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7 participants

<p>Cllr Webster. B, would you like to give a pen picture of yourself?</p> <p>B. Hi. I'm a deputy head. I've had a whole career in education. I thought I knew education until my eldest child was diagnosed with autism two years ago, nearly two years ago. I'm a governor at the school where she was. I'm still a governor there. My other daughter is still there. And I really can't tell you what utter hell we've been through in the last 18 months.</p> <p>It's been absolutely horrific. It's nearly broken us as a family. We've spent tens of thousands of pounds. The point we're at now, it took 53 weeks to get an EHCP [Education, Health and Care Plan] issued for my daughter. Her needs assessment—I'm giving you the very quick version, so don't worry—her needs assessment was turned down.</p> <p>And actually, even though she already had an autism diagnosis, that's illegal. We then thought we went through mediation, didn't get to mediation. Had a phone call 4 minutes before mediation to say that they would give her a needs assessment. She's been issued an EHCP on week 53. That's because I have pulled every lever available to me. I've got Claire Coutinho [MP] involved. I've had Clare Curran [Cabinet Member] involved. I've written to everyone possible. I've had a stage two complaint upheld. I'm now with the Ombudsman—take your complaint against Surrey further. We have been given an EHCP that just says specialist school to be identified, so my daughter still hasn't been given a school. And now we've gone to appeal where the barrister and the dates been set for December. That's a very short version.</p> <p>A. I'm A. I've got two sons of 15 and 12. They're both struggling with SEN [Special Educational Needs], but this really is about my younger son who's 12 in year seven. He's always struggled with accessing school. It wasn't easy even in primary, but since we've gone to secondary, things have got a lot harder. He's not really attending school regularly. I've had lots of contact with the SENCo [Special Educational Needs Coordinator] and various people at the school but get very little help. I've raised a complaint but, recently, had a letter from the Chair of Governors saying they think they're dealing with SEN issues brilliantly.</p> <p>What am I complaining about? I think the school just wants to fit everyone into the same round peg—putting a round peg into a square hole. You know, it doesn't work that way. So, at the moment, he's not accepting school. The school are not in contact with me at all. And I'm at the end of my tether, quite honestly.</p> <p>C. I'm C, I live in Ewell and my 7-year-old was identified as speech delay at the 27-month check-up. Since then, we've advocated for him and felt that we were on it, you know. It got referred for the NHS Route. Got some support from there and then have been working on the journey with school.</p> <p>That was when he was 27 months. He's now 7 and he's still behind on all aspects of learning. The speech has, now, kind of, impacts on social</p>	<p>Emotional/health impact (both)</p> <p>Financial impact Timeliness - to issue Plan No to EHCNA despite autism diagnosis</p> <p>Perception of illegality</p> <p>Last minute agreement before tribunal</p> <p>External advocate</p> <p>Ombudsman</p> <p>No school named on Plan</p> <p>Secondary school not making (enough) adjustments for SEN</p> <p>NHS support for speech delay</p>
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<p>relationships and other areas. But I'd say actually, he's had a positive school experience otherwise. But we are supporting him outside of school because we know that the resources just aren't there.</p> <p>I'm a school governor at the school and the governor lead for SEND [Special Educational Needs and Disabilities] is on maternity leave at the moment. So, I've just taken over that role and am just starting to really understand the workings and, you know, behind the scenes as well. The challenges that schools face when there's no magic money tree, you know. And so how do we as a school and as a community here support that?</p> <p>E. Hello, I'm E. I've got three children aged 21, 18, and 13. My 21-year-old made it through school but really struggled and, with benefit of hindsight, we could have done with a huge amount more support at that time.</p> <p>My 18-year-old is, on the surface of it, thriving in school and will probably come out with three A* at A levels very soon, so is okay in the system.</p> <p>My 13-year-old found things a little hard in primary but went to a very, sort of, nurturing, gentle, flexible primary school and made it through primary school with a little bit of extra support here and there. When he started secondary school, things became very much harder. Anxiety shot through the roof—this is a very familiar story I can see people nodding—he got diagnosed as autistic.</p> <p>You'd think that that would then initiate all the support coming round and making it all better. What sort of happened, people made noises about support, but because the slight bits of flex didn't make him suddenly be fine. The pressure piled on more and more and more, we were referred to the inclusion service and we got bullied.</p> <p>It was the most stressful experience. It was awful and the stress on the family at that time was beyond anything I've ever experienced.</p> <p>He became more and more stressed. Pressure continued. It was despite having the diagnosis. Despite the EHCP [Education Health and Care Plan] referral, despite all of that, the pressure continued, and he became really unwell. He ended up covered in psoriasis so that his face was just red raw, and it was only at that point that his absences from school became authorised and the pressure from the inclusion service stopped; and that was awful.</p> <p>E. So, in all honesty, the EHCP process was difficult, but the process that we went through with the inclusion service was beyond anything.</p> <p>D. I live in Cobham. I have two boys who—I think because when they were babies and little—I used to work for the local children's centre, so we did a lot of play groups in the area. I did a pram walk and so therefore my children have always kind of been around children. Always been extremely out there, sociable, you know, they've always had to be around a good mix. So, they're kind of—they have both been diagnosed being autistic with ADHD [attention deficit hyperactivity disorder]. And my eldest also has ODD [oppositional defiant disorder]. But I think because they were not the norm of social—because they were actually fairly sociable, I think because of just constantly being out with children like they never got to stay in—they weren't actually picked up until they was, what, year one.</p>	<p>+ primary school</p> <p>Under-resourced</p> <p>Unsupported</p> <p>+ primary school</p> <p>Timeliness (Delayed support led to crisis)</p> <p>Secondary school not making (enough) adjustments for SEN</p> <p>Pressure from Inclusion service</p> <p>Emotional/health impact (both)</p> <p>Pressure from inclusion service</p>
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And I think it was more of the academic side that they started to say, well, actually, like the motor skills aren't really there and they are struggling compared to their peers.

And so therefore the problem was of my eldest. When he hit year one halfway through, we hit lockdown, so therefore that whole process of having him diagnosed and getting help, it took a lot longer because of lockdown.

D. And so, he actually has only just managed to get his EHCP, and he's in year five now, and whereas my youngest is in year three and he's got his EHCP around the same time as his brother and he's [been] diagnosed.

They're both diagnosed via the paediatrician in Epsom. And again, it was just so much quicker process than my youngest because we didn't get that lockdown stint in the middle.

But they definitely both have struggled throughout school, and I think my biggest thing is the school there at the common free school there—and rightly so, they're really, really strict on their physical, like aggressive, kind of behaviour policy.

So, with my two, you know, they slap, or they might throw a chair or, you know, it's an instant they are being excluded. Like, they will not come back for another day or there's a suspended and they literally get shut out completely and they don't actually want to hurt people.

They'll throw a chair, and it won't be anywhere near anybody else. It's just that was the kind of, you know, the kind of battles—they are both medicated now.

So, we're kind of going through the whole medication process of whether that's helping. And I do think a lot of the behaviours, you know, they can't be helped with medication. You know the school seem to think if I get the medication right, then it's gonna be like 'one-fix-all', but I don't believe that.

I think some things are genuinely their behaviour and you have to manage that behaviour whether they are medicated or not, like it's not going to make the difference. You know what I mean?

Like because, I don't see some of the behaviours at home that they see at school, you know?

F. I've got two daughters, my eldest is 15 now. She's got an autism diagnosis, and we think she's [unintelligible] profile. So, the [unintelligible] time with mainstream school and an independent specialist school, she's on [unintelligible] at the moment, but she's struggling to kind of really do much with it.

The math teacher's great, the tutor I should say, but yeah, it's not exactly what she wants, so her interest is kind of waning.

My youngest is 12. She's in year seven, so the first year of secondary school it's been a little bit bumpy, but at least the SENCo is quite understanding and they're trying to make some reasonable adjustments. But it's difficult that the teachers are not really with it and the sort of excuses of 'oh yeah, we get new teachers and we gotta make sure the training comes back around again' kind of runs a little thin.

Covid barrier
Timeliness - diagnosis

Lack of SEND
knowledge - teachers

+ secondary school
making adjustments
Lack of SEND
knowledge (teachers)

<p>When—you know, some of the things they're allowed to say is just horrific really. You know, you wouldn't get away with saying that to any other sort of disabled child in a wheelchair or something.</p> <p>It's safeguarding in my mind, but they don't see it that way. So it's frustrating.</p> <p>And I'm on these and—I go to everything. I volunteer with PDA [Pathological Demand Avoidance] Society. I go to all the [Family Voice Surrey] and NAS [National Autistic Society] and everything. Just trying to explain what autism and PDA—especially in trying to see that—We do need something more especially, in the East Surrey because it's quite devoid of things around here and just want something different so I can feel confident in knowing my daughter is in a safe environment—she has opportunity to learn, and I can try and get back on with my life as well, rather than just a full time carer.</p> <p>Cllr Webster: The first question is, what barriers have you encountered accessing support for additional needs?</p> <p>B. Yeah, communication with Surrey County Council.</p> <p>My comms log runs to 90 pages I think and that's me contacting them and then simply not replying, just ignoring me.</p> <p>I'm a big fan of the school where my daughter was at. I'm still a governor there. She's no longer there. They got to a point where they just couldn't meet need. They didn't have enough stuff or enough training, and they just said, you know, she was school refusing. We tried, they tried. But they just couldn't meet need. That was that.</p> <p>Cllr Webster: Number three?</p> <p>B. I'm going to go for Surrey County Council again. I mean it would just—</p> <p>Cllr Webster: Which bit of Surrey County Council?</p> <p>B. Just it, it has felt—I know it's not personal and I'm maybe other mums and dads understand this, but it felt really bloody personal that it's been a no at every single turn and a slammed door and no explanation. And you know, for example, my daughter's case just went to panel last week to name a school that was our parental preference and it's come back with a no, not enough evidence which is absolutely rubbish because we've given them all, all the evidence and then some. It just feels like everything is an absolute no until you fight like crazy for it.</p> <p>E. OK, so I would say, the first thing I suppose is that there's the, there's—When you first identify that there's a problem, nobody really takes it seriously. And as parents, you kind of know, you know, first. And so, when you're starting to say we need a bit of help, we need a bit of support, we need a bit of flexibility, nobody takes you seriously until you've got sort of, you know, many letters from doctors and assessment and things. Actually, if you could just get that bit of flex quite early on some of these problems wouldn't maybe even occur.</p> <p>The barrier, the harassment from the inclusion service was awful for us, so that's got to be on there for me.</p>	<p>Incendiary language (teachers)</p> <p>SCC communication</p> <p>SCC not replying</p> <p>Under-resourced Lack of SEND knowledge - teachers Primary school not meeting needs</p> <p>No explanation</p> <p>School not parental preference</p> <p>Fight/battle</p> <p>Not listened to/dismissed</p> <p>Timeliness (intervention)</p> <p>Treatment by Inclusion service</p>
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Cllr Webster: So, can you just explain the harassment for me just a little bit? You raise—it seems very important.

E. I mean, yeah, I know that's a very loaded word to use, but it was like the so they the first thing I that happened was they came to the visit us at the house.

They asked us many, many questions and we tried to answer them as honestly as you know, we could and as with giving as much information as we could. I mean I naively thought it was going to be quite a supportive meeting. I thought, you know, nobody is gonna come out to a child's house and not have the child's best interests at heart. How could that happen? So I thought this was going to be something quite supportive.

We were sort of grilled and then we thought we we're not being supported here, we're being challenged, we're being disbelieved. It was those I felt it was quite disquieting.

But we explained the situation and we and then we got a letter listing all the things we'd said, and then it said something like, 'However, we still expect we now expect your son to be arriving at school and on time, starting from now.' I was like we've just explained the whole situation we're dealing with. So I think not being believed was really, really difficult.

Cllr Webster: Not being believed. Third one?

E. The inclusion service—So then, I guess, the EHCP process. It was tricky and slow, but not as distressing as the process with Inclusion. But our son is now not in school, so he hasn't, he's not getting any— He's getting like one day a week at a therapy garden, and that's the entire funded education he is now receiving.

Cllr Webster: So, can I ask you, because I think it's so: this was this the first time, with all respect in your parenting life, you'd actually ever been treated in the way you were treated because the up to up to that point, yeah?

E. Yes, yes, yes, exactly. And I think that's why it was. Yeah, from for, you know, to use you sort of simplistic language prior to that. I thought we were, you know, one of the goodies. It was like, we did the right thing. The children, you know, were people like them. They were in their lessons, you know, we got good school reports.

Generally, then all of a sudden your child starts to struggle, and you think now, okay, my child's struggling. So now the system will help me. So the medical system and the school system and all the people out there will say helpful things and do and know what we need and help us. And it was like, it wasn't even that there was a lack of support.

It was that we were suddenly being targeted like you know, we felt like we were being treated like criminals. It was, really, I'd, I'd say it was frightening. It was really frightening.

Cllr Webster: Okay. Thank you for sharing that. C, would you like to go by the way, if you if you're top three, you're include ones that are already gone, then just say them anyway. But if you want to add new ones, please do so. C, what were your top three in terms of barriers encountered?

Feel blamed/accused

Difficult to navigate
EHCP process
Timeliness – EHCP
process
Inadequate AP

Unsupported

Feel blamed/accused

C. I think I just, you know, every school works differently, but I think the role of the SENCo is a challenge in our school. The SENCo is also deputy head. And also, you know so the time is a challenge. They're doing a really great job, but actually the number of cases that go through one person and becoming a bottleneck. And when I, as when I was a parent in the early days, I didn't understand what was going on behind the scenes in terms of the relationship with the Council. But it felt like a holding pattern which just poor SENCo you know, is like the face off. And so, parents are constantly at this person's door, going what's happened to this thing that I, you know, I raised, you know, a while ago. And now, knowing what I know as a governor, actually they're, you know, the waiting game and waiting for the cases, you know, for assessments, etcetera to go through.

So, there's something around actually, how do we help schools? And make sure that it's not just one person. That is, is, is that kind of SENCo knowledge, but I think every teacher should be trained in SEND and not just as a bolt on, but actually as part of their core understanding and training of a child and ways with that, just to help relieve the pressure, if that's, that's part of it.

The second one is the feeling that my child's SEND needs aren't as serious as others. I know that resources are tight and actually a child with speech and language delay feels like they're not--gonna be kind of qualified for an EHCP. And so, I know that there are lots of parents with children where you know who are desperate for help with autism to get even assessed and diagnosed. And so actually I feel that I don't have a right as a parent to kind of go and ask for resource.

I'm lucky that we have access to resource. Both you know in terms of getting a private speech therapist support outside of what school or Council can provide. we've got the emotional and brain capacity to do that as well in terms of actually, create space in our lives and I reduce down the number of days that I worked to support Joe.

Now for you know any you know for that that's not the norm and how do we advocate for parents who just don't have that resource? And because when you think about it later on down the line, it's going to be more costly later on down the line if we don't get early intervention sorted for parents.

And so, and Jonathan, you've got your hand up.

Cllr Essex: Firstly, is it a primary school you're talking about?

C. Yes, it's a primary school, yeah.

Cllr Essex: Secondly, your son, have they had a diagnosis? So, what it sounds like you're saying is, is that for children that the EHCP route is not going to give them what they want because it's more severe than the need your child has—that there's still value in having a diagnosis and then having that linked to provision, am I understanding you correctly?

C. Yeah, absolutely. We had a diagnosis early on. So we always knew, through the NHS—before they reached primary, before Joe reached primary school, and then he joined primary school and we were early into school saying, he's been diagnosed and on the NHS and then it transferred to Surrey Council and that's where the wheels kind of became slow turning. The school had some money to bring in, they were

Under-resourced

Not informed who does what

SEN training for all teachers

Later intervention more expensive

<p>waiting for speech and language therapist to come in, and that was very delayed. And this is pre COVID. I think we were waiting for a year or something like that at that stage and then finally we have five sessions, or it might have been six sessions or something and that was the end of that. But then we would be back on the waiting list, and we wanted another six sessions which he needed.</p> <p>And so, and what the school did do was provide some funding to bring in a private speech therapist to help those children most at need. Because at that stage of a loads of children - this is now post-COVID - loads of children with speech and language and delays, and Joe was one of the more serious ones. So, we did get some private support which the school paid for, and then we decided to then continue that ourselves.</p> <p>Now I know that and there are lots of other parents who just can't afford to do that. I think there may be a handful of serious cases at the school are able to pay for or fund the speech therapists, but there are a lot of other parents who can't.</p> <p>C. I guess the other thing is, the language, the process, and I'm reflecting the needs now of parents in the school who would like to get who would like to go down the EHCP, it's complicated. You have to have almost that legal mindset.</p> <p>Even just to kind of get through it and I've got a parent who is, you know, trying, you know, asking me for support—But I'm not the person. They are getting support from the school. But again, with EHCPs, the school—only a certain number you know, every year only a certain number will get through. And this is not the right word for it, but the qualification—what the thresholds look like, so they know which ones they should be putting forward through, and the ones which might not meet that threshold.</p> <p>Cllr Webster: Yeah, yeah.</p> <p>C. If I was to reflect parents in need at the moment, it's just the no man's land of where parents are just needing help, but just can't.</p> <p>Cllr Webster: But are you saying they're befuddled by the language, or they just find it so arcane? Or what is it?</p> <p>C. Yeah, I think if you're a parent who understands the language, understands this is a process we need to get through. In addition, to trying to advocate emotionally for your child as well, and have that all that capacity and you, you know, you're at an advantage already.</p> <p>I'm just thinking of parent that is asking me for help. She's a full time working single mum and has got three kids. One child really does need to, and you know she doesn't quite hasn't got a full assessment for him yet, and it's just very hard, you know, to do the process on your own, yeah.</p> <p>Cllr Webster: Thank you, C. That's lovely. So, A, and your three barriers, if they if you can add or mention ones have been mentioned already, it's up to you.</p> <p>A. I think E mentioned something about the school not having your child's best interest at heart. I really feel like I do not trust the school at this point to look after my son and to make sure he's safe in school.</p>	<p>Timeliness – SLT provision</p> <p>+primary school</p> <p>Process and language complicated</p> <p>make eligibility criteria for EHCP less opaque</p> <p>Unsupported</p>
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It's really horrible position to be in and its horrible position for him because he's now not going into school. I've had lots of communication with the school, many meetings and I just always get confronted by the same thing— 'Well, he has to come to classes'. **There's no flexibility at all** and I just find that really difficult now.

So now he's not going in, and nobody's reached out to me.

I've emailed every day, so he hasn't been in for a couple of weeks. **I've emailed every day. That he's not coming in because he's too anxious and I've had nothing back. So, I just feel I don't trust the school to look after him.**

I just don't think his needs are being met.

Cllr Webster: OK, so that's a big one. Any others that you want to mention that have been mentioned already for instance?

A. I think **how difficult it is to get assessed as to be to get him assessed for ASD. So, he's been on the MindWorks waiting list for probably 2 years.** I know it's probably going to be a couple more years, so we're actually now going down the private route. Umm so that, yeah, it's a frustration now. And **I'm gonna have to pay more money out, which of course I'll do.**

Cllr Webster: Right.

A. And then, I think, also, **a bit of a barrier is getting good sign posting for other support. It should have been easier to find out who I should speak to get better information.**

Cllr Webster: Right. Yeah. OK, excellent. Okay, D, you're there. What about your three?

D. I think a big barrier, a big barrier for me were probably a bit **like what other people have said about signposting. So being given the right route as such, I mean when I talk to families, you know, it seems that everyone's gone down a different route to be diagnosed.**

Everyone's gone down a different route to. And you know everything— basically, everyone's journey is so different and not because their child is different, but **genuinely like we've just been given different information** and I think that the second one is my two.

I feel like the past two years of the school trying to get any EHCP for them and they finally got it this year in January. But I do feel like that whole EHCP route was just traumatic because they were-- I don't know, is it that phrase like 'poking the bear'? I felt like the school would kind of poking my two constantly to make them react so that they could have evidence of something for this EHCP because actually a lot of the behaviours they were displaying, like they don't do that at home, and they don't do that when they're in other people's company.

So why were they being so aggressive? Why were they being so? You know, why were they getting so upset? Why? Why was it such a big thing?

You know all these things? I didn't really quite get it, and even now they've got their EHCP. We're not seeing those behaviours. We haven't

Secondary school not making (enough) adjustments for SEN

Timeliness – Mindworks assessment

Financial impact

Not signposted to support

Not signposted to support

Lack of consistency in giving information

Timeliness – to issue EHCP
Emotional/health impact (both) - Traumatic (EHCP process)
School provoked behaviour to get EHCP

had an exclusion since January, but then the last two years before that, we were having an exclusion like every couple of weeks.

I mean, I had to completely change my job. I had to change everything to accommodate the fact that my two were barely in school than last two years. But that's because they wanted this EHCP, and I suppose it's that whole thing that people have said.

The barrier of needing to be a bit like a lawyer, you kind of have to know what kind of what kind of evidence you need to put in there in order to get the EHCP. And I will see all of that poking the bear worked, but it wasn't very nice time and I think the final barrier would probably be me understanding things and so now that they've got their EHCP, you know me understanding actually what that means now because no one's really gone through with me what the EHCP means—there's loads of stuff in it I don't really understand half of it.

I don't think anything's really changed in the way that the school have been supporting my children and I don't understand.

How do I know if this is the right school for my children? Because actually I've looked at other schools that have, for example, COIN units, and I've thought, oh, wow, they look amazing because that's I think that would have really helped them. But then now that my two are that much older, they're in year three and year five. Is it worth moving them?

I think it's getting that really early intervention because meet me being a mum who I didn't send my children to nursery until they were 3 1/2 because that's when I got the first bit of funding for them. I didn't get any 15 hours before that because we're a household where we have two parents who work, but we're not earning so much that we could afford a nursery. So, we waited and we had to wait until we got that 30 hours funding, so therefore they weren't going anywhere until they were 3 1/2.

So therefore, that early intervention, I feel like wasn't there and no one was seeing them until they were not 3 1/2 and then even at nursery, they just used to say oh well, you know they're three-year-old little boys. They're like with kids, they're just running around. They, so they say, hyperactive. That's fine because there are nursery and having so much fun they'll calm down when they get to school. And they didn't calm down when they go to school. And then it just took that bit longer.

Cllr Webster: I'm intrigued by what you say about you expected someone to actually explain what it meant, the EHCP. Who in the school do you think should take that responsibility?

D. Well, again, like in their school, they've got a SENCo and they've got pastoral teams, they've got—I think it's part the pastoral team and they've got ELSA. There's why we chose the school because they've got Emotional Learning Support Systems as well. My boys see at least once a week for, you know, on the regular.

But again, I don't think any of them really explained much to me. The SENCo is always like, oh, we're going to get this EHCP and it's going to do this and it's going to do that. And then nothing changed, and we got it. And I thought, what does it mean? Because even now I said to her, I've heard from parents, you get like one-to-one support and stuff. She said, you don't get anything like that anymore.

Complicated language in EHCP
No explanation

Lack of action resulting from EHCP

Lack of trust in the system

Timeliness - intervention

No explanation

It's all to do with banding now, and she said the banding that we've got for your boys is not enough. It works out about 20 hours each. Boys from the old banding and she went, it's just not enough. I was okay I did that. You're saying nothing's changed with it, so they didn't have any time. I don't think to actually have those sit-down conversation—

Cllr Webster: Yeah, that that's coming across right. So, finally on this question then F, have you anything else that you'd like to add? Oh, Jonathan, do you want to say something before F comes in?

Cllr Essex: Yeah, I just, I just wanted to ask if the EHCP process in your case was initiated by yourselves or by the school?

D. It was initiated by the school because they felt they needed the help at school.

Cllr Essex: What was your view of it at the time? Did you feel that that was needed?

D. The thing is I don't see at home, but obviously all of the evidence they were giving me as to how they were at school, I thought, well, I'm going to have to do it because they keep getting sent home, they keep getting excluded. They keep getting suspended, they keep going.

I mean, I was heartbroken. They're out at times that they were excluded from school, and once my little ones, the first ever sports day he ever had in his life. And they excluded him from the whole sports day because they said that he was a liability. Basically, they thought he was going to run into the road or something silly, and I was like, I'm going to be there.

F. I think is there's no one seems to give the air of truly understanding, sort of like the needs of autism and certainly PDA profiles, you know, like someone's parents can be confident in the process is it is not easy for parents and it's even worse for new divergent parents.

Cllr Hughes: At the school?

F. You know, just really, really struggle with it.

Cllr Hughes: Do you mean the school F or the people in the County Council Directorate?

F. Both yeah. Yeah, that the whole process is everything. I agree with this, sort of, as I think—I said to you in the first meeting, you know, SEND literacy for all staff, you know.

They don't believe it. And they just think the parents are bonkers and they know better. And it's so infuriating and it's just the, you know, that the lack of types of provision. So even if you do manage to get through all of this and you get to the end and you get to use EHCP and they get, you know, you end up going to a special school which you think is going to be fantastic and it isn't and the amount of children that have slipped through they're now traumatized, they're now EBSNA [Emotionally Based School Non-Attendance] and that there's no way they're going to be able to go back into any kind of sort of school-like infrastructure without a lot of specialist sort of provision to kind of ease them back into. And there isn't that in most of Surrey, let alone in the East. So those are the barriers I'd say at the moment.

Lack of SEND knowledge of autism and PDA (school and LA)

Need SEND knowledge for all staff
Not listened to/dissmissed
Timeliness-delay in support led to crisis

Emotional/health impact (CYP)-
Trauma (EHCP process)
Sufficiency of specialist places

Cllr Webster: Alright, that's very good F. Thank you. So, the second question then is on **what assistance you encountered in accessing support**, so you know we're anxious of, it's obviously to know what works well. So, I don't know. Maybe because E at the top of my screen now. So, tell us, E, what existence has actually worked. So, who came and said look, it should be like this and was helpful obviously don't make it up if no one is there. But who came forward and was helpful?

E. It's quite difficult to answer that. I mean, I'd say in the first when it first became very difficult, I would say the school tried quite hard to be helpful. So, **we had the home school link worker and the Deputy SENCo in the initial stages of year seven. I would say I felt that they were helpful**, but because the level of interventions they were able to offer didn't sort of in inverted commas work because it didn't switch him from sort of 60% attendance to 100. Then it then got passed on to sort of senior leadership. And then the sympathy and the empathy and the understanding of the child in our situation seemed to fall to the floor.

And I think perhaps one of the issues in in all this is that the people in the schools that have the most understanding of neurodivergent children, if you're lucky and there may be an understanding SENCo or an understanding homeschool link worker or something like that or, you know an ELSA or some or a, or a TA, the people that may have more understanding generally have less power.

And so as soon as they they're saying no, we need to give them more flexibility. No, we need to just let him come a bit later because he's doing all these routines and that's what's making him feel safe.

They may be saying that, but then if the senior leadership saying no because we need to meet our targets, no, because that won't look good at an Ofsted. No, because you know it doesn't meet the regulation. Then they get overruled. So all of the work that maybe was done to build trust with us was rather undermined when the same home school link worker that had in theory been supporting us was the one that had to come and say to me we're now going to start marking his absences as unauthorised.

And that kicked off all the inclusion things. So, it felt very I felt that the people I'd put my trust in, I maybe I was. It was misjudged. Or maybe they just didn't have the power to stand by what they were saying.

Cllr Webster: OK, so a nice, a lot of warmth that, that, that that's if you like with respect the junior levels and the people actually interacted with the children, but further up people just had to tick boxes. And that's when you felt, yeah.

E. And I mean with, you know, it's the usual thing you hear people say.

They, you know, they treasure what's measured because it's like—it's they're measured on attendance, and they're measured on results. And so, when you get to senior leadership, I think that's all they can really focus on, cause that's what they're going to be.

Cllr Webster: So, in no particular order, F, something that a piece of assistance that you really valued when you're accessing support.

F. Uh, I suppose it would have been **the parent-to-parent groups. Really. Because you finally found someone who understood where you were coming from, and you weren't crazy.**

Home school link worker and SENCo tried hard to be helpful

Lack of SEND knowledge (school senior leadership)

School focus on grades

Parent groups

Cllr Webster: Parent groups. Right. Okay, both done. So, talking to people at similar issues, you mean?

F. Yeah.

Cllr Webster: Okay. And then and the similar understanding. OK, C. What piece of assistance that you find particularly useful?

C. I think nurse at the school nursery and reception teachers just identifying early other things that might have been we were on to the speech and language, but like motor development and identifying early, we have not identified that and then they were very good at working with the SENCo and accessing early. And actually, looking back, I think what they knew was that it would be easier to do it before a certain age around getting the help before the age of five. I don't know whether that is, you know, parents don't know that and so and yeah, that that was really useful.

Cllr Webster: Excellent. Okay. B, what was the piece of assistance that you got was that was really very, very useful or pieces?

B. Initially the school tried. They really did. They did try when she started not attending and then they got to work where they couldn't. The GP was actually really useful.

Cllr Webster: The GP?

B. CAMHS were not useful at all. As F said, I've had to find out so much information for myself on forums. Basically, on kind of Facebook groups and—just educating myself, the most useful intervention that that we've had has been Learning Space [children and young people's mental health charity] in Redhill.

So, we've had some therapy there and that was a game-changer, but every time we went through CAMHS, we were pushed back to because she's autistic, go to the National Autistic Society.

If yeah, nothing, nothing to do with, you know, waving clinical psychologist reports that in their face saying, you know, how her anxiety has not to do with her autism—

Cllr Webster: Good, right.

B. Oh, it is, it's because she's autistic.

Cllr Webster: Can you explain why the GP was particularly effective?

B. The GP felt like they had time and I would, I would take those with me even at times when she was nonverbal and they would, you know, see that she was well and being looked after and just couldn't access school.

Cllr Webster: Fine.

B. It was actually when we were pushing for a needs assessment, it was the GP's letter that really helped. And again, with, again with attendance, you know, GP tried multiple times to expedite the process with CAMHS and to speed things up and never really got there.

Cllr Webster: The GP's letter?

Nursery helpful-early identification

Unsupported by CAMHS
Reliance on social media forums
Third sector

GP tried unsuccessfully to speed up CAMHS

B. I felt like their time and their letters carried quite a lot of weight with school and with the Council.

Cllr Webster: Right. Excellent. A, a piece of assistance that you valued or pieces.

A. Yeah, the need to leave the school when he transitioned from year 6 to 7 because he was already on the SEN register. They invited him to a summer school and the home school link worker did help us quite a bit to start with. In the first couple of weeks, but then it sort of dropped off a Cliff after that because I don't know why.

Cllr Webster: Why do you think it dropped off a cliff?

A. I think he didn't know how to answer my questions or how to help and so then I went through. I've been through various other people, the SENCo, the head of year and nobody seems to know what to do next. They just say he has to come in and it's unauthorised absence. That's frustrating.

Cllr Webster: Okay. And I think D, finally, what was the piece of assistance that you found useful?

D. Yeah, so I definitely do think that GP helped us too. The teachers at school very supportive, teachers always know the children don't they. So I think the teachers are always very positive, even when we've had teachers who haven't wanted to use like when we've got specialist teaching practice involved, they've said, oh, you know for example, a wobble cushion.

It didn't work with mine. Put it under his feet because the wobble cushion under his feet was much better and we did have a teacher who was like, I'm not using that one cushion in my classroom. He's fine and I think what I will say about school though, even though they're very supportive, I think that I do see that they treat my eldest son very different from my little one.

And I think it's because my eldest wants to be in school. His autism profile is that he likes rules. He wants to stick to the rules. He wants to do his best. He doesn't want people to see that he's upset or anything else, whereas my little one is the opposite scale.

He doesn't like school, wants to do everything, so he can get home, you know? He and I do find. I think they do treat the two of them very differently. So I think that they're hugely supportive for my eldest because his profile is easier for them I suppose, whereas the little one, his behaviour is harder to manage because his profile is he's very emotional and very against school and doesn't have that will to learn like my eldest does.

Cllr Webster: But you see, I suppose the thing that's coming to my mind then is this is ancient thing about, you know, if things becoming a self-fulfilling prophecy. I mean they, they, they, they lose confidence in the child and so they're interested in the child diminishes. And that's such a human thing, rule warned about it all our lives that if you reinforce this stuff, you know, then it can be it can be very bad.

D. I feel I feel like they're very quick to tell me like I've had such an amazing week. And then if they have a really bad day, it's like the worst

Secondary school not making (enough) adjustments for SEN

thing that could have happened, you know, And I'm like, yeah, but you've said you had such a good week, but yet Friday, he's obviously come downhill. They do things like they'll try and reward them and they can be like, amazing Monday to Thursday and then something go wrong on Friday and it's like all of that good work Monday to Thursday meant nothing because they've literally had such a bad day on that one day. Do I mean it's like a really hard, hard one, you know?

Cllr Webster: I like to pick that up with my colleagues later on. So, D, while I've got you on you, you're in the hot seat. So, if you had to, **if you had to summarize what your key areas of concern with regard to the Council were, what would they be? And then what should we Surrey do differently?** So, there's I'm wrapping 2 questions up. So, what are your key areas of concern with Surrey and what could Surrey do differently now? It might be the Surrey should be doing things to be schools, or Surrey should be doing whatever with these SEND officers or whatever it is. So, is that OK?

If you if you try and tackle both those questions, OK, so, key areas of concern with the Council and then what could the Council do differently?

D. I don't feel like I've had a lot of input from the Council, to be honest, and I feel like, as I said before, with the EHCP process, the school very much just did it all. **I didn't really get much involvement.** I think that actually a lot of parents have spoken to about it, especially those who weren't given the EHCP by the Council.

I think a lot of them are very shocked that my children actually got given EHCP because whenever they see me with my children, they don't understand how they got it. That's the kind of influence I get, and because actually they are just different boys at school, I think and.

Surrey County Council's local children's Centre in Cobham, they shut all that down and just before lockdown, I think it was 2018, 2019.

They shut all that down and I think **that was a huge resource that got shut and in Cobham. Now we don't have a lot of places for mums to go anymore, so I think that the Council shutting that down for the Under 5 particular is—it's hard** and I think the nurseries are now completely overrun with children because there aren't those local, those local playgroups, those local and I think a lot of mums now.

Well, in this area, I think people do just scrimp and they they'll pay for a nursery. But actually, I think if they still had the local playgroups, the local program walks all the things that we did at the children centre, then I think a lot of mums, we would have kept their kids at home a bit more.

But I think mums worry and they think well, parents worry, and they think we must send them to nursery because they need that social. You know, I can't give them that at home. And actually, because there's nothing to take them to, it's I think that that was a huge thing.

Cllr Webster: So, alright, so us removing a source of early help and support affected you. If you know what you're saying is maybe, sorry, we should revisit this issue.

The whole issue of early support is that have I summarized that as your main concern?

D. Yes.

Not involved in process

Loss of early help resource

<p>Cllr Webster: That's lovely. Nicely put. So, A, what about you? So, what are your peers are concerned with regard to the Council and what could the Council do differently?</p> <p>A. Honestly, I haven't had much to do with the Council. I've really been dealing with the school up to this point. I hadn't actually thought about reaching out to Surrey County Council. So again, maybe that's a signposting issue knowing actually who to speak to. What is Surrey County Council's remit would be helpful.</p> <p>Cllr Webster: So maybe if it was clearer to you that there were areas of support within the Council, okay, Alright.</p> <p>A. Yes, to know that there are people to reach out to.</p> <p>Cllr Webster: Let's go to F. So, your area of care is of concern and then what could the Council or should the Council be doing differently, F?</p> <p>F. It's lack of Services, lack of targeted services and they need to be working together with parent groups. Charities to fill these missing services and I know that at the moment they have partnered with NAS Surrey branch, but again, as far as I know it's another round of parent training which is good for those who are new but not so good for those of us who have been in the system, ran around for quite a while.</p> <p>To co-produce things like mental health services that are autistic, relevant respite services that are PDA relevant, uh school provision, that is PDA relevant exactly, etcetera. It's filling these services and just get them, just get them up and running.</p> <p>Cllr Webster: OK, well done. Uh, C. So, your queries are concerned with the Council specifically, and what should the Council be doing differently?</p> <p>C. Yeah, so wait times which are hampering early intervention, probably my key area of concern. Specifically, I guess it's the number of educational psychologists, clinical psychologists, speech and language therapists available and to enable that?</p> <p>I do agree with the point made earlier around the transparency on what the remit of the Council is and how it works with schools. I don't really see the Council as I know that, so there's somewhere in the background of part of the process, but the SENCo is very much the voice of Council and school and there is something that F was talking about earlier around. And how do you get in one place for both parents and the school of what's available in terms of the services?</p> <p>I know while ago we had Barnardo's in the school helping, you know, with some place places that helped children who were really in need. Now that service has been pulled and they are not doing that anymore. So, I think there is some you hear about things through the grapevine, which are the schools have had access to or other parents outside of your school haven't had access to. And you think there should be somewhere centrally?</p> <p>Cllr Webster: And E, the two questions, So, what should the yeah key areas and concern and what should the Council do differently?</p>	<p>Not knowing SCC's remit or how to access help</p> <p>Need for co-production</p> <p>Timeliness of assessments Early intervention hampered Under-resourced</p> <p>Want transparency on Council's remit</p> <p>Want centralised directory of help available</p> <p>Pressure from Inclusion service Not involved in process</p>
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E. So key areas of concern I've got to say, obviously the **inclusion service** and the **lack of collaboration on the EHCP process**. One thing that hasn't been mentioned, but I think is really important is the level of Admin on parents. When children begin to struggle, the admin is absolutely vast, and it could be a full-time job. Just processing the forms and it takes you away from what you should be focusing on, which is your child and **their parents can become very, very isolated** and a lot of money is spent by the Council on gatekeepers.

And **I just wonder if some of that money could be diverted to just some support straight away** in terms of what Surrey do differently—

Cllr Hughes: Sorry, could you just pause—the gatekeepers? That's the effect that sort of series of officials you have to engage with to go through these to see the process?

E. Yes, as soon as my son started to struggle, we were having assessments for, you know, forms for early help, but which then I went through a process and was declined because we weren't considered needy enough.

Then you fill in loads of forms for CAMHS and then you're told that they can't support you because they haven't got enough whatever money, or that he's not suicidal enough.

And then you fill in a form for steps and then you fill in a sense reform and then you fill in all the forms for the autism type diagnosis and all the—they're just, I mean, **I can't describe to you the amount of paperwork.**

Cllr Hughes: My daughter has described it so I know.

E. See, you know from the inside. Then yeah, you know from the inside, and I just want and then there's all these people that will assess you and tell, you know, you can't have any support. And I would just wonder if their salaries could be diverted to some alternative provision, it just cut out all that process because it feels like there's so much process and probably a lot of money being spent on it.

So in in terms of what maybe could be offered done differently, I think if **as soon as the child starts to struggle, maybe some flexibility in alternative provision offered straight away.**

So, my son now goes to the therapy garden once a week and that's been really brilliant. But it took us ages to get him settled, and if that had months of me going with him every week, sitting in the garden, and then then sitting nearby, then sitting in the car outside and then now he goes in happily. But that wouldn't have happened **if it had been offered straight away, he wouldn't have reached crisis.**

I think if things **if alternative provision could be offered on the basis of parents or teachers saying I need a bit of help here rather than waiting 'til the child is in total crisis** and I think someone else may have said this as well. If there was somewhere as a family, you could go. If your child's now unable to go to school, which was maybe a hub of resources that had maybe people that could, maybe some low demand gentle activities for the kids, maybe some drawing or some gardening or something, you know it would be a tick box for safeguarding. They'd get to see people and it would be low demand and **parents wouldn't be isolated because I didn't find all the support groups straight away. So when it first**

Time parents need to fill in forms

Feeling isolated
Council perceived to be 'gatekeepers'
Should offer support before assessment

Under-resourced
(CAMHS helping only the most serious cases)

Timeliness (Delayed support led to crisis)

Not signposted to support

happened, you know, we were just all on our own. Sorry, I've talked a lot, but—

Cllr Hughes: No, no, no. That's lovely. Jonathan, did you want to say something just then or not you?

Cllr Essex: So, when you were talking, E, what it made me think of is when you give money to Oxfam, how much money goes out to Africa and how much gets spent on the way.

And then I was thinking, OK, well, Surrey County Council., how much money does the highways department spend actually resurfacing roads and filling potholes, rather than the process of getting there? And then okay, well, how does that compare to children's services, and you know how much money gets spent on the children versus spent intervening to decide what needs to be done by whom and where?

I don't know if there are stats out there in terms of how that compares the different councils across the country because we could be spending the same amount as another Council) but not actually spending the money giving the outcomes.

But then the other way would be to look at would be a timeline. So where were we 20 years ago? Where will be 10 years ago? Where are we now and in the children's department of the Council?

How much money did we have and how many people did we have for different job titles? I don't know if that work has been done by anyone, but it what you said really did make me wonder, let's say.

Cllr Webster: Well, it deserves to be done, Jonathan. No, no, no, you're right. Because—for people who don't know, I was a social worker in Surrey and I always felt that for every 5 minutes spent with the child, I spent 55 minutes writing about them, talking about them and all the rest of it.

I've said I have some innate sympathy with what's here, so last but not least, there's asked for B about her for her key areas of concern, B, and what might the Council do better?

B. Yeah, I could probably write a book on this. I've been appalled, honestly, by the dealings with the council. I have tried and I pulled every lever possible. I've found out by going through the back channels who all the names of the heads of departments are and directors and everything. The only person who's ever replied to me has just been the case officer.

When the stage two complaint was upheld, I part of it was that Surrey had to keep me updated every three weeks and without fail they have not kept me updated every three weeks and I've had to go back to them, go back to the complaint every three weeks and say can I have an update?

They have not answered my questions that, you know, for example, now I have no idea what's happening with my daughter's education. She's got an EHCP issued, but no school named. So, who's going to provide the provision on it?

And you know, you speak to them, and they say, oh, that's a good question. I'll ask my manager. I'll get back to you tomorrow. And then you

Not getting reply

No updates

Poor quality EHCP-No school named on Plan

Promise to get back to you and don't

Passed around staff

wait another three months and nobody you cannot get hold of a person and you know you get hold of the department heads, you email them, it bounces back saying this person's on long term sick leave or this person no longer works for the Council and you bounce around. And I've pulled all my strings in education to get people to, you know, you don't know with your emails were being read because nobody answers it. And I think what's most frustrating is that, you know, there's, you know, talking E is talking about the paperwork.

Time to do paperwork

No answers given

I mean this, this is just my one file from last year. That's literally a full-time job and, you know, hours and hours and hours and hours of my life. But you can't get a straight answer from anyone. You can't get any answers. You can't just pick up the phone and say what? I've done everything myself. I did the EHCP, I've done all the appeals. I've done everything we got to the point where I physically can't do anymore. We've had to go to barrister. Sorry, Robert's got a hand up.

Cllr Hughes: I just want you to go back to when you were promised there would be an update every three weeks. Who promised that? Was that in the court or what?

Financial impact

B. That was from that was from BeHeard. You make the complaint to Surrey, and the email comes from BeHeard and there were many other things that I meant to do so when it when it's all finalised we will be then looking at getting some compensation from them because we've spent tens of thousands of pounds.

Cllr Hughes: I imagine. Thank you.

Fight/battle

B. You know, we're obviously I, I get the impression like a few other people on the call, we're in a privileged position that we've been able to fight. And you know, my husband had to stop work so that he could look after at home.

Answer communications
Not child-centric

We've had literally no provision from the state. So, in terms of what can be done better, I mean literally just answer emails or pick up the phone or just communicate because I think what's most upsetting in all of this is—you get a bit of paper with a one-line response on it, which is mostly saying no, but there's a child at the centre of it.

Emotional/health impact (both)
Suicidal ideation

You know, there's a child who's not just a diagnosis and not just an EHCP. And you know the impact is immeasurable on my family and my child, the impact and that no amount of compensation can ever get back that time when that sheer, bloody stress, my daughter's been driven to suicidal ideation. And you pick up the phone to CAMHS my 9-year-old, they say, literally, hide all the knives and if she hurts herself, take her to hospital. I mean, it's like living in, you know, this is the UK in 2024 and we've had no help.

I've set up my own, not for profit now to help other people in this situation because it's driven me to absolute madness.

D. I just wanted to quickly ask with the case officers for Surrey. So, when my two got their EHCP, as I said in January, they both had two different case officers and then I've tried to email them, but obviously don't hear anything. I was told via another mum that actually the case officer at the moment she lives down in Devon, apparently so you won't actually get her to come around here. I don't know how that works at the case. I'm confused.

Not informed who does what

Cllr Webster: Yeah, D, they're a case officers to my interests are not professionally qualified people. They have 177 cases and they're their role is administrative and to bring things together. But there's a management this management above them and this management above them and so on. It does seem to me that that you know, just talking from my point of view before I come to back to Jonathan is that I think there may be ought to be streams here that some cases are straightforward, but some of the cases that we've been told about by your good selves are not straightforward. And I'm kind of surprised that, you know, even on a human level that's not picked up and dealt with.

That that worries me because as a as a social worker, you see we, you know, it was very clear, you know, your caseload, you know, went along in a in a smooth way. But you knew that there was maybe 10 or 15% of your caseload you had to pay special attention to.

Statement from G:

Sadly I must give my apologies for this evening's focus group as I feel attending and discussing my situation will be detrimental to my mental health. My mental health has suffered significantly since **my fight for support** for my daughter started 5 years ago when she was transitioning to secondary school, with high anxiety and suspected ASD.

Perhaps this is a good time to emphasise the effect this has on parents, siblings and family members. I am a shell of my former self and struggle daily to deal with my role as a full-time carer and suffer from depression and anxiety, the latter of which is caused by my anxiety over how my daughter will cope or manage with each day.

To cut a long story short my daughter was diagnosed privately with ASD. age 12. when emotionally based school avoidance (EBSA) started in year 8. **Had I have not paid for a diagnosis my daughter, currently 15, would have only just been diagnosed through the NHS. My daughter's ASD presented as anxiety for many years and this was not taken seriously by either primary school or secondary.** She is an academic girl, who showed impeccable behaviour at school. She was quiet, polite and did her work, however this was my daughter masking, and at secondary school she could mask no longer, she crumbed and her anxiety took over in the form of panic attacks and EBSA. My daughter had no diagnosis, no EHCP, no difficulties with her attainment levels, **no difficult behaviour and therefore both myself and my daughter were not listened to or her anxiety taken seriously.** I had to apply for an EHCP as a parent, she was assessed and an EHCP refused even though she was unable to access her education at her secondary school. She had told the Educational Phycologist that she felt 'traumatised to come into the building' and that she felt unsafe in school because of all the people and feels panic when in school. All this was ignored by the LA and an EHCP was refused. I appealed, during which time, **the school and all professionals involved said mainstream can no longer meet need. This evidence was ignored and although an EHCP was given the LA continued to insist Sophie could cope in mainstream and named her secondary school, which she had not attended for a year, on her EHCP.**

This devastated both myself and my daughter, as we had found a small independent nurturing school which was suitable and had a placement available for Sophie. This moment is when **our lives fell apart. Going through an appeal was exhausting and time consuming. My mental health had now been seriously affected and my daughter was distraught.** It took a further year of a second appeal which went to tribunal to get my daughter Specialist provision, by which time **she had been out of school**

Fight/battle
Unsupported

Timeliness – diagnosis

Secondary school not making (enough) adjustments for SEN

Not listened to/dismised

EHCP refused
Trauma (school environment)

Poor quality EHCP- names secondary school that says it can't meet need

Emotional/health impact (P/C)
Emotional/health impact (CYP)
CME
Timeliness (Length of appeal process)

<p>for 2 years, and become isolated and too anxious to go out for leisure as well.</p> <p>Most specialist schools were unable to take her due to EBSA and severe anxiety, and it became apparent that there was nowhere for my daughter to go. All she wanted was a small school with people like her. There are very few specialist schools suitable for well-behaved but anxious, academic Autistic girls. The local authority did nothing to support us finding a school and I found a small mental health recovery school that would take my daughter. Sadly, as she started at the school and couldn't cope it became apparent my daughter was suffering from trauma, 3 months later she was diagnosed by CAMHS with PTSD/Complex Trauma around school and school experiences. She continued to suffer from EBSA and remained out of school. It was only in December last year 2023 that the panel agreed EOTAS. She now attends a therapy farm twice a week.</p> <p>My daughter is in year 11 and should be taking her GCSEs within the next few months and leaving school. This cannot happen and she remains out of formal education, which we hope at some point she will be able to return to.</p> <p>My main drive for doing this focus group is to highlight the difficulties faced by girls with Autism, particularly those who are academic. My daughter was in the top English group and studying both Latin and mandarin before she crashed. The education system has failed her. The education system has failed me. My daughter is an intelligent beautiful soul, who is about to turn 16, has severe anxiety, PTSD, ASD, depression, and is isolated from her peers and struggles to participate in life. She will require a lot of support for many years to come as she moves into adulthood. I hope my story can help to address the difficulties faced by Autistic Girls and their parents. We just want to be listened to and anxiety taken seriously.</p>	<p>Delay in support led to crisis Sufficiency of specialist places (for autistic girls)</p> <p>Trauma (school environment)</p> <p>Not listened to/dismisssed Lack of SEND knowledge – teachers (of autism in girls)</p>
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