

20 March 2024, Woodhatch Place Reigate.

Cllr Jeremy Webster, Cllr Jonathan Essex, Cllr Mark Sugden, Julie Armstrong (Scrutiny Officer), Participation & User Voice Senior Manager

5 participants

<p>Cllr Webster: Tell me about your experience with the Council.</p> <p>A. I've had 30 SEND case workers. I went to the Local Government Ombudsman and won.</p> <p>D. Without the drive of the head at Dorking we wouldn't have an EHCP. At times it's poorly written, you end up correcting the English. Without direction we would have struggled. There's a shortage of occupational therapy. I don't know what services are out there.</p> <p>A. I was a late mum, 39. I had no idea what PDA or autism was. There's no user manual, no leaflet signposting you. I was classed as a bad parent for years. She bit the head's finger on the first day of school. CBT is in her EHCP. Four years later, she still hasn't been given that. I was struggling massively from age 2, sent on parenting courses, I rang social services so many times for help, I was crying. It took them three years to put in the right team. Every other week I rang.</p> <p>B. One thing was good – they found an EP very quickly at the time, which really shocked me after what I had read. And then the number one bad thing was they then sat, I believe, deliberately on the EP report for a good two weeks, which meant my first delay. So we should have actually found out about it all the 26th of December. We actually got a solicitor involved and so we have a solicitor which we're going to have to take a bank loan for. And you know, I contacted the caseworker and I said, you know, why have you not got the EP report they said oh, I don't know it's not come yet. So I contacted the EP directly and it was a Surrey locum and I said where's the EP? And she said, Surrey have had it for at least two weeks.</p> <p>Cllr Webster: So a report was done and you weren't informed?</p> <p>B. Yes, and neither was the SEND worker apparently. I don't actually know, because I don't know what to believe, but she said, oh that's funny, I've chased it up and it's</p>	<p>Case officer turnover Fight/battle</p> <p>Proactive nursery Poor quality EHCP (standard of English)</p> <p>Under-resourced-OT shortage Not signposted to support</p> <p>Not signposted to support Feel blamed/accused</p> <p>Not had provision in Plan</p> <p>Unsupported Timeliness (social services)</p> <p>EP found quickly</p> <p>Solicitor Financial impact</p> <p>Poor case officer communication</p>
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<p>arrived. And I said, well, I believe Surrey have sat on it deliberately to delay for at least two to three weeks. So then, that was the first deadline missed.</p> <p>Cllr Essex: What's the deadline that you missed?</p> <p>B. I've forgotten all the stages now, but apparently by the 26th of December the EHCP was due to be done, and by that point they haven't even got the [EP report].</p> <p>Cllr Webster: Second example?</p> <p>B. Second example I would say is that they wrote a really poor EHCP. I'm not professional person, I've never seen an EHCP before, but I looked at it and I laughed.</p> <p>Cllr Webster: Can you give an example of something in it that wasn't right?</p> <p>B. It was just so vague and woolly. In my belief so they can get away with stuff – your daughter must have access to small groups – what's a small group, 5/10/20? It was littered with words like that. Things that didn't make sense, you know 'Your child should have psychoeducation' – what is that? And by whom? I still don't know.</p> <p>Cllr Webster: Third example?</p> <p>B. We paid for an OT assessment and a SaLT assessment because we thought it might speed things up a bit if they've got the information. They did sort out their own EP very quickly. Surrey wanted to do their own, which they did sort out very quickly. They would not consider our SALT assessment, the one that we commissioned privately. I was quite shocked by that because it is done by a professional person who can go to court, we made sure that she ticked all the boxes. Of all the assessments my daughter has had done, that one shows the level of support she needs. My belief is that Surrey don't want to accept it because they would have had to pay for the stuff.</p> <p>Cllr Sugden: Did they give you any reasons why they wouldn't accept it?</p> <p>B. They chatted to a Surrey SALT who felt that my daughter doesn't need it; this is someone that's never met my daughter, never spoken to her, not liaised with myself or the school.</p>	<p>Lack of trust</p> <p>Timeliness, issuing plan</p> <p>Poor quality EHCP (lack of clarity and precision)</p> <p>Complicated language No explanation</p> <p>Financial impact</p> <p>Not considering privately commissioned assessment Not listened to</p> <p>Lack of trust-suspect refusal due to money</p> <p>Not involved in process</p>
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Cllr Webster: So that's three examples of when it's just not worked. Vague and doesn't seem to reflect the true issues and delays when they shouldn't really have been necessary. And a feeling really that that's around something else, which isn't to do with the child, it's around

B. Money. We've got a solicitor who has a 100% success rate against Surrey.

Cllr Webster: How did you find that particular solicitor?

B: It was actually through the school. Our school have been really supportive because they do believe she needs an EHCP. They can't help as such with one, because they're an Independent school, but they've given us sort of resources. They're a wonderful school. They suggested a solicitor that other parents had used. So they suggested him and at our cost we are using him and the appeal's been sent in.

Cllr Essex: Both of you have EHCPs but quite a long time after you thought there was a problem.

A: Yeah, I thought there was a problem and all the people around her thought there was the problem.

Cllr Essex: And you said that you before you went down the EHCP route, you went through the CAMHS route. So is it just possible to explore a little bit the story of how you found out about CAMHS, how you went through CAMHS, I think you said that you went through CAMHS four times?

B. Yeah.

Cllr Essex: So presumably then the first time you went to CAMHS, it was not considered urgent. My concern here is that quite often we focus on a bit of the story, in this case that EHCP journey, but your journeys have both been quite a lot longer than that.

A. CAMHS have been appalling, CAMHS have let us down.

B. Same.

A. My daughter was suicidal from six years old and threw herself out a window. I had to tell the school that they had to be careful not to let her upstairs by an open window. We were rushed in ambulances to A&E, A&E did nothing.

Under-resourced

Independent school  
supportive of getting EHCP

Not supported by CAMHS

Incendiary language

CAMHS kept saying, well we're gold dust and I said my daughter's worth gold dust. Her life is important and worth gold. They just said they're a privileged entity and why should my daughter be? They, without even ever meeting me, blamed my parenting, again. I've had 10 referrals to CAMHS minimum.

Feel blamed/accused

Cllr Essex: How did it take so long, from when you knew as a parent something was up, to starting on the EHCP journey? It sounds like it wasn't running in parallel. Sounds like CAMHS comes first and then the EHCP happened last.

B. In reception we notice there's something a little bit different and then processing, the first referral went in maybe year three, something like eight/nine years ago. So the first one was passed away. It went off to CAMHS and it's like, no, don't you know really it's a bit of anxiety, get her to read these books, you read these books. Our second one we went on course, my husband and I, I think it was like a little bit of parenting 1:1 run by the YMCA. We just had one lady who was going through possible could be this, could be that. Third referral again she didn't meet the criteria to be seen. And then the 4th one went via the GP because my daughter had a meltdown saying there's something wrong with me, I think I've got ADHD, there's something wrong, this shouldn't be happening. By then, she was just in the process of getting diagnosed with dyslexia, going into year six, so probably about 9 or 10 then. She's a screener, so she recognizes some of possible autistic traits, so I phoned CAMHS up and I said, look, you've had the fourth referral that's gone in through the GP. I said I have a 30 page document which on there recommends getting her tested for autism, I'm sending it your way. And then three months later she had an appointment, not with CAMHS directly but to get assessed for autism.

Not supported by CAMHS

Lack of SEND knowledge (teachers)

C. My daughter X was very well behaved, so when I went to the school and said, I think there's something wrong, they said, she's absolutely fine here. What's happening at home? Then I went off and got her assessed privately when she was five. That came back that she wasn't dyslexic, although the school told me again they've done their screening and that she didn't present with any dyslexia symptoms. Then I think when she was a year three, she was very academic but fidgeting around and she masked a lot of these behaviours so again, private assessment which we paid for, referral to CAMHS. There was a diagnosis of ADHD through CAMHS and then it

Financial impact

Timeliness, autism assessment

was literally just medication reviews every six months. Then I started going through the EHCP process and educational psychologists. They said, strong characteristics of autism, but you'll be waiting three to four years.

So fast forward to lockdown. Because I was working, she was able to still access education at school, small classrooms, and she came home one day and wasn't herself. Didn't really want any dinner, went up to bed and took 65 paracetamols. And she had presented absolutely fine at school. She just couldn't cope with the lockdown, the isolation, knowing there was something different with her.

Cllr Webster: What did you know about what was available from the county in terms of EHCP?

C: I didn't, I literally stumbled across everything. Everything I knew about EHCPs in the sense that her older brother had an EHCP, but he had it at mainstream school, minimal support and we didn't know about specialists. Again he was privately assessed. You know, no one would help us. No one would help us, and ironically at the time when she took 65 paracetamol I was actually working for the Hope service so I worked with young people with significant mental health. So, and there's my daughter in hospitals. But taking an overdose though, you know and I remember being on the hospital ward and hiding from the doctors that are at Hope, you know, because I was so embarrassed, I was like, you know how I got to this? I fought so hard and then we finally got the EHCP agreed. Again I paid for a private assessment for autism following the stay hospital, the doctor said to me, if I hadn't found her when I did that, she wouldn't have woken up in the morning and so then we got this EHCP and then fought for her to go to a specialist. And I was so relieved when we got this specialist school, I just thought ohh you know, that's come in and it was the worst thing could have ever happened to us.

Cllr Webster: What support were you receiving from the SEND officers?

C: I didn't get any support. Call constantly, they'll call you back, they're not in the office, they're off sick, the case worker's changed. Half the time I didn't know who my case worker was. We can't deal with that because it's a specialist school, we've got no power.

Delay led to crisis

Not signposted to support

Unsupported

Fight/battle  
Financial impact

Unsupported  
Poor case officer communication

Case officer turnover

Not knowing who does what (case officer)

<p>B: Is a case worker, is that the person that liaises between the Council and yourself for the EHCP?</p>	<p>Solicitor</p>
<p>Cllr Webster: Yes.</p>	<p>Solicitor</p>
<p>C. We had to get a solicitor because I think things move much quicker.</p>	<p>Financial impact</p>
<p>A. I managed to find a solicitor on legal aid.</p>	<p>Not signposted to support (special schools)</p>
<p>C. We had to pay. If we have to eat beans on toast for dinner, then that's what we will have to do because no one else is gonna help us.</p>	<p></p>
<p>A. I think there's a lack of knowledge of these specialist schools given to parents, we've gone down a warren den trying to find the school, no one supported us with that. We've been thrown names here, thrown names there. They're not allowed to go and view these schools and environmentally check them out before it's actually in a correct process. So I've been waiting years for the correct school, no advice on what the correct school is or being able to view that school effectively.</p>	<p>Timeliness, getting appropriate school</p> <p>No personalisation</p> <p>Child not in best learning environment for them</p>
<p>C. You don't get a list of specialist schools.</p>	<p>Not signposted to support (special schools)</p>
<p>A. It's like trying to put a square peg in a round hole and no one seems to choose the right environment for our children.</p>	<p></p>
<p>D. We didn't know what schools were going to be available to X our youngest. We knew she wouldn't be in mainstream, but we were still told to follow the mainstream process in case she didn't get any school, the various people from Team Around The Family (TATF) meetings. So we sat through meetings with SENCO in mainstream saying, oh well she'll soon understand how to use the toilet when she starts primary school, and she's probably going to be incontinent for her whole life so to be told that... and knowing all the time that she might be able to get into one of these special schools. But again, no one gives you a list, even the nurseries don't have a list. It's only asking the therapist and getting the head to ask around. One we weren't even able to have a look around, they stopped doing visits because they were too disruptive.</p>	<p>Lack of SEND knowledge (SENCo)</p> <p>Lack of empathy</p>
<p>D: I just thought that the therapists and the case workers were just incompetent at writing specific things, specific</p>	<p>Poor quality EHCPs (SMART goals)</p> <p>Lack of trust</p>

<p>targets. I'd assumed and this was my first experience that no one knows how to write a goal that's specific and measurable. So now hearing this, is it actually avoidance at having to provide a service?</p>	
<p>B. That's what I think it is.</p>	<p>Knowledgeable case workers</p>
<p>D: Is it incompetence or is it avoidance?</p>	
<p>C: It's not incompetence. Some of the case workers are really knowledgeable.</p>	<p>EHCP error</p>
<p>D: They're knowledgeable but are they capable of writing specific goals that have specific, measurable objectives?</p>	
<p>A: I've had an EHCP draft sent back to me and it's had somebody else's name on it. A different child's name on it.</p>	
<p>Cllr Webster: This has come up in other groups. Is it because people don't know how to write SMART objectives, or is it avoidance?</p>	
<p>D: I've written down, perception of avoidance.</p>	<p>Under-resourced</p>
<p>Cllr Webster: Or is it about the money?</p>	<p>Under-resourced</p>
<p>D: Yes, rather than just the level of skills people have to write these reports.</p>	<p>Under-resourced</p>
<p>C: It's always about funding.</p>	<p>No personalisation (OT report)</p>
<p>A: It is about the money.</p>	
<p>D: They warned me at nursery school to watch out for therapists' goals because there is a tendency for them to be vague. I just received my child's latest OT report and it is just a pile of rubbish. I don't know if she's met my child. The previous OT didn't even turn up to TATF meetings and didn't even contribute to the handover from nursery to school, called me at the end of September, 'oh I've been very busy'.</p>	<p>OT failed to attend TATF</p> <p>Loss of knowledge at key stage transfer</p>
<p>The occupational therapists who did pick up once she started school didn't look back at all the work that Dorking nursery been doing around very simple self-care objectives. You know this is a child who can't even feed herself. You know, child will sit in a high chair, you know, without tipping the highchair over. And I'm still waiting for a chair that she can sit in that isn't going to be tipped over.</p>	<p>Suitable equipment not provided</p> <p>Poor quality EHCP (health section)</p> <p>EHCP error</p>

So we've focused a lot on education, but the health piece of the EHCP I feel, it's massively lacking from her perspective.

Provision not fulfilled due to EHCP error

A: We've struggled with that. We've struggled with the wrong bits in the wrong part of the EHCP so they haven't been fulfilled because they don't know that's down to health section and they put it in education.

Perception of illegality (no to assess)

D. Without a diagnosis, the EHCP process is a real struggle. We got a diagnosis right at the end of her EHCP so we were able to include it, but that makes it really hard.

Nursery and TATF meets led to referral

B: The first thing Surrey did was refuse to assess her for an EHCP. I said, surely that's unlawful because she meets the threshold.

D: We only got that referral because of Dorking Nursery School and those TATF meets.

A: In X's case, she did have a diagnosis. As soon as anybody saw 'PDA' they ran a mile, so if you do put your diagnosis on an EHCP it can't always be the best thing.

Lack of SEND knowledge

Well it has to be there but no one seems to understand, even doctors have to Google the definition of what her condition is.

D: For X's condition there are no specialists.

A: That's hard.

Not signposted to support

Cllr Webster: The end game here is sort of proposed improvements. Those people who are sometimes in unlikely jobs, but they actually come forward and help you, whether that's in the name of decent solicitors, or you know, why don't you go this way or that way?

D: But you have to have sought them out. I had a conversation at a party with speech and language therapist mum who said I've heard Dorking nursery are really good. I rang up on the beginning of September, happened to get through to the headteacher who was answering the phone so that day because the term haven't probably started and explained the situation we're in and she said come along. I can find a space now. Without me driving it, God knows...

Facebook groups



Cllr Webster: That's why I said it's random you see, it's not systematic.

B: Social media has been really good in that respect because I found out information. I belong to quite a few Facebook groups, local SEND groups, autistic groups, I've found a lot of my information from there and other people saying locally, you could try this.

Participation & User Voice Senior Manager: Is the local offer communicated?

D. Yes it is communicated. But it doesn't add any value. I was referred to Short Breaks providers, one of them has a year's waiting list, other one can't put her on a waiting list until she's 5 and then there's another year's wait. And then they told me, this isn't childcare, this is respite care for people who are in need. What am I supposed to do in the summer holidays, give up my job? I've got a really understanding employer but all the millions of appointments that I go to. I have two other children to support, I have a mortgage to pay.

A. They put a medical in the education part the wrong part of the EHCP so it wasn't fulfilled.

Cllr Webster: To summarise what I'm hearing - an information service that can be relied on and is professional, that shares information. Then we have the list issue which is I don't know where to go, who do I talk to. And people are finding their own way through the system.

A. It's like being on a roundabout and nobody gives way to you. You try every avenue but doors shut everywhere you go. And in the meantime these children are suffering, looking for an education.

Cllr Essex: Is the process that's taking too long the EHCP process which is whether it takes more than 20 weeks - I'm worried that we're focusing on an iceberg above the surface.

[laughter at the mention of 20-week deadline].

D. It is the EHCP process, there is a need to focus on that. But as a parent, by the time you've got to that

A. You've burnt out.

Local Offer unhelpful

Shortage of short breaks provision  
Incendiary language  
Lack of understanding/empathy (LA)

EHCP error  
Provision not fulfilled due to EHCP error

Unsupported

CME

Timeliness, to issue Plan

Emotional impact

Timeliness, waiting lists for help  
Reliance on social media  
Fight/battle

Lack of SEN knowledge (teachers)

<p>D. It's taken too long to get any help that you have just gone round accessing through social media, battling against waiting lists to see anybody. Dorking nursery should be held up as a model of the support they gave.</p>	<p>Train all school staff</p>
<p>B. The teachers' lack of knowledge and experience within special needs. SENCO half of heard of visual stress but it's giving out coloured overlays. You should have heard of it.</p>	<p>Case officer failed to attend TATF</p>
<p>C. SENCo worker is sent on training and they say they're gonna feed it back, but then they are feeding back their perception of it. All the staff should be doing that training.</p>	<p>Case officer turnover</p>
<p>D. The SEND caseworker didn't come to our team around the family meetings.</p>	<p>Not aware of local offer</p>
<p>C. Legally they don't have to attend.</p>	<p>Not aware of local offer</p>
<p>D. And it changes all the time.</p>	<p>Not aware of local offer</p>
<p>Participation &amp; User Voice Senior Manager: The Local Offer have done a really comprehensive guide on what the SEND officer is.</p>	<p></p>
<p>B. What's the local offer?</p>	<p></p>
<p>D. Most people didn't know they had one.</p>	<p>Poor communication with schools</p>
<p>CIr Essex: Why not put the information where people are looking to find it?</p>	<p>Send parent guide with school newsletter</p>
<p>Participation &amp; User Voice Senior Manager: We've just launched the guide for parents and carers; this goes through hopefully the process of what to expect.</p>	<p>Too much paperwork</p>
<p>D. How many of our mainstream primary schools even know that exists? Could they send that out on a termly basis with the newsletter? There's a massive disconnect in mainstream.</p>	<p>Nursery helped with paperwork</p>
<p>A. I've tried to support a few of the parents through the process on they can't manage it. It is too much for them. Even the DLA form.</p>	<p>Poor case officer communication</p>
<p>D. I'll come back to Dorking Nursery School, they supported the families to fill in that DLA application.</p>	<p>Case officer turnover</p>

Cllr Sugden: When you get to the EHCP, how much consistency is there with the personnel you're dealing with?

C. A case worker takes 10 working days to reply to one email

A. They chop and change like the wind

Cllr Sugden: So there's a significant problem with consistency of personnel.

A. 110%.

B. They get a load of stick don't they, I'm guessing it's probably a horrible job to do.

D. By the time the parents get to them they're at their wit's end.

A: I've been told by a duty case officer to go away and I'm a pushy mother. And I said what would you do if it was your child? They said I'd do exactly the same. I'm trying to allocate who my next case worker is for my educational health care plan for my daughter because the lapse of communication has gone by the by and then eventually you get through to the duty officer after calling, calling, calling, emailing, calling, I will speak to the so called Duty Officer. They will say, well, what do you want me to do about it? I've had the exact answer from this particular male. Then you're accused of being a pushy mother and I said, well someone's got to fight for my daughter. I said, how would you feel if your daughter hadn't been in education for over 4 years? Well, exactly the same.

Cllr Sugden: And the duty officer is meant to...

A. Meant to liaise with your information until you get allocated a new case worker, so whatever your query is, they should be able to support it or guide you to who you are actually allocated caseworker will be. The duty case officer should pick up the case if there is no allocated caseworker at the time.

B. It's cost me my mental health. I'm on anti-depressants now. It's a huge amount of stress on my relationship with my husband. He is working, my job is fighting for our daughter. So it's put a strain on our relationship and on the family as a whole.

Incendiary language

Poor case officer communication

Lack of understanding/empathy (case officer)

Fight/battle

Emotional/health impact (P/C)  
Fight/battle  
Strain on family relationships

Financial impact

Timeliness

Last minute agreement

Emotional/health impact (P/C)

Financially, we have spent £50,000, our life savings on school fees and private assessments. I want an EHCP for my daughter whatever the cost. I don't care if we have to remortgage the home. We're doing it to future-proof her. I feel quite strongly that Surrey, it is about the money, it's delay delay delay, which costs us more money. I've been told by my solicitor who deals with different councils that Surrey is probably the worst followed by Kent. It is normal for them to delay and drop at the last minute and give in when it has cost you a fortune in energy and money.

A. My health is deteriorating to the point of me calling social services in lockdown complaining that I could not cope and I love my daughter, she nearly went into care. I never wanted my child in care, what I wanted was the necessary support to get her an education to prevent her life from being like mine is. Without an education that my daughter hasn't received, where will she be in the future? Will she go on benefits like me? That's not what I want. What is £1,000 damages for a lost education and the child's future?

B. I think they waste a lot of money in their delays issuing to deadline and saying no we're not going to issue, oh OK we'll have the tribunal and then oh, lastminute.com we'll pull out. That must cost the Council thousands and thousands of pounds, and I think that money could be better spent on the education of kids with autism and ADHD.

D. People that actually care and they're not just turning up for a job. There isn't a recognition in the people that are processing the EHCP, those case officers, they don't know the struggle that as a parent of a seriously disabled child, that you go through every single day, just to get up in the morning and get your other children out the door to their school.

C. The keyword is fight the everyone of us has used in here today.

D. Every day is really difficult anyway. To then have to battle this. Even if you want to pay for it yourself, you don't even know how to find out something. It's fundamentally about, your day is hard enough. Why can it not just help you and I can understand why they won't help you because they want to not have to spend the money.

Child nearly went into care  
Unsupported

Future prospects of CME

Last minute agreement

Unnecessary taxpayer expense  
Initial agreement would direct the money into education

Want staff to care

Lack of understanding/empathy (case officers)

Fight/battle

Not signposted to support

Under-resourced

Case officer with lived experience

Train SEND officers

Lived experience

Train LA staff

Train LA staff in personalisation

<p>C. I had a caseworker who had children with SEN and she was phenomenal.</p> <p>Cllr Webster: What's the one message you want to give us?</p> <p>A: Train SEND officers.</p> <p>D: Lived experience.</p> <p>C: Stop allowing people not qualified to pass judgement on parents.</p> <p>D: So they recognise that every child is different.</p> <p>E: You need training plus, so not just the knowledge, we need to make sure that they understand it. We need to make sure they accept it, that they believe it and then they employ it in their day to day and then you need to go back and test and check it out.</p> <p>B: I've come across this wonderful charity [Lucy Rayner Foundation] and I was amazed to find out that they go into local schools talking to students and teachers. They offer free six weeks counselling. Why are schools not using it?</p> <p>A: Parents generally, when they find out something's different, we need a guide, a foolproof self-explanatory, in really simple easy terms of different avenues of support, a support guide for parents and schools really.</p> <p>B. Help with completing forms e.g. DLA. I stumbled across Surrey Carers by mistake and I've been to Family Voice.</p>	<p>Check knowledge</p> <p>Third sector</p> <p>Schools should make use of mental health training</p> <p>Want simple language parent guide</p> <p>Want help with paperwork Not signposted to support Third sector</p>
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