainstream schools not differentiating
Couldn't access mainstream

Lack of PDA knowledge (EPs)

Poor quality EHCP (EP report)

Pressure to meet EP advice targets

No to assess

Under-resourced (EP shortage)

Not listened to
Not accepting privately commissioned reports

Timeliness, to issue Plan
CME
Poor case officer communication
Not aware who case officer is

worker is. I've emailed, can we relook at the evidence? Nothing. She just shut down communication and I've had nothing since. And this isn't a one-off.

Cllr Webster: What barriers have you encountered? We're already hearing the barriers, we're hearing they're working to time so the quality of assessment is poor. Another thing you have all mentioned [except one] is that you've all had to go to a tribunal to get what you want.

B: I've had to start 10 tribunals over six years for four girls. We're looking at a cost of about £300,000 because we have been failed by every single service. My second daughter's case is shocking. CAMHS, social care, education, have all failed her catastrophically. The social worker failed to do his job, we've had accusations from him saying that we as parents weren't good enough. Before this we've had two S47s, we've been on S17.

Cllr Webster: It's where it's felt the parents putting their child in danger.

B. They got nothing. Social care still refused to support us. We are the first family in Surrey to get social care funding through a tribunal.

Cllr Webster: Why do you feel they're doing this?

B. It's all about money.

Cllr Webster: What evidence have you had or is this something you perceive?

B. They said it wasn't appropriate funding. What's really shocking is that if an EHCP had been given in 20 weeks, none of that would have been needed, my children wouldn't require such huge budgets now. Three of them are going to require lifelong support, they wouldn't have needed that. The damage that's been done by this process, the trauma. One's already been put back a year, they've not saved anything.

A. Families have been ripped apart by the pressure of trying to get an EHCP. What do they think these children are not sensitive, they don't know what's going on? They take it on themselves and think, if I didn't have this brain, you wouldn't be fighting.

C. They lose their hair.

B. It's traumatic.

Financial impact
Failed

Feel blamed/accused

Unsupported

Suspect refusal due to money
Under-resourced

Unnecessary cost to taxpayer

Delay led to crisis
Emotional/health impact-
Trauma

Strain on family relationships

Emotional/health impact (CYP)
Fight/battle

Trauma

Emotional/health impact (P/C)

I get into bed and I know something's wrong, but I collapse, I've not slept in over three days. I'm still having one or two hours a night, I've been like this for two years. I just can't keep my eyes open and there's no hope. Would she be better off dead? Am I being cruel, keeping her alive against her will? I've just had to tell her that she's been turned down for the Plan. Her eyes fill with tears, and there's nothing. There's no hope, black hollow circles on a too thin pale face. My husband checks later, turns on the light and screams, adrenaline courses through my body like an electric shock, all tiredness gone. She's hanging from the curtain pole in her bedroom, lips bluish purple, eyes no longer sunken but bulgy and red. He's holding her up, undoing the belt around her neck. Is she conscious, is she breathing? No. Running to get the ligature cutter felt like hours. We got her down.

Emotional/health impact (CYP)

I know what to do without even thinking, it's what life has become. When she's asked later on she simply says, 'There's no point in living if I can't get an education because I'm not worth it'.

Emotional/health impact (CYP)

Cllr Webster: I'm hearing that there's an unsaid barrier that's money but if they got their act together early on that doesn't need to be a barrier.

B. 100%.

Cllr Webster: The second thing I'm hearing is that there's inadequate training going on.

D. Yes it's a fundamental crisis of expertise. We need more training, we need more caseworkers, but not all training is the same. Training from certain charities is much better and you can tell it's sort of parent-led and it's good but there's gaps. And then there's training from charities with lived experience from autistic adults and it's 100 times better. Or it's a charity run by an autistic parent with autistic children, and that is straight from the horse's mouth, is 100% authentic. It is a spectrum and you have to remind every professional who thinks they know it all, it needs a variety of training.

Under-resourced

Third sector-Training delivered by people with lived experience

Variety of training to reflect spectrum

A. I'm presently on this National Autistic Society training course for 9 weeks of my life to be a better parent, right? They said they offer free training to schools, half a day workshop. I contacted the school, please do this, no we don't do it. If it wasn't for the fact that the form head has an autistic son...

Lived experience of teacher

D. And if he retires and is replaced by someone who doesn't believe in it or understand it...

Lack of empathy without lived experience

Cllr Webster: I'd like to know where you've encountered good.

<p>C. Charities.</p> <p>D. Parent support groups. WhatsApp and Facebook groups.</p> <p>Cllr Webster: There's nothing that the County's fixed for you?</p> <p>C. God no.</p> <p>B. Those courses set up people with lived experience.</p> <p>Cllr Webster: Have you encountered good in a SEND case officer?</p> <p>A. Can I give you a quote from someone and it's not good. She phoned up her case worker who said, Have you got a new number? I wouldn't have answered if I'd known it was you. A parent in my SEN group.</p> <p>C. There was a good one but she left. She was good because she had a kid with special needs. She would answer the phone. I gather they've got something like 100 kids on their caseload. How long do you think it takes to read the evidence for one child? Half a day. They don't have that time. They have parents shouting at them, they burst into tears, they all go off on long-term sick.</p> <p>D. They have no understanding of it [autism], they just have no idea. So in their frame of reference all they can reason is that it must be bad parenting, they think it must be a broken home. They are defaulting to what the majority of the population would assume in their position. Their child probably hasn't kicked them.</p> <p>B. I thought the case worker's job was to transfer what has come from the professionals into a Plan that goes to the Governance Board, but actually what is happening is that that case worker is removing evidence. My daughter just had her annual review, we just got the Plan and half of it's missing.</p> <p>Cllr Essex: What's the spot check with that? If it's down to individuals and some are doing it intelligently and faithfully and some are not, for whatever reason...</p> <p>Cllr Webster: They're supposed as you rightly say to assemble evidence, and to manage the process.</p> <p>C. A 38-page report saying what his social needs were was taken out. That's their own evidence.</p>	<p>Third sector</p> <p>Parent groups Facebook groups</p> <p>Unsupported</p> <p>Training delivered by people with lived experience</p> <p>Incendiary language Poor case officer communication</p> <p>Responsive case officer (lived experience)</p> <p>Under-resourced (case officers have inadequate time)</p> <p>Case officer turnover</p> <p>Lack of SEND knowledge Lack of understanding/empathy Feel blamed/accused</p> <p>EHCP error-evidence edited</p> <p>EHCP error-evidence edited</p>
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<p>B. I've had professionals contacting the case worker to say, you have to change this, this is not correct, they've written addendums to say this is what needs to go in and the case worker still hasn't put it in.</p>	<p>Quality assurance</p>
<p>A. Do they check the quality of the work before sending it out, benchmarking against others? There are numerous problems of case workers making glaring errors and failing in their basic duty.</p>	<p>poor quality EHCPs</p>
<p>D. Case workers are assigned to schools not assigned to families with children. Whether it was mainstream, independent or whatever we end up getting a new one every time.</p>	<p>Case officer turnover</p>
<p>A. We had to apply for ourselves and somebody else I know she's got a Down's Syndrome child, she's had three caseworkers in a year. So one of my questions was, why? Are they not paid enough?</p>	<p>Under-resourced</p>
<p>Cllr Webster: We were told some of the confrontations with parents...</p>	
<p>A. Do you think we enjoy being confrontational?</p>	
<p>C. We try not to be.</p>	
<p>A. We're fighting for our children's lives.</p>	<p>Fight/battle</p>
<p>Cllr Webster: You've put your finger on it though, if things are right early on, it doesn't get this far.</p>	<p>No explanation of decision</p>
<p>C. You just get told, We don't do that in Surrey. A SENCo was told, Tell the parents to manage their expectations, we don't pay for children to go outside of Surrey. Well if there is only one place that teaches it and the alternative is repeating what he's already done. You can't restrict children going elsewhere if you don't do that for children without disabilities. Disabled children have a lesser experience.</p>	<p>Different policy for children with disabilities</p>
<p>B. Why was the system changed? It was changed from a Statement to an EHCP so that services worked together. No service works together, it's completely fractured. Nobody talks to anybody else, there is no communication between services.</p>	<p>Poor communication between services</p>
<p>C. The education bit is legally enforceable, they "must" do it, not that they do. But the other bits, that funding is not ringfenced, why is why they're trying to shift everything onto social care.</p>	<p>Under-resourced</p>
<p>B. The Children with Disabilities don't have the funding because they're now under Safeguarding.</p>	<p>Under-resourced</p>

CAMHS can't meet need, they don't know how to help but they won't outsource because they haven't got the budget.

C. There's nothing wrong with the Code of Practice, it's just they don't do it.

A. More and more children are being diagnosed and that's making the system even slower.

C. They still think it's 2% of children with SEN – no, that was in the 70s and actually it's more like 20%.

Cllr Webster: So you've said this thing which is the stuff being edited out and that's not right.

C. Or they haven't had time to read it the first time.

Cllr Webster: I tried to push you a little while ago on what's good. So what can we do differently to make your lives easier?

C. Don't say we won't assess. If you assess a child they say no, actually that child's coping completely fine, there are no issues, you've wasted a tiny fraction of one EP's time. You could get the Portage checklist and parents could go through it, it's a tick-box exercise and if you get a profile then you think hang on, this child needs therapy, and that would be an easy process to do for every kid coming into school.

Cllr Essex: You fill out the red book when your child is two and then there's a huge gap and then you might go for an EHCP. As far as I'm aware there's very little in between, in terms of your ability to have a diagnosis.

C. There are parents whose first language is not English, there are parents who have learning difficulties themselves. That's not uncommon and those people just don't know where to start. We try and help on forums but you've got a two-tier system and it shouldn't be.

B. There is a big gap.

I had post-natal psychosis and that's been used against me. I was blamed. That's where your training would be vital. If they knew the different presentations of autism, all my children would have been identified.

C. Just assess every kid when they come into school.

A. But 4/5 is too young for some.

Unsupported by CAMHS
Under-resourced

Don't follow CoP

Under-resourced (Increased demand)

Assess all children at statutory school age

Reaching parents with varying standards of English

Support not equally accessible to all

Not listened to
Feel blamed/accused

C. Maybe year two then. Not waiting to see if they show up in exams.

A. Councils are saying they don't need a Statement now. The problem is not now, it's the future, because as these kids get older, the anxiety kicks in.

Cllr Webster: What else for the list?

B. Accept private assessments.

If there is a Plan in place then Surrey need to **make sure the provision is happening**. EOTAS, section I of the EHCP – when the child has gone through the whole process and there is no school that can meet their needs, they have an individual package built for them.

C. Penalise schools who exclude illegally.

A. My school have their head in the sand and they think if they could just get rid of all the autistic kids. I've heard of other **independent schools** that are recognising this can't be ignored. **Some are bringing in OTs and SALTS and helping parents with EHCPs.**

Schools that have taken all the SEN kids, sadly get a new head who says we're going to change things around and only take high-functioning.

C. This would be unfair dismissal if it were a job, but **they just make them so uncomfortable they have to leave.**

The teachers are under enormous pressure to get the grades and every year the grades have to go up. The teachers are going through Hell.

B. I just want to demonstrate the effect this has. We were a very healthy, happy family. **Two children tried to kill themselves, had hospital admissions.** My eldest is a significant self-harmer, she doesn't have skills to be safe outside because she hasn't had the provision all this time. My other daughter won't ever live independently now. Seven suicide attempts. CAMHS don't want to deal with her, she is damaged beyond belief. My other children have seen the trauma. **CAMHS refused to treat my daughter for PTSD, they have treated the other two but they won't treat the third, we don't know why.** They've seen her hanging. This is a result of failings in the system. My husband and I have pretty much come to divorce now. He's in a good job, he earns a lot of money, I'm very privileged to have married him, but we have nothing left. We struggle to pay our bills.

Accept private assessments

Ensure provision in Plan is provided

Penalise schools for inappropriate exclusions

School focus on grades

Some independent schools provide therapists and help with EHCP process

Lack of empathy (schools)

School focus on grades

Emotional/health impact (CYP)

Trauma
Unsupported by CAMHS

Strain in family relationships

Financial impact