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**OXFORDSHIRE PARENT CARERS FORUM
REPORT ON CHILDREN WITH SEND WHO
ARE NOT CURRENTLY ACCESSING
EDUCATION IN OXFORDSHIRE 2022**

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Introduction and Background

Every child of compulsory school age has a right enshrined and protected in law to an education. Local authorities have an absolute duty to provide this. The only exception to a local authority's duty to provide an education to every child is if the child's parent or legal guardian formally chooses to make alternative arrangements, and educates the child outside of the traditional school system.

We will explore the legal obligations of the local authority to provide education to children, and the specifics of providing that education when it includes Special Educational Provision (SEP) to children who have Special Educational Needs (SEN).

We also explore the difficulties and common themes that Parent Carers, children with SEND (Special Educational Need and/or Disability) and their families are experiencing at the current time in Oxfordshire, and the real-life impact on their well-being when these duties are not adequately fulfilled.

Oxfordshire Parent Carers Forum engages with families of children with SEND daily. We are committed to ensuring that the voices of parent carers in Oxfordshire are heard. Where we become aware of common themes amongst parent carers, we collate information and share it with the local authority.

It has become apparent over recent months that a growing number of parent carers are experiencing various issues and great difficulty with their child accessing their education. As a result we have gathered their experiences, run a short survey, and produced this report.

The Legal Obligations

It is assumed that all children of compulsory school age will be educated in accordance with the law, and generally in an education setting (such as a school) except for such cases where a parent or legal guardian has chosen to make alternative arrangements and electively opted out of the traditional school system. Still, the parent or legal guardian is required to ensure that the child is educated. A key word here is 'electively.' The definition of electively in this context is 'by choice' and it is an important point to consider when discussing children who are not being educated in a school. A child who is not attending school because they are unable to do so as a result of their Special Educational Needs, but whose parents wish is that they be able to attend with their needs appropriately met, should not be considered as electively home educated.

For children with Special Educational Needs (SEN) and/or Disabilities there are additional duties which the local authority must meet.

The definition of SEN is contained within section 20 of the Children and Families Act 2014, which states: *"A child or young person has special educational needs if he or she has a learning difficulty or a disability which calls for special educational provision to be made for him or her."*

The definition of SEN has two parts to it. Firstly, the child must have either a learning difficulty or a disability. Secondly, that learning difficulty or disability must require SEP to be made for the child.

SEP is defined in section 21 (1) of the Children and Families Act 2014: *"Special educational provision", for a child aged two or more or a young person, means educational or training provision that is additional to, or different from, that made generally for others of the same age in (a) mainstream schools in England, (b) maintained nursery schools in England, (c) mainstream post-16 institutions in England, or (d) places in England at which relevant early years education is provided".* The key wording here is 'additional to, or different from.' If a child or young person requires educational or training provision that is additional to or different from their same-age peers, on a national (not local) standard, then it is SEP. The legal definition of a 'young person' is an individual who is over compulsory school age, but under 25.

Children who have SEN who do not have an Education, Health, and Care Plan but who are on a school's 'SEN Register,' (which is sometimes referred to by different names internally) are owed a statutory duty by the governing body of that school to use its 'best endeavours' to secure the Special Educational Provision (SEP) that they need. This is set out in section 66 (2) of the Children and Families Act 2014: *"If a registered pupil or a student at a school or other institution has special educational needs, the appropriate authority must, in exercising its functions in relation to the school or other institution, use its best endeavours to secure that the special educational provision called for by the pupil's or student's special educational needs is made."*

This duty is not absolute. Regard needs to, and in practice will be, given to any resource constraints that the school may be under.

Children who have SEN and an EHC Plan, in contrast, are owed an absolute duty by the local authority to provide the SEP specified. This duty is set out in section 42 (2) of the Children and Families Act 2014: *"The local authority must secure the special educational provision for the child or young person"*. Any resource constraints at the named school are irrelevant once SEP has been identified and specified in the EHC plan. The provision must be funded by the local authority via 'top up' (known as element 3) funding. This is provided in addition to the Age Weighted Pupil Funding that schools receive for all children, and the Additional Support Funding (known as element 2 funding) that schools receive for children on their SEN 'Register'.

This duty has no 'best endeavours' clause that can be utilised to justify a failure to secure the provision that has been specified.

When naming a setting or school on Section I of an EHC Plan, the local authority is required, where possible, to ensure that the child is educated in accordance with the wishes of their parents. They are also required to support the child to achieve the best possible education and other outcomes. These requirements are made clear in section 19 of the Children and Families Act 2014: *"In exercising a function under this Part in the case of a child or young person, a local authority in England must have regard to the following matters in particular—*

- (a) the views, wishes and feelings of the child and his or her parent, or the young person;*
- b) the importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned;*
- (c) the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions;*
- (d) the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.*

Schools may formally object to admitting a child under an EHC Plan (and so, being named in Section I) if they feel that they cannot meet the SEP set out in Section F of the 'draft' Plan, even with the additional funding. They may do so for new children attempting to access the school for the first time, or for pupils who are already enrolled. There are limited reasons why these objections may be successful. The school is required to evidence to the local authority, who must agree as the burden of proof is on them if they are to refuse to name the requested school in Section I, that:

(a) the school or other institution requested is unsuitable for the age, ability, aptitude or special educational needs of the child or young person concerned, or

(b) the attendance of the child or young person at the requested school or other institution would be incompatible with—

(i) the provision of efficient education for others, or

(ii) the efficient use of resources.

This can be found at section 39 (4) of the Children and Families Act 2014.

Once a school has been named in Section I of an EHC Plan, they are required to admit the child under the 'duty to admit,' set out in section 43 (2) of the Children and Families Act 2014: *"The governing body, proprietor or principal of the school or other institution must admit the child or young person for whom the plan is maintained."* It should be noted that there is no allowance for mainstream schools to refuse to admit a child on the basis that they are simply 'full' nor are schools able to apply their own blanket policies to prevent admittance such as 'we cannot meet the needs of any child who needs 1:1 support,' for example.

In admitting the child, the school (via the funding provided by local authority for this purpose) must provide the SEP that is set out in Section F on the EHC Plan. The local authority is ultimately responsible for ensuring that they do so.

It is important to also consider what the legal obligations are on the local authority when a child is not able to attend school. The reasons for a child not attending school are wide ranging and varied. They include but importantly are not limited to: exclusion, illness (mental or physical) and detention.

On this point there is no ambiguity in law. Where a child is unable to attend school, the local authority is still required to provide that child with an education. Section 19 (1) of the Education Act 1996 sets this out explicitly: *"Each local authority shall make arrangements for the provision of suitable education at school or otherwise than at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them."*

In the next section we will look at real-life experiences of children with SEN and their families in Oxfordshire, and the impact on these families when these clear legal obligations are not fulfilled. All experiences were gathered in September 2022.

Family 1

"My primary aged child has a diagnosis of autism, dyspraxia, sensory processing difficulties and PDA. It took fourteen months to obtain an EHCP. This included an appeal for 'refusal to assess' but the local authority (Oxfordshire County Council) conceded before the hearing.

I have a further Tribunal appeal booked for February 2023 for EHCP Sections B, F & I. In its current state the EHCP is not fit for purpose. I have gone through two rounds of complaints with the local authority. The process was lengthy and none of my concerns were addressed.

I have an LGSCO [*Local Government Social Care Ombudsman*] complaint case dealing with their failure to provide alternative provision, delays in dealing with my complaints as well as the delays in completing the EHC needs assessment. I have the draft report, which finds the local authority at fault on all counts. The LGSCO have informed me they will be making this report public once it is finalised so further details can be shared then.

In the LGSCO evidence from the local authority, the lies were shocking as was the complete lack of evidence. The complaints, reports etc have not been recorded. It is very concerning that despite over a year of submitting evidence, letters etc; there are no trace of them on their system.

The school and the local authority have not supported me or my child, despite me doing all I can and making both parties fully aware of the law. I have been constantly dismissed and/or ignored.

My child has been unable to attend school for over a year due to deteriorating mental health arising from the trauma that he suffered in a mainstream school that did not meet his needs. School have now finally admitted they cannot meet need. He has remained on roll despite the school's best efforts to try and get me to deregister him. I have refused, as this is an easy get out clause for them and leaves me with less legal standing.

The local authority stated that as a mainstream school is named on the EHCP they do not provide alternative provision. When challenged on this inaccuracy I have again been ignored, by the SEN case worker right up to the Director of Children Services.

I have been extremely determined and have told the school to instruct an alternative provision using the EHCP funding or I will seek legal advice. They have now done this and, as of today, we have had one session. The plan until October half term is to have two sessions of three hours each week (six hours per week). Whilst this is a start, it does not equate to a full-time education. I now have the battle of securing funding after half term so that my child is not left with nothing again.

I have evidence from an NHS professional that my child's mental health difficulties result from school trauma and that having no provision in place at all for such a lengthy period has had a further detrimental impact. The impact on us has been immeasurable. It has negatively affected us every single day and I am fortunate that the more abhorrently the LA act, the more it fuels me to fight harder."

Family 2

"I have a 5-year-old son who attends primary school. He is currently on a reduced timetable due to just starting back at school. We have had 2 early EHCP Annual Reviews as school have said they cannot meet his needs. The last Annual Review was in March and we are yet to receive anything back from Oxfordshire County Council. Myself and my partner have requested [*child's name anonymised*] go to a special needs school due to his high needs and we have heard nothing.

We have emailed and called the local authority. School have as well, and I've contacted SENDIASS. Nobody has had any luck. *[child's name anonymised]* is now having to do another year in a mainstream school that he isn't coping with at all. We are at our wits end. We are holding another Annual Review in two weeks but I won't hold my breath for anything to happen there either. He needs to be in an environment that will help him thrive. Currently school is just a glorified babysitter for him. He is not learning anything."

Family 3:

"I have an 11-year-old who should have been going into a Year 7 specialist school. Unfortunately, he is still being forced to attend the local mainstream school. We have a Tribunal date for January 2023. Until then we are waiting for Panel to approve an EOTAS *[Education Other Than At School]* package which will be funded by the local school where he is on roll. The local mainstream school have agreed that they cannot meet my son's needs and the local authority has encouraged them to do so.

We rewrote my son's EHCP with the help of SENDIASS and it was submitted to 3 specialist schools in Oxfordshire. Two have said yes, however, they are full.

So currently my son is at home with me, with no education in place. I never expected to be in this situation. Words cannot describe how I feel for myself and our son"

Family 4:

"My son got an EHCP during lockdown, which was applied for by his nursery. He stayed on there during Reception, but he did not attend February-September because he wasn't coping. Then lockdown happened and during that time the EHCP was finalised. He started in Year 1 with the EHCP in place. He was diagnosed as autistic at age 4, with ADHD at age 5 and with a PDA profile at age 6. The paediatrician said it was the most severe case of ADHD he'd ever seen.

His mainstream primary initially were great with very gradual transition, he had a lovely 1:1 teaching assistant and a desk in his own space. But that wasn't enough to meet his needs, and he started self-harming at home and school refusing in week one. He managed just one week of full time attendance in the November, that was it. The problem was the school did not understand masking, and so dismissed the reports from home regarding how extreme his behaviour was on the basis that he was "coping" for the two hours that he was in school.

We withdrew him in May 2021 on advice from an autism consultant. At that point he was severely self-harming, had attempted suicide twice (age 6) and had injured his 8 month old brother. He had realised if he killed him, he'd not go to school anymore. He was waking screaming with nightmares and having visual disturbances. We took him to A&E in the May half term before school restarted to say he needed to be taken into secure care as we were covered in bruises and the baby was basically living with the neighbour at that point.

He did not go back to school after that.

The Headteacher marked his absence as unauthorised and told me that my son was manipulating me to avoid school. They then made a MASH *[Multi-Agency Safeguarding Hub]* referral against my husband. Early Help were sent to see us. The Early Help worker came with a plan to get my son back to school. Within ten minutes said she was not going to do that, and would request a disability social worker assessment. This request was turned down twice because my son is "just" autistic. The disability social workers would not assess him.

We had an Annual Review and the school said that they could meet need, so we appealed. At Tribunal six months later, my son was awarded a full EOTAS package. The Judge explicitly said the Headteacher (who was present having been called as a witness for local authority) did not understand his needs.

Between May and January, my son received no education. Following a legal letter from us, he got a tutor for two hours a week at home and three hours a week elsewhere.

Instead of implementing the EOTAS package, Oxfordshire County Council appealed it. They did not inform us; they just never replied to my emails asking when provision would be arranged. The EHCP was finalised in January and we got my son's Personal Budget in May. The local authority still has not implemented the EOTAS package properly nine months later. Key parts of the provision (like a trained teacher to manage the plan and train the tutors) is lacking. He is aged 7 now. He got his EHCP initially in 2020 and has never had his needs met.

The impact on our family has been devastating. My husband had to give up work. He was previously earning a good salary, and commuting to London every day. We now survive on Universal Credit. His mental health has been hugely impacted. I have been near breaking point for six months. My 1-year-old does not get the attention he should, as our whole life is dominated by my elder son's needs.

We had an Annual Review in June and received a letter from the local authority saying his amended plan would be with us by 26 August. We've still not got it. We have had no explanation as to why it's been delayed. We go weeks without any response to urgent emails that any functional service would reply to AND action within forty-eight hours. In response to me highlighting their failings, one SEN officer told outright lies saying they had previously offered provision that I had turned down and that they were waiting for me to send them information. I had sent the information several times."

Family 5:

"We started to see difficulties with our daughter in Year 2 (in 2016) where she started to get anxious going to school. She was not wanting to go to school and having meltdowns as soon as she was at the school gates. CAMHS [*Child and Adolescent Mental Health Service*] got involved. Me and my husband did a six-week anxiety course for parents. The CAMHS worker went to observe her at school. I thought afterwards that she asked me some quite strange questions such as asking me why my daughter took her shoes off in the classroom. This led me to research, and a discovery about my daughter. I had never suspected she was autistic before, but a friend sent me an article about girls getting missed due to mimicking social situations and masking. I recognised a lot of the signs, so asked I CAMHS to put her on the waitlist for assessment.

During this time, the school constantly told me 'She's fine' and treated me like an over-anxious and 'helicopter' parent. One teacher told me that if my daughter was 'happier she would make friends more easily.' I was put on a parenting course through the school.

In Year 5 my daughter had a very 'shouty' teacher, and the school refusal escalated. She got an ASD diagnosis in December 2019 and finally the school took me seriously and started making some adjustments. My daughter never wanted to be seen as 'different' and the changes led to total school refusal in February 2020, a month before everything shut down due to COVID. She was very anxious and withdrawn but that time at home helped her. She was always engaged in her school work. I applied for an EHCP at that time but it was refused. Due to covid, SENDIASS advised me to reapply later.

Her attendance in Year 6 was 85%. She used to miss Mondays in order to cope with the rest of the week and she used to miss swimming on a Tuesday morning. When I spoke to the SENCO at the new

secondary school, they said they wanted her to try and attend full time. They did not want her to start on a reduced timetable.

She started at secondary school. Her attendance to begin with was good and she had a very understanding tutor. Quite quickly I could see the wheels coming off. Again, whenever I brought this up with the SENCO I was told 'she is fine' and 'she is excelling.' The school did make some adjustments; allowing her not to attend PE, passes to go to a different area when she wanted, passes to use a specific toilet etc.

It was getting increasingly difficult to get her to school on time and she was becoming very withdrawn and aggressive at home. We had a hideous week where she was having to attend just one hour a day, when she sat alone and read a book. At the end of that week as a family we were all exhausted, mentally, and physically. She wasn't sleeping. It was taking hours to get her ready and out of the house. I told the school I would not be trying to get her in anymore as it was badly impacting the whole family.

From then we have had disastrous interactions with the school including a meeting where staff came to our home and told me I was a bad parent, letting my anxieties affect my daughter. I asked them to leave. My daughter and I were both traumatised by that meeting. We later found out that none of her teachers were even made aware of her diagnosis on the basis that they don't like to create 'prejudice' and want the children to settle in on the same level as everyone else. I was shocked and upset that my daughter had been subjected to a 'sink or swim' situation.

I was very worried about my daughter's mental health. She couldn't get out of bed. She was depressed and stuck in very negative thought cycles. She has developed Obsessive Compulsive Disorder with excessive hand washing, washing her hair repeatedly, her whole body twice daily. She needed adult involvement with this. She had difficulties sleeping. She would only wear three or four different outfits on a cycle and needed those cleaned daily.

My daughter will not engage with any professionals; CAMHS, Psychologists, Occupational Therapists. She has no trust in adults or health care professionals. This makes it very difficult to get any help or support as a family.

We have self-funded a tutor to come and be with her while I am at work using her Disability Living Allowance. She just played games with [child's name anonymised] for the first month, to gain her trust. We are now at the stage where she can do some work with [child's name anonymised] and their relationship is very strong. The school do reluctantly and sporadically send work for her to complete. The feedback received from them is not great or consistent.

I have applied for an EHCP myself, which the school have been supportive of. The school arranged an Education Psychologist meeting when the EHCP was initially refused. This helped with getting the local authority to agree to an assessment. We are in the process of that assessment currently. The deadline for the local authority to obtain the evidence for the assessment was the 11th September, and we are yet to be contacted by anyone.

I have been in contact with the attendance officers at the local authority to explain that my daughter has been without sufficient education from the school. Each time I was told that they will 'look into it' but I receive no further response. The school have done an early help assessment for us and we are due to have our first TAF [*Team Around the Family*] meeting soon.

As a family it has been extremely stressful. I lost my job during COVID and due to my daughter's difficulties, it has been very difficult for me to go back into full time employment. I get Carers Allowance.

I have struggled with my own mental health. I have had to access support from MIND charity and I also did a course with Silvercloud during lockdown.

It is very intense being with my daughter 24/7. I get very little respite. I find the stress extremely challenging. The whole process of applying for the EHCP and the assessment is overwhelming and anxiety inducing. My other daughter is neurotypical but has started experiencing anxiety too, I am sure, due to her sister telling her what she is anxious about. She is picking up learned behaviour from how her sister deals with situations. She finds it very difficult to be in a room by herself now. She also has had to take on some caring responsibilities for her sister."

Family 6

"My son is aged 10 and was diagnosed with ASD, Dyspraxia and Sensory Processing Disorder when he was 5 years old. He coped in a mainstream school, albeit with adaptations (like not attending assemblies, a quiet space, sensory toys, etc) until lockdown. He did not have an EHCP at this point.

After the lockdowns he had forgotten his coping strategies. It was incredibly difficult for him to go back into the school grounds. It took from July 2020 until approximately November 2020 to be able to get him into the school and working at a table outside the classroom for a few hours each day. I needed to accompany him so he could cope. Without me he would get very anxious, shout almost continually, hit himself, scratch his face and run to hide in a bush. He would roar or shout at anyone that came near him.

There was another lockdown and that was the end of him being able to enter the building, even with me. He started on a part-time timetable as we thought the predictability and structure may help and I left him for short periods. He would get so distressed that he would walk around the grounds of the school for hours. He knew how long it was until break times (when he would hide behind a tree and growl at anyone who came close) by the position of the sun in the sky. It was heart-breaking how isolated he must have felt but if any staff came near, he would growl or shout and it would make the situation worse. By May/June I would hear him from outside the school, shouting and wailing. I could see him wearing his hat, sunglasses, balaclava and puffer jacket to hide due to his extreme social anxiety. He was wailing and frothing at the mouth. The teacher and I both said "Enough."

From that day I accompanied him again. We kept going in when he had the energy (approximately three days a week) as we understood that we needed to collate "evidence" to send to the local authority to be able to get him a place at a special school. However, both school and I were not prepared to put him through any more, so when he had had enough each day we left. My son never refused to go and even when I suggested we leave he would often ask if it was the best thing to do. By the end of June, a successful day for him was going in after everyone else had gone, running to a bush, hiding there until the TA had gone too and then quickly exiting through the office. He would then have a meltdown, and have to build up to doing it all again the following day.

The school was fantastic although they were at a bit of a loss as to what else to do, as was I. They listened to me, communicated and really had his best interests at heart. They applied for an EHCP in October 2020 which was finalised in March 2021. It confirmed 30 hours extra funding in a mainstream school. Although this was a lot of funding in hours, it missed the point; that my son was unable to enter the school building or interact with a single member of staff. The EHCP could have confirmed 100 hours funding in a mainstream school and it would not have worked. It was essentially all 'help' he was utterly unable to access. It felt ridiculous to sign off this document that was at best; useless, and at worst; going to make the situation far worse if enforced. Any intervention in that environment made him run, hide, and hurt himself.

The school confirmed they were unable to meet his needs. We agreed and we waited for the CAP [Countywide Admissions Panel] meeting where we understood his case would be reviewed. We were hopeful that he would be offered a place at a specialist school, or at least the promise of one. He needed this to know help was coming. He couldn't cope with the unpredictability of his situation. We were told later that as no specialist school had been agreed on the EHCP that his case in fact wouldn't go to the CAP. Instead, his EHCP was sent directly to the special school that we had requested, but whose Headteacher had stated that based on his assessment (which did not reflect him at all), his needs could be met in a mainstream school.

My son was absolutely broken. He was either building up to going to school for 'the bush visit', doing it, or recovering from it. He was so distressed and saying "I can't do this anymore." I spoke with the Headteacher, the school were furious at the local authority for not helping him. We agreed that we as a family should deregister him. EOTAS was suggested, but realistically I knew if he couldn't cope with a place and people he knew well (school) he would not cope with a new setting and different people either. We felt that there was no other alternative but home education. We had no choice.

Emails that I sent to the SEN officer were either ignored or stated that it had already been decided that he was fine in a mainstream school. I wrote to my MP, who contacted the head of Children Services at the local authority. They said they had arranged a meeting with me and the school to establish 'the next steps' to get my son to engage in his current setting. They had not. No meeting was ever arranged and we had had no contact from them. I asked my GP and an autism advisory teacher to write supporting documents, these were received and acknowledged by the local authority. As far as I know no one even read them. I honestly felt there was no one to talk to. No one was listening, we were just a number on a massive list that they needed to get rid of.

We deregistered my son in June 2021 as we could not keep putting him through the daily distress and meltdown to gain evidence for something that was never coming. I didn't want to go to a Tribunal as I have seen what they do to families, and we were already at rock bottom. At that point I needed to put my energy into rebuilding my child and not into fighting the system. I had my own business as a Chartered Physiotherapist which I had to close. I have given up practicing, my livelihood, to be able to home educate my son. As a result, we have gone from two incomes to one income. It has been really tough financially and emotionally. I adore my son but it is hard being with him 24/7.

I do not want to home educate him. He does not want to be home educated. He would love to be at school. He really misses seeing his friends but he knows that he cannot cope in a mainstream school. I'm also now not sure he would cope in a specialist setting because he cannot cope with other people having meltdowns or behaving unpredictably, so he seems to be in this no-mans land between a mainstream and specialist school.

On the plus side my son's mental health has gone from strength to strength over the past year. He is much more confident and more independent, even with sleeping and toileting. The negative side is I truly believe he has PTSD from his time in school. Any formal school work we try to do causes huge anxiety and a meltdown, it is just not an option. It is so frustrating as he was able to do all these things before the lockdowns. He also has PDA traits, meaning formal work can be a demand. Everything must be child led or following whatever his special interest is at the time. It is really hard work and not the education I want for him. He is an incredibly intelligent boy and dreams of being an astrophysicist. He will need qualifications for this and I don't know if he'll ever be able to access them.

My younger son had to endure seeing his big brother wail and shout in distress in the school grounds for almost a year. This has affected him deeply; he has developed huge school anxiety. I took him to a

child psychologist for eight sessions at the start of this year as he was really struggling with school. It was clear that his brother's experience had significantly impacted him."

Family 7

"Our daughter started school and struggled through her initial year. She started well in Small Infants (Year 1) but then struggled. We had one incident where she tried to get out of school and come home. School referred her to CAMHS, and sessions were held in school 1:1 with my daughter and at home. Procedures were then put in place when she went into Year 2 to help with a move to a classroom upstairs.

CAMHS supported us with the move to the main Primary School for Year 3. Our daughter received further 1:1 sessions with a school support worker. The sessions ended, but we were told if we needed support again to contact them. When our daughter began struggling again in Year 4, we did just that and the person who had supported her before had left. Our case went to the bottom of the list.

Our daughter was bullied at school and spent time on the "buddy bench". The school would not accept there was an issue. She started refusing to go to school. She would cry, have meltdowns that would last for hours and would fall asleep, exhausted.

For Year 5 we decided to move to another school, which she would attend with her sister. We explained the support that she needed. At this point we did not know that she was Autistic, we just knew that she was struggling. We were finally able to get an appointment with CAMHS but the first one was awful. Our daughter was left extremely upset. We then attended without her. The lady running the sessions was very 'textbook' and didn't seem to understand what we were saying. We had to attend the sessions to tick the boxes of their procedures until we were able to get an assessment.

Finally, in Year 6 we were able to get an Educational Psychologist's report. She spoke with teachers, with us, and observed our daughter in class. She suggested that our daughter may be autistic. We were then able to get an assessment and diagnosis from Oxfordshire CAMHS.

When we went back to school to repeat our daughter's needs and explain the diagnosis to the Headteacher, the reply was "well, we are all a little bit autistic aren't we!". Which summed the attitude that we were faced with. I was in school one day waiting to go on a school trip to support my daughter when I witnessed the Headteacher pass her and say she was "lucky to be going on this trip today" in a very horrible tone. She had had been struggling to attend school and it had taken a lot from her to be able to go that day, even with me there to help and support her. I dread to think what was said to her when I wasn't there.

One week after her diagnosis my daughter was called into the Headteacher's office and told off after making a comment about a TA. It had not been meant in offensive way and was taken out of context. The Headteacher would then not support us in applying for EHCP as 'it was too much paperwork.'

Our daughter was due to start secondary school and we were extremely worried about her transition. We contacted SENDIASS, who were amazing, so supportive. We also contacted the Locality Team for support. We were able to hold our first TAF meeting at the primary school, with her secondary school also in attendance. The Headteacher walked out of the meeting several times, and clearly had not committed the time needed to support it which made it so much harder to express the degree of support needed at the secondary school. They decided that they wanted to wait for her to join them so they could observe her and see what she needed. We explained the support she needed and that she may seem OK initially without it, but would be struggling by the October half term.

Unfortunately, we were not listened to. She had no support when she started at the new school. She inevitably started to "wobble" and school were not quick enough to intervene. We attended the SWIFT training course along with a TA from our daughter's class. The TA had not even been made aware that our daughter was autistic, or that she needed help! We were also called in for an attendance meeting at school. The attendance officer had also not been made aware that our daughter had any special educational needs.

A tutor was assigned to her for 1:1 sessions with the aim of helping her back in to school. The sessions were held in another part of the school, off the main site. She could not cope with it. We spent one of the sessions in my car as she wouldn't get out. The 1:1 session tutor asked at that point if our daughter had any additional needs? Predictably, the tutor was also unaware that she is autistic and by this point was also suffering from severe anxiety. We felt that this was a safeguarding issue and said that we would not continue with the sessions because it was causing too much distress to us all.

The school was still refusing to apply for an EHCP so we applied ourselves and she was accepted for assessment first time, which confirms how clear it was that it was required.

She attended for one term of Year 7 and then a few weeks of Year 8. By Year 9 she was set to attend an Alternative Provision. The SEN officer at the local authority would not return emails or phone calls. The Alternative Provision had been agreed at the end of Year 8, but an email from her the first week of September in Year 9 said the local authority would not approve the application. After a lot of fighting, she was able to start. It started well but again, predicably, by October half term I was dragging her in and out of my car to get her to attend. By Christmas she was not attending at all. The staff came to our home once a week for one hour. Our daughter would either not leave her bedroom or would sit on the sofa with a quilt over her head.

The EHCP Annual Review should have been completed in April 2022. We attended the meeting with the school, SENDIASS and her alternative provision provider. The local authority did not attend. There was no agreement and another EHCP Review meeting was held in July 2022. Again, no agreement. We were well outside of the statutory timeframes. School put us forward for further meetings as our daughter's attendance was less than 40% (she wasn't attending at all).

At their first meeting in June 2022, CAMHS attended and agreed to support with the school's application to the hospital school. Before the EHCP meeting, the application could and should have been made. We had a further meeting held in July but CAMHS did not attend and the school had not applied for hospital school as previously agreed. It was confirmed at the meeting that the school would use the minutes from the meeting to apply. Again, this did not happen.

The day before that meeting, we received a letter from the school to say congratulations on your daughter achieving 100% attendance at school. She had not even attended one day that school year! I am concerned at how the school are recording absences. Obviously in terms of Ofsted it looks good to have 100% attendance, but it is not a true reflection.

By the end of the academic year again we had no EHCP, and nothing planned for our daughter to attend in September. She'd started medication in June 2022 (prescribed by CAMHS) and following a meeting with them in late July they emailed a letter in support of an application to hospital school. We then had several telephone conversations with a new SEN officer at the local authority over the summer.

A meeting was due to be held in early September. Unfortunately, it was cancelled by the school as they'd had no confirmation from the hospital school that our daughter could attend. So now, all of her friends

and her sister are back at school and she is left with no plan, no support and no education. This causes her more anxiety, and stress for us all as a family.

Over the years we have worked tirelessly to support our daughter. We have used our own money to pay for things that we think could help her. She attended a few sessions with Animals Anticks and enjoyed them, but then stopped getting out of the car. We have paid for computer programs, after primary school said she was so far behind. We have also started paying for a private tutor. Though she now has the EHCP, it has not worked at all for her at all.

The system is very broken and does not work for so many children and families. I have been lucky that financially I was able to go from a full-time job to extremely part time (4 hours a week) to be able to be with my daughter at home. Now, due to marriage breakdown from the stress of it all, I am not sure how we will cope going forwards. Parents are not listened to and the support (or lack of it) does not work. We are expected to fit into a system that does not help.

We are having our final meeting at the end of September. After this, we will be looking to take further action as our daughter has been let down so many times. Unfortunately, our story is not rare and I feel very sorry for all the children who are being let down and for the parents who are not being listened to."

Family 8:

"My daughter is 10 years old, in Year 6 and has a diagnosis of Autism Spectrum Disorder and Sensory Processing Disorder. She also presents with Anxiety, but has yet to receive a diagnosis for this as CAMHS have still not seen her. Her diagnosis was obtained privately in Year 4 as she has been on the CAMHS waiting list since Year 2, but things were escalating in school. We wanted to get the assessment and diagnosis to access support. The school had incorrectly told us that they could help more once she was officially diagnosed as autistic. I now know this to be incorrect and that they should have done what they could, even before diagnosis.

The diagnosis was received in the December and I immediately pushed for an EHCP. The school delayed, saying they would do it after the February half term break, then after the Easter break etc. It was finally requested in July 2021. As part of the local authority's assessment, they commissioned an Educational Psychologist who spoke with me and the school SENCO on the phone only. She did not see or speak to my daughter. Her report was then essentially copied and pasted to form the EHCP 'needs and provision.' When I received the draft EHCP, I replied straight away to confirm that that we wished for her to be educated at *[school name anonymised]* school. The local authority told me that the school did not take my daughters age, and proceeded to issue the final plan which named her current mainstream school. The information they gave was incorrect.

When the local authority did eventually consult with our preferred choice of school, they were full, as I had expected. The Panel then disagreed that a specialist setting was right. After speaking to SENDIASS an early Annual Review was requested, less than two months after the plan had been finalised. The C&I *[Communication and Interaction]* Team and a behavioural consultant the school had working with my daughter explained her struggles in the Review, and provided reports. Following the Review, the Panel offered the option of a C&I resource base, but in the same message stated there were no spaces and that my daughter would be placed on the 'unallocated' list.

I took it upon myself to research resource bases and spoke to the SENCO at one. I gave her an overview of my daughter's needs. Her immediate response was to say that type of provision offered was not suitable, as my daughter tends to run and try to exit the school site or hide when she is distressed. Their

adult to pupil ratio does not cater for that. I explained to the local authority that a resource base was not suitable and that [school name anonymised] was our choice of school. They did not reconsult with the school.

After the Review, things worsened in school and my daughter was unable to attend for around a month after the Easter holidays. She was physically unwell at the thought of school. The school suggested a slow reintegration with my daughter accessing their early intervention hub 'when it was not in use.' This resulted in some days her attending for 3 hours and others for only 2. No demands were placed on her at that time. She attended, played, and came home. This continued until the end of term.

A new TA was recruited for the next term to work with my daughter. She is lovely, but has no experience with autism or anxiety. It is stated in the educational psychologist report that my child needs support from a member of staff who is trained and experienced. My daughter has started school a week later than her peers, going 9:15 until 12. She will again work in isolation from her classmates. I have informed the county SEN Officer every step of the way, and have received no acknowledgment, response, help or input in reply.

I have now lodged an appeal to the SEND Tribunal over sections B, F and I (Needs, Provision and Placement). Our Tribunal date is in March next year. I do not feel the local authority have any urgency or even care that my child is missing time in school. She's missing her education when she is of compulsory school age and she remains fully isolated from all other children.

Her father has had to step away from all meetings and involvement as he becomes so passionate about our daughter's life and future that people feel intimidated. Everything is now down to me. I fill out all the forms, chase for responses and attend meetings. I work full time but thankfully since the pandemic I work from home. If I did not have that flexibility, I would be unable to work due to my daughter's timetable and the fact that she is with me most of the day. She is desperate to see children her own age but cannot do so despite me asking the school to provide help for her to access the playground. Overall, it is desperately upsetting for us all as a family knowing that just a placement in the right school could have a life changing impact."

Family 9

"My eldest son is now 10 years old. He was officially diagnosed with ASD, ADHD and severe anxiety in March 2020. Prior to this when he started the school (following a family move) in February 2019 I had raised concerns regarding anxiety and possible autism. The school had put some support in place and supported me in getting the diagnosis, but didn't see the need for an EHCP. The support in place for him was not adequate.

I applied for an EHCP myself. It was finalised in May 2021, but all of my comments on the draft were ignored. I didn't feel it was adequate so I immediately filed for appeal. By this point my son was deteriorating in school and was only attending part time. He persevered with school on a significantly reduced timetable but his TA was changed so many times due to COVID and general staff changes that it wasn't the supportive relationship it should have been. At times there was no support at all. Even on the very reduced timetable, he became regularly suicidal. He was put on very strong medication for his anxiety, and by Easter 2022 we decided that it was doing too much damage to him to go even for the three hours per day timetable, so he stopped going to school entirely.

Since May 2021 I have been asking for alternative provision, so that the time he was not in school could be helpful to him. I finally got three hours a week for him in June 2022. We paid for a further three hours a week that we organised ourselves, and the school agreed to fund in July 2022. Since he stopped

attending school my son has not once expressed suicidal feelings. He has been able to come off all the strong anxiety medication and made huge progress both in his alternative provision and at home.

Unfortunately, he is still without educational input, despite me constantly asking for tutors and input at home. We also have not yet had a Tribunal, to enable us to request a special school placement. I had asked for this under parental preference at the EHCP draft stage, however no special schools were consulted.

My middle son is now age 8. He started the school in February 2019. He was a sensitive boy, but it was only when my elder son was assessed that we realised that he too may be neurodivergent. The consultant suggested that both he and my youngest son should be assessed as she felt from our discussion, they might also have ASD.

When he started school, my son was being assessed by the GP for unexplained severe stomach pains and nose bleeds. After multiple rounds of testing, they concluded he had severe anxiety and stress which were causing these symptoms. Despite keeping school up to date, they regularly dismissed him when he said he felt sick, saying to 'just go to the toilet' or 'have some water.' By January 2022 I was picking him up almost every day because the school had called saying he felt unwell. Still, they did not take the anxiety seriously and put no provision in place for him. During lockdown the pains disappeared completely, and we tried a phased return to school in September 2020.

At this point he was awaiting diagnosis for ASD having already started the assessment process, which school were aware of. No further provision was in put place for him at school and in November 2020, he had a breakdown at the age of 6. Again, I applied for an EHCP for him myself because the school saw no need for one. He had to be assessed at home because he could not attend school. It took four months to get him to leave the house and go into the garden following his breakdown, and months and months more work to help him recover to the point of tolerating the assessment. His EHCP application was successful and awarded him 35 hours support a week. Again, I requested a specialist school and the county failed to consult any. They decided the school that he had not been able to attend in nearly a year, was the appropriate placement.

The school used the funding from the EHCP to employ a Teaching Assistant for him. He still could not attend school. No alternative provision was provided despite it being asked for repeatedly until June 2022. He has had six hours a week educational input since March 2020, despite my regular attempts to obtain more provision. We appealed his EHCP as soon as it was finalised in July 2021. We are yet to get to Tribunal.

My youngest son was in preschool when the consultant suggested having him assessed. He was seen by a community paediatrician who, referred him for a Multi-Disciplinary Assessment based on her findings. There was a wait for this, but the consultant informed the school that she was seeking an ASD and Sensory Processing Disorder assessment for him based on her initial observations, as well as referring him for an ADHD assessment.

No provision was put in place for him in school. Following lockdowns and multiple attempts to help the school understand the extent to which he was struggling, they reduced his timetable. He eventually stopped attending in March 2021. We tried to get him back into school but were informed there was no staff available to do 1:1 support for him, or do anything other than meet him at the door. Again, I applied for an EHCP myself, as the school said there was no need. Despite not attending in over a year, again Oxfordshire County Council named the school as an appropriate placement. We filed for appeal immediately. We are, again, yet to get a Tribunal date for him. Since July 2022 he has had 3 hours non educational alternative provision a week, with no educational input since March 2021. We have repeatedly asked for more and get nowhere.

The effect on the whole family has been devastating.

I cannot work and our finances are stretched. We used all of our savings to employ a barrister at massively reduced rates to try and fight our case for us. We have had to pay for independent assessments by Speech and Language Therapists and Occupational Therapists because Oxfordshire County Council refused to at the Needs Assessment stage for all three children. We have had to borrow money from family to do this.

The mental health of the children has declined rapidly. Their confidence and self-esteem are horrifically low. My husband and I have no family or friends in the area as we only moved here in February 2019. We are completely alone and the stress has been debilitating at times. My husband has had to come home from work, or work from home to help. There is a limit to what his employer will allow before he loses his job. Our daughter has missed out on so much from not being able to have play dates, and having to frequently witness challenging behaviour.

It is just me and the three boys at home all day, with my daughter at home in the afternoons. It is not safe for me to take all three boys out on my own, because they are at risk when they bolt and have meltdowns so we are stuck in the house all the time. We had a TAF [*Team Around the Family*] meeting which got escalated to LCSS [*Locality Community Support Service*]. They escalated our situation for an Early Help Assessment who said there was nothing they could do, and closed the case after one phone call. Social Services say the children 'aren't disabled enough' for the Disability team, and as there are no safeguarding issues, they will not support us on the other team. They refused a needs assessment for the children. I have had a Carers Assessment, which gave me £300 towards our needs this year, but could provide no further help.

We are stuck. Our lives have been devastated. Our children, who used to be so happy, are broken and their educational needs are ignored. They are behind in their education despite having no cognitive impairments. My middle son has an IQ above the 99th percentile!

The impact of this will last our whole lifetimes."

Family 10

"My child is 12. He suffered with separation anxiety when attending nursery. He used to scream and he hated it when I left him there, but he would settle down. It was similar in primary school. I used to practically carry him into the school and the staff would help me get him into the building. They would then lock the door behind him to prevent him from running away.

The doors are not locked at secondary school, so he is able to leave when he is distressed. He once ran all the way home in his PE kit without his mobile phone after an incident in PE. He had misunderstood an instruction, the situation escalated and he ended up threatening a member of staff with a hockey stick. I highlighted this as a safeguarding issue to school as no one knew where he was!

We applied for an EHC needs assessment when my son was at primary school. Our application was declined. I have been trying to put together another application, but I am struggling to have the capacity to do it. The SENCO at school has refused to help me do it and I missed the window to appeal the original decision.

It has become apparent that the secondary school did not read any of the hand over notes from the primary school that were provided to aid my son's transition in September 2021. The school runs three 'Nurture' sessions per week, which are an hour long and have been very helpful. One of the Nurture

practitioners is exceptionally helpful, and has built a good relationship with my son. The SENCO and Headteacher are not listening to her advice, and have decided he should attend full time after he went in for the first time and managed to stay for the whole day. Unfortunately, he hasn't been in since! When I first requested that the school make reasonable adjustments for him, they told me that 'they are not a special school.'

I have had to fight for my son's best interests every step of the way, especially at the secondary school. It is exhausting trying to get him in to school, having to chase them, and get them to bend their precious attendance rules to accommodate him. I have been unwell and I am waiting for a hysterectomy. School knows this and do not care. My mental health has suffered, as has that of my husband. The situation has strained our relationship.

[Child's name anonymised] has been put under pressure to attend school and this has affected him greatly. He wants to attend but does not see the point of lessons, they are boring and pointless to him. Last year if he did manage to go in after suffering with high anxiety, he wouldn't be listened to when he was struggling and would walk out of school. They lied to him one day saying I wasn't in the car park waiting for him, to try and keep him there. I was there. This broke his trust in the school staff. He doesn't sleep well and worries about things as he is lying in bed for hours trying to get to sleep. It is heartbreaking."

Family 11

"My daughter is 7 years old. She was diagnosed with Autism at the age of 4. She was well supported in her early years setting but we had to hold her back a year because she was non-verbal at the time and we just did not feel she was ready to attend school at that stage. She started Reception a year later than her peers, with children a year younger than her. Because of the enormity of her Special Educational Needs arising from her disability, we had her EHCP finalised prior to starting primary school. We were not sure if a mainstream setting was the right environment for her, but decided we would see how it worked for her and make any further decision from there.

In Reception she received constant 1:1 support but as a result of her SEN she was unable to access the mainstream curriculum. Most of Reception year was spent away from her classmates and the main classroom, in a garden building. Her 1:1 Teaching Assistant essentially babysat her. It was confirmed in May 2021 that the mainstream school could not meet her extensive needs, after discussion at her Annual Review. We all agreed that she needed a specialist setting.

There was an unexplained delay in her case being heard by the Panel at the local authority. We were told that it had been heard in December 2021 but that further clarification was required. It was never explained what this delay was. After chasing weekly, I was eventually told the case was heard again (9 months after the Annual Review meeting) in February 2022. The Panel also agreed to a specialist setting.

She moved to Year 1 in September 2021. As she is unable to join her classmates in the classroom or access the mainstream curriculum, she is in isolation with her 1:1 TA most of the time. School do try to educate her (teaching numbers, increasing her vocabulary, doing mark marking etc), and she does take part in music sessions with her classmates occasionally. The school simply are not able to provide everything, or educate her in the environment, that she needs. It requires specifically trained and qualified staff, external professionals, experts in a child like mine. These are just not available in a mainstream setting even with an EHCP.

We have now been waiting for over a year for a place at a specialist setting to become available. We have looked at all possible schools, in and out of county as far as we could reasonably travel. No spaces are available. They are all 'full'. My daughter remains stuck in a school that, despite their best efforts,

cannot meet her needs. She is not being 'educated'. She is being kept safe but in an unsuitable and sometimes stressful environment for her and learning very minimally, while we wait for a place at a specialist setting to become available for her.

We do not know what the future holds. Next academic year, when my daughter's year group move to Key Stage 2, there is no space for her to move with them and have the isolated area/room that she needs if she is in a mainstream school. It is a small school. She cannot remain in the Key Stage 1 area permanently. Even if she could it is incredibly upsetting to think of her, already a year older than 'her' year group having to remain behind at age 8/9 in the same area of the school as the children who are barely out of the Early Years. It is also a question of safety. My daughter is not always able to be in control of her physical and verbal actions, through no fault of her own. She is as you would expect, much bigger and stronger than your average 5-year-old. She is always supervised, but it is another reason why we need to have her educated in a more appropriate setting. The current school and the staff as individuals have all done their best, they have been very supportive. My daughter's future rests on the chance that a space at a specialist setting 'might' become available for her.

It is a huge worry that we will get to the end of this school year and she will have nowhere to go at all. Both my husband and I work. We cannot give up work, and nor should we have to. Home education is not an option.

We have had nothing but delays and excuses from the local authority. There have been multiple changes of SEN Officers with no notification. Emails go unanswered, or if they are responded to, they are vague and don't actually answer the questions that I've asked. I have left countless phone messages; they are not responded to. There have been multiple, lengthy, and unexplained delays at Panel stage. Still, even now that everyone agrees about the need for a specialist placement, a year on and we are no further forward. My daughter will not get these missed years (years where she could have been in an appropriate setting learning, progressing, and thriving) back. I have even contacted my local MP for help. I did receive a response, but still nothing has changed for my daughter.

The impact of this on us as a family has been huge. It is incredibly stressful. Being stuck in limbo and not knowing what is next for our daughter or even when is devastating. We all feel completely let down by the system."

Family 12

"My daughter is 14 years old. She has, after a three year wait, had her NDC [*Neuro Developmental Clinic*] assessments which confirmed diagnoses of Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder and Oppositional Defiant Disorder.

The EHCP was three months over the 20 week statutory timeframe. My daughter has not attended school properly for nineteen months. This is due to the school being woefully inept and unable to cope.

She was on a restricted and reduced timetable which amounted to one lesson a day, for four days a week. Literally 4 hours a week education. That is on top of unlawful isolations (the SEN Code of Practice states that children with autism and various other issues are NOT to be separated from their peers). During these isolation periods my daughter was sent to an annex boarding house fifteen minutes away from the school. She was left 1:1 with a teacher. -As a parent, you try selling THAT to child who desperately doesn't want to go in the first place: "you'll spend an hour, sitting with your teacher, on your own"...

There have been over twenty unlawful exclusions. The exclusions are based on their "behaviour points system" which should never apply to a child with disabilities. My daughter was sent for a term to a place

called [*school name anonymised*] which is for "naughty children" on the verge of permanent exclusion. That did not work because their program is for neuro-typical children with environmental factors that influence their behaviour such as neglect, drugs etc.

[*Child's name anonymised*]'s issues are neuro-divergent so that did not go well. To make matters worse, they sent her there AGAIN for another term totally against my wishes. This time it failed so badly that the college ended her placement. Because her school "hadn't had time to put anything in place" she was then at home with me for a month. If all THAT seems bad (and in seriousness, it really is) I have saved the best till last. This all pales into insignificance compared to the fiasco the local authority has presided over.

The EHCP was outside of the statutory timeframe time by three months. The local authority omitted two assessments that STILL have not been completed. I asked them to name a specialist school. They refused. They refused because they said that my daughter would be able to return to the mainstream school. That's right - the one she hadn't been present at except for four hours a week, the one that had sent her to a "naughty school" the one that left her sitting at home with me for months...THAT one.

They said she could return to that school "with provisions, and it will be fine". That was literally their words "it will be fine".

The provision given was that two days a week she would attend a local college that has placements for neuro-divergent children. I argued bitterly against this. It was wrong on so many levels, and too much to write here. But they ignored my extensive list of objections. The local authority said the case would have to go to Tribunal if I disagreed. The waiting list for Tribunal is so long that my Tribunal is booked for NEXT summer!

So, at the start of the summer holidays that was their plan. My daughter [*child's name anonymised*] would be returning to her old school AND going to a college. All this, with all her problems. Wow. Things did not work out. Unbelievably.

The "specialist college", the backbone of their master plan to save themselves money by not paying for a specialist placement, read her EHCP during the summer holidays. They refused the local authority's request to send her there, stating that they could not meet need. My daughter's school then told the local authority that THEY also could not meet need. They said she could no longer attend.

So... here is where we are. My daughter currently has NO SCHOOL AT ALL.

The SEN Officer who has been dealing with my daughter has called me to say "yes you can send her to the school you asked us to send her to back in June." Except they can't. Why? Because their own rules mean they cannot now change Section I of the EHCP unless there is a "significant change".

There actually is a significant change, the diagnoses arising from the NDC assessments. I explicitly asked for the local authority to wait for these to take place BEFORE naming the school that they did. I knew a confirmation of her conditions combined with her extensive needs would mean they'd agree that a mainstream school wouldn't be adequate for her needs. Now we must wait another MONTH before that report is officially released, due to CAMHS being so slow. In another two weeks from now the report might mean my child can go to the school that me and the doctors at CAMHS originally asked for...almost a year ago!

My child has been so badly let down. Right now, as I write this to you, she is upstairs in bed with no school to go to. It is outrageous."

Family 13

"Our child has been unable to attend a school setting since they stopped attending pre-school in Spring 2021 following a lot of difficulties separating from us there. They were going 2-3 days a week. Staff reported they were fine once settled, but they were often upset in the lead-up and morning of going, and then later in the days before. We persisted as recommended by the pre-school who said it was 'just' anxiety and the best way to overcome it was to attend more. This resulted in burnout. Towards the end of their time there they were only attending with a parent present and for just one hour per week. They clearly had unmet needs. Towards end of their time at pre-school we began to think they were likely autistic with a PDA [*Pathological Demand Avoidance*] profile. Following assessment, this was confirmed with a formal diagnosis.

We tried small primary school in September 2021. Though the school used PDA-friendly strategies like a phased start, providing 1:1 support for transitions, allowing freedom with choice of clothes and choice of activities centred around their interests, they were only able to go in for a couple of short sessions before becoming extremely distressed. This included self-harming behaviours and saying that they did not want to have any more birthdays as they didn't want to have to go to school more, which was devastating to hear. According to research carried out by The PDA Society, approximately 70% of children with a PDA profile are not able to be in school, or regularly struggle to attend.

Our child is still on roll, but has been signed off for over a year, initially as they were not at compulsory school age and then later due to their mental health. School got an Educational Psychologist's assessment which agreed it would be harmful for them to attend. School has stated they cannot meet their needs. Throughout this time, we have had no support for their education from the local authority. Nearly all the support we have had, we have had to pay for privately. We have funded an independent Occupational Therapist, Speech and Language Therapy, an Educational Psychologist assessment, a distance learning trial and our own educational materials to use at home. It is a lot.

We have just had an EHCP issued, though initially it was declined by the local authority. We complained, it was referred back to the Panel and they agreed to issue it on the same evidence that was provided the first time. However, the EHCP is centred on education in a mainstream school and our child cannot access this.

Our highly-experienced independent Educational Psychologist, Speech and Language Therapist and Occupational Therapist's reports all recommend EOTAS [*Education Other Than At School*]. The local authority has refused to take any of their diagnoses or recommendations into account, citing "internal quality assurance". Instead, they have relied upon the report of a locum local authority Educational Psychologist who did not meet our child or talk to her school, and whose report we have an outstanding complaint about along with the NHS Speech and Language Team who declined to assess our child. The local authority ignored requests for other assessments, for example from social care.

The EHCP includes ableist and inaccurate content but the local authority refused to make nearly all of the changes that we requested at draft stage to remedy this. These are failures to follow the SEND Code of Practice. It appears that the local authority's strategy is to force parents to go to Tribunal to get the needs of their children met, in order to save money in the short term. All of the mainstream schools that were consulted when the EHCP draft was distributed stated they could not meet need. EOTAS is the only way that our child can access education without a terrible impact on her mental health. They have essentially been in mental health burnout for one and a half years and are only just coming out of it. Going back into the school environment would set them back, they are unable to cope or learn in a school. I would describe the local authority as totally obstructive, and totally not understanding of such children."

Family 14

"We are a shockingly awful story; I sent an email to the school last week saying the stress and trauma I have endured as a parent is beyond anything that is humanly acceptable. I have got comparison here. My husband almost died when said child was in primary school. It was a full life support in the Intensive Care Unit situation. What has happened to us with our child at secondary school beats that.

There is just so little kindness. I found myself in the A&E Department one Saturday night after a psychotic episode. I went to make the safeguarding call they had been requesting, only to find that I could not speak. I either muted or just jangled, but my brain was still coherent. It followed a previous situation at Christmas where I had had vertigo. These are all signals of extreme stress, and trauma.

I am now working on a restful recovery. Working, but we are definitely talking "light duties".

My daughter is now 15. She never really liked school. She would scream all the way there and back. I was always told she was 'fine.' In hindsight, some of that was likely so that I didn't worry during the hospital period. But even before then I was always told 'she'll grow out of it' and 'stop fussing!'

By Year 4 we were having meetings with school and they were taking additional measures. A psychologist from the John Radcliffe Hospital said that she had signs of neurodivergence, but basically that she seemed to look fine so why bother assessing.

In Year 5 a new teacher in school said straight away she could see there was a problem. She referred us to CAMHS and we stared the excessive wait and did parenting courses. She had a disastrous transition to secondary school. When I called SENCO to talk to her about my daughter, I was told that she is not on the SEND register and that she didn't have time to look into it. She sent me back to the form teacher, who also did nothing. By the time we got to Year 8 we were having sleepless nights and evil looks in the car. My daughter was having to be removed from us in the school reception. We were receiving phone calls from her, sobbing to us at lunchtime in the toilets. She was withdrawing from friendships.

Lockdown hit, which felt like a blessed relief. We had to shield as my husband is ECV now (he is doing well, but it is a condition). We received no support. I asked what we could do for the September return, so that she got her education but we were still putting our family's safely first. I was told that she would just do the homework that was being set for those at home who were at home self-isolating. She would do this whilst sitting in the isolation area at school. We said she might as well stay at home, if she is only going to be given the 'homework' to do. School agreed. She stayed at home with no challenges.

In February 2021 we had another attempt to return her to school. By this point she had her autism assessment, had been diagnosed and was waiting for an ADHD assessment. This was also diagnosed. The school made no provision for her. A meeting was held to talk about it, they offered nothing that resembled a transition. There was no kindness or understanding.

That was it. She had already said at home she didn't want to go back and explained what the problems were. School heard them. They did little to no reassuring. She dived straight downwards after that. In summer 2021 she was offered an ill planned programme that was basically being run by a TA with zero training with zero back support either.

Just before term, Dare2Dream started and they were brilliant. It took six months of their work, reassuring and trust building, before she felt she could do it.

Two days before term started in September 2021, following no further contact we received an email about part time timetables, confirming options and asking which corridor did she want to use as her

safe space. Needless to say, that might have been the point I combusted. There was a meeting later that month with the local authority's attendance team. They agreed they wouldn't fine us and to be blunt I told them we'd like to see them try. We started with CAMHS in December 2021. Our sessions with them are finishing soon. They were an absolute godsend, she wasn't leaving the house by this point and was often rendered mute or pushed into meltdown.

The Dare2Dream sessions were stopped by school May 2021 because they said they had run out of money. She was too fragile for any other education, but she has made great steps over the summer and she will be doing some learning. My daughter is clear she wants to explore and enjoy things before she commits to those exams. After the last five years, I would say that's fair enough. We have booked a cookery course that we will do to enjoy, with other stuff at home and other booked activities.

We are still negotiating with the school. An EHCP has been declined, twice. I spoke to the SEN Officer in early July to ask for the latest feedback. All I got was a repeat of 'school should be doing more.' An agreement has been made that school would submit proposals to the local authority for special funding for their consideration. The SEN Officer left over the summer. We do not know who our new one is yet.

After a horrific standard issue attendance letter was sent out to all parents last week, I am now back on the tablets that were given to me after the major stress episode resulting in my visit to A&E in January. I had been feeling much better, but this was a massive trigger. As I said, I have told them about this. I have now stated that we are on new terms on matters, contact and treatment, enough is enough!

We have set up nice activities and learning to do at home, but our hope is that an alternative provision that can help our daughter socially, emotionally and to improve her outcomes will be arranged. Even if it is a return to Dare2Dream.

By chance I saw another parent in the local supermarket who raised her worries about the school's attendance letter and the general approach it seems to be taking. This is about her steady, 'in school' daughter who has no attendance issues, and she was outraged too. The letter was sent even before the 'hello, welcome back to school' message."

Family 15

"My son is 9 years old and has just started Year 5 at a local mainstream primary school. He has been on the waiting list for CAMHS Neuro-Developmental assessment since he was in Year 1. We're still waiting on an assessment and any diagnosis, but *[child's name anonymised]* clearly has numerous and evident autistic traits.

He has had an EHCP for just over a year, this provides him with a full-time 1:1 Teaching Assistant. He was recently 'unofficially' diagnosed with Dyspraxia by an Occupational Therapist. We have not yet seen a paediatrician to get an official diagnosis on that.

[child's name anonymised] finds school incredibly stressful and anxiety inducing. He is a bright boy but has not been making progress academically. He gets really upset and overwhelmed which escalates to anger. He then lashes out, especially if he feels cornered. The Educational Psychologist had said that this is due to the impact of sensory overload when he is in a busy classroom. Over the past nine months he has had two fixed term exclusions because of his behaviour, which resulted in him hurting an adult. In March, the school called an emergency Annual Review and told us that they could not meet *[child's name anonymised]* needs.

The Panel agreed and confirmed that he needed a specialist placement, and we were lucky enough to be offered a place at *[school name anonymised]* in July. It seems that this school know how to meet the needs of children like *[child's name anonymised]*. However, we have been waiting for nearly two months for the offer to be reviewed by the Panel to see whether we are permitted to accept the offered place. Apparently, his case was heard last week, but we still do not have a decision. We have had nothing in writing. The process has been opaque and difficult to navigate. It also means that he has missed the start of the new school year in the new placement.

As parents we have felt powerless, and we have had to continue to take *[child's name anonymised]* to the current mainstream school, even though they are continuing to not meet his needs. This means that he risks being excluded again. It is really upsetting and difficult.

Although compared to the experiences of other people, it seems that the process has happened quickly so far, it has still had a huge effect on *[child's name anonymised]* and the rest of the family. *[child's name anonymised]* is very unhappy at the mainstream school and wants to move, but we don't have any answers for him. It has been incredibly stressful for us as parents, and it has caused physical and mental health issues for me and my husband. Every time the phone rings I am worried that the school are calling to tell me he's been excluded. I am often in tears after I leave him, and then I'm anxious all day.

Although not directly linked to the wait for specialist provision, I did have to leave the role that I was working in at the time. My workload was such that I found that I wasn't able to support my son after school as he needed. It was unsustainable. My daughter (who is 13 years old) has also been affected by this situation. We have had to put so much time and energy into *[child's name anonymised]* that she has felt left out.

For *[child's name anonymised]*, there is the ongoing trauma of being in a placement that cannot meet his needs; where he feels unhappy, lonely, and unwanted. He has a reputation as 'naughty' amongst his peers. We find that he can be targeted and 'wound up' because they know it will provoke a reaction, which they find entertaining. The other school parents won't make eye contact with me at the gate. There are huge feelings of shame and isolation. It also feels like there is no support for parents in these situations. Some support groups won't help because *[child's name anonymised]* doesn't yet have a diagnosis, others only offer support during working hours. I tried contacting Autism Oxford but the webinar about difficulties at school had already happened, and wasn't due to happen again for another year! This has all left us feeling very isolated."

Survey

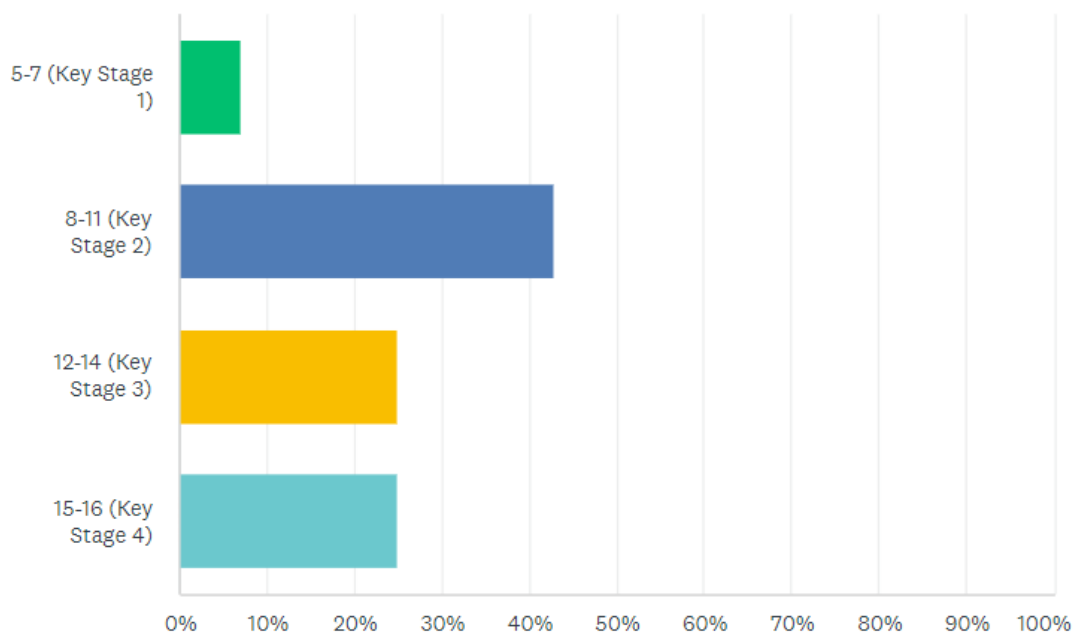
Oxfordshire Parent Carers Forum ran a short survey online from 11th – 14th September 2022 to gather data on the key themes of this topic. The survey was shared on our social media channels and distributed by email to our mailing list.

28 parent carers responded in that time period.

The results are as follows:

Q1

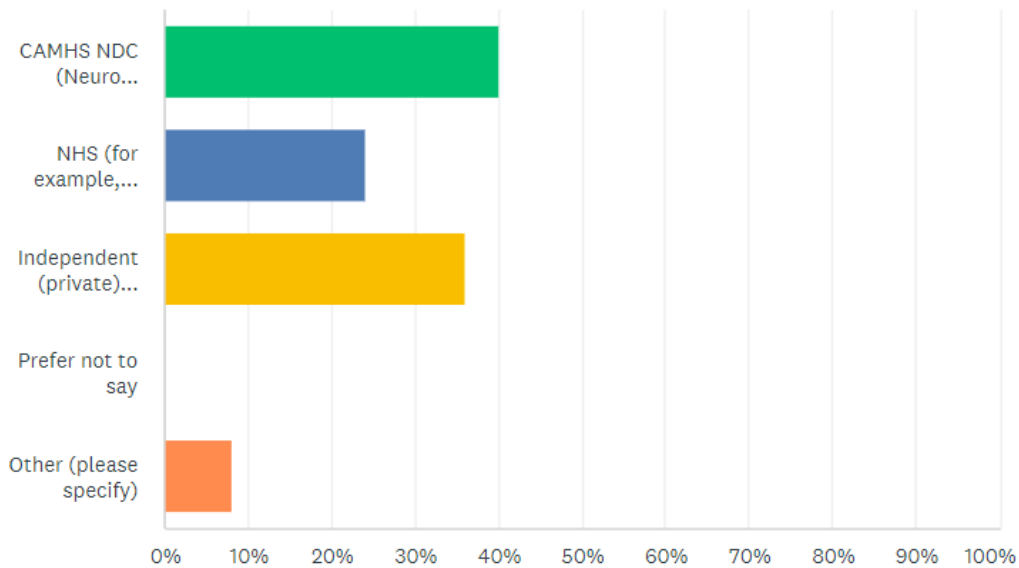
How old is your child?



ANSWER CHOICES	RESPONSES
5-7 (Key Stage 1)	7.14%
8-11 (Key Stage 2)	42.86%
12-14 (Key Stage 3)	25.00%
15-16 (Key Stage 4)	25.00%

Q2

If your child has a diagnosed Special Educational Need and/or disability, how did you obtain the assessment?

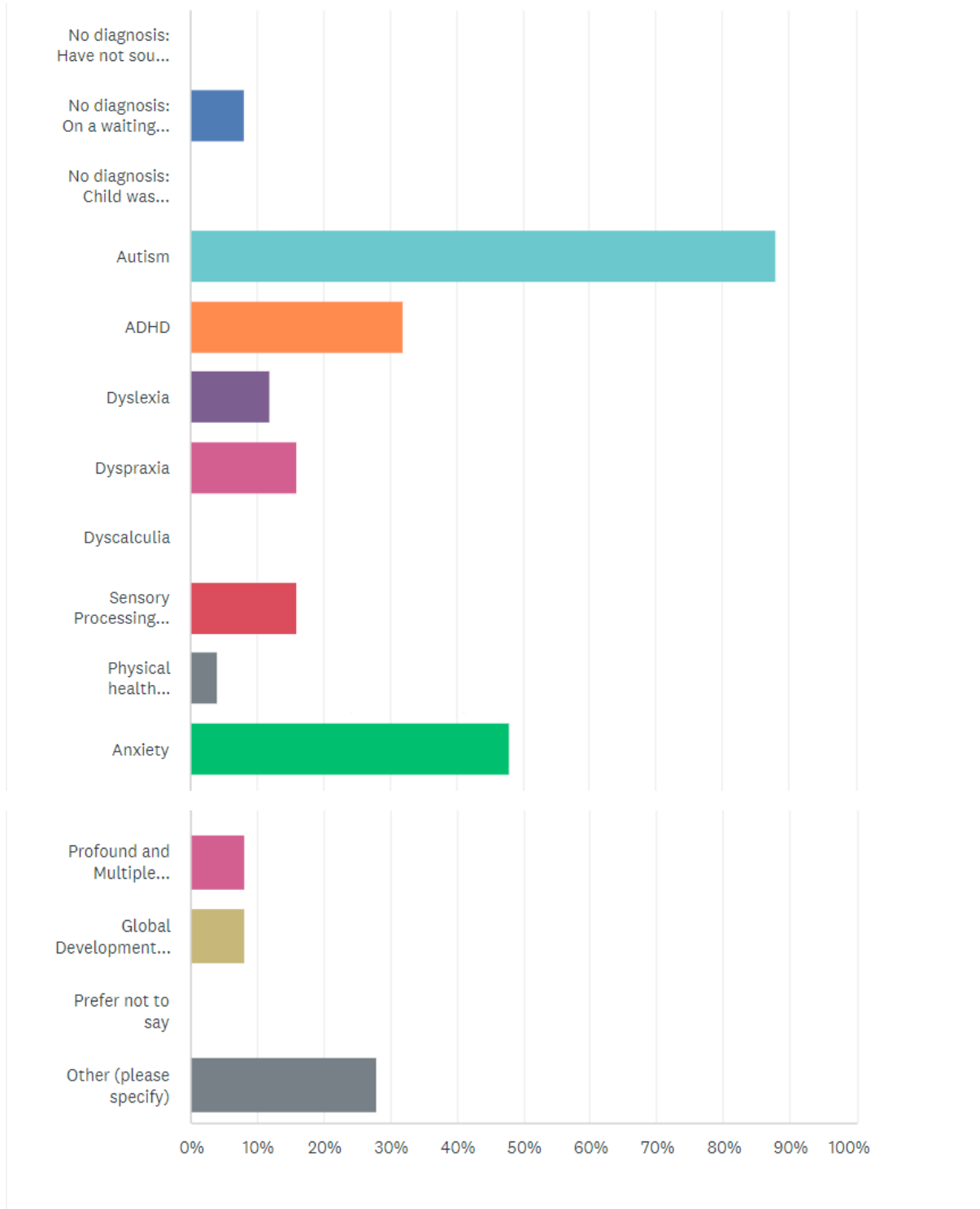


ANSWER CHOICES	RESPONSES
CAMHS NDC (Neuro Developmental Conditions) Pathway	40.00%
NHS (for example, Community Paediatrician)	24.00%
Independent (private) provider	36.00%
Prefer not to say	0.00%
Other (please specify)	8.00%

The 'Other' responses included the fact that some children were still waiting on the CAMHS NDC pathway, with one parent commenting that the wait had been 'four years so far.'

Q3

What is/are your child's diagnoses? Please tick all that apply

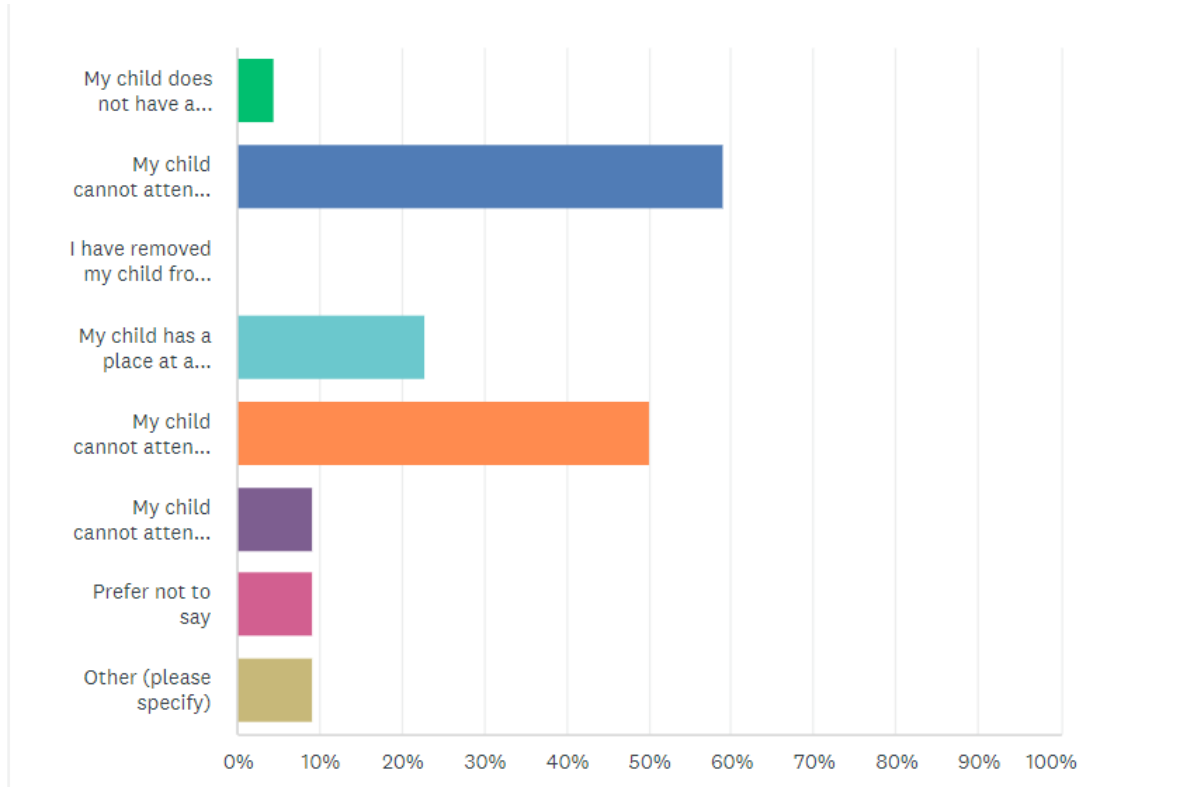


ANSWER CHOICES	RESPONSES
No diagnosis: Have not sought assessment	0.00%
No diagnosis: On a waiting list for assessment	8.00%
No diagnosis: Child was assessed and no diagnosis given	0.00%
Autism	88.00%
ADHD	32.00%
Dyslexia	12.00%
Dyspraxia	16.00%
Dyscalculia	0.00%
Sensory Processing Disorder	16.00%
Physical health condition	4.00%
Anxiety	48.00%
Mobility Impairment	0.00%
Sight Impairment	0.00%
Hearing Impairment	0.00%
OCD	0.00%
Eating Disorder	0.00%
Profound and Multiple Learning Disability	8.00%
Global Development Delay	8.00%
Prefer not to say	0.00%
Other (please specify)	28.00%

'Other' conditions listed included examples of Pathological Demand Avoidance (PDA), Autism with PDA, an unspecified 'genetic syndrome' and low mood.



Why do you consider that your child is not receiving a full time education?



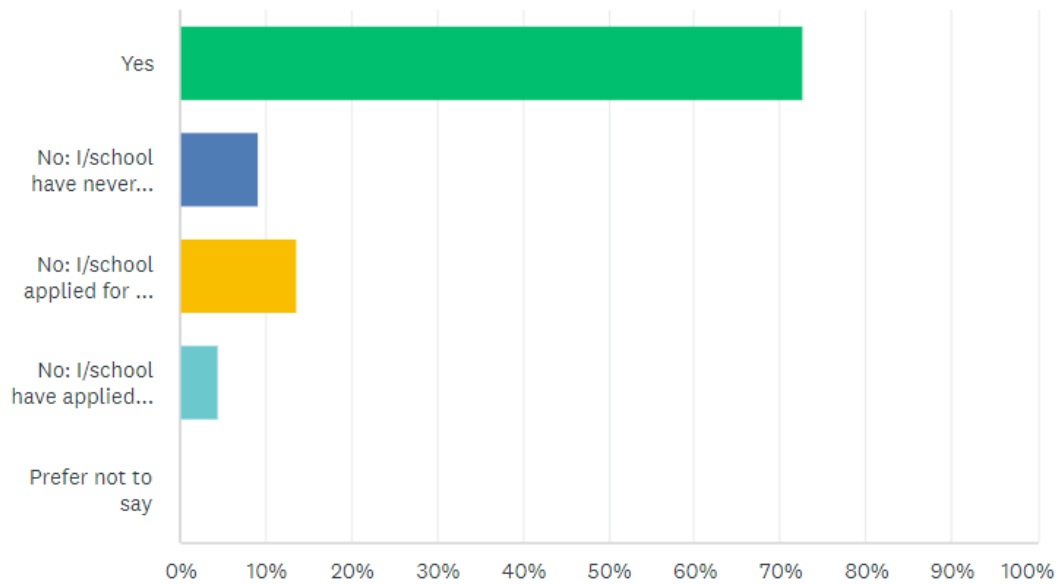
ANSWER CHOICES	RESPONSE
My child does not have a school place	4.55%
My child cannot attend school because school cannot/are not meeting need	59.09%
I have removed my child from school entirely but am unable to provide home education myself	0.00%
My child has a place at a mainstream school but is waiting on a place at a special school to become available	22.73%
My child cannot attend school because of their anxiety levels	50.00%
My child cannot attend school because of issues involving school transport	9.09%
Prefer not to say	9.09%
Other (please specify)	9.09%

The Other responses collected included examples that schools named on children's EHC Plans could not 'meet need' and that children couldn't attend due to the 'size of the school'.

Q5



Does your child have an EHC (Education, Health and Care) Plan?

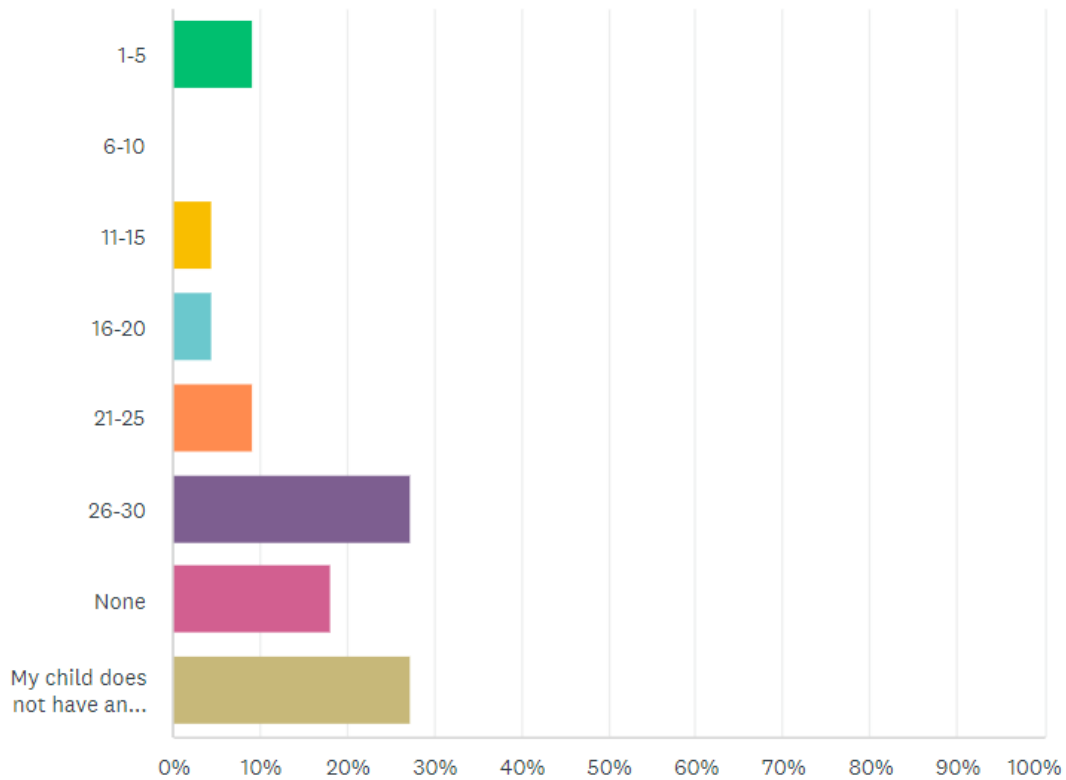


ANSWER CHOICES	RESPONSE
Yes	72.73%
No: I/school have never applied for a Needs assessment	9.09%
No: I/school applied for a Needs assessment but the application was declined	13.64%
No: I/school have applied for a Needs assessment which is in progress	4.55%
Prefer not to say	0.00%

Q6



If your child has an EHCP, how many hours per week is the setting named in Section I or the Local Authority providing education to your child?

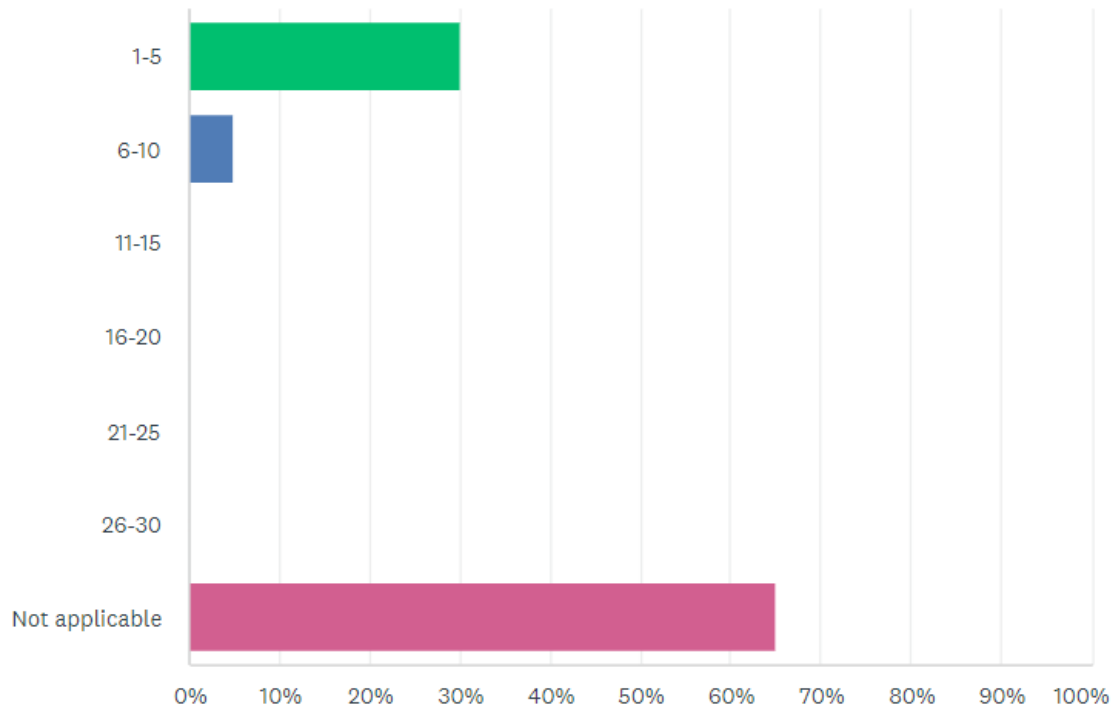


ANSWER CHOICES	RESPONSES
1-5	9.09%
6-10	0.00%
11-15	4.55%
16-20	4.55%
21-25	9.09%
26-30	27.27%
None	18.18%
My child does not have an EHCP	27.27%

Q7



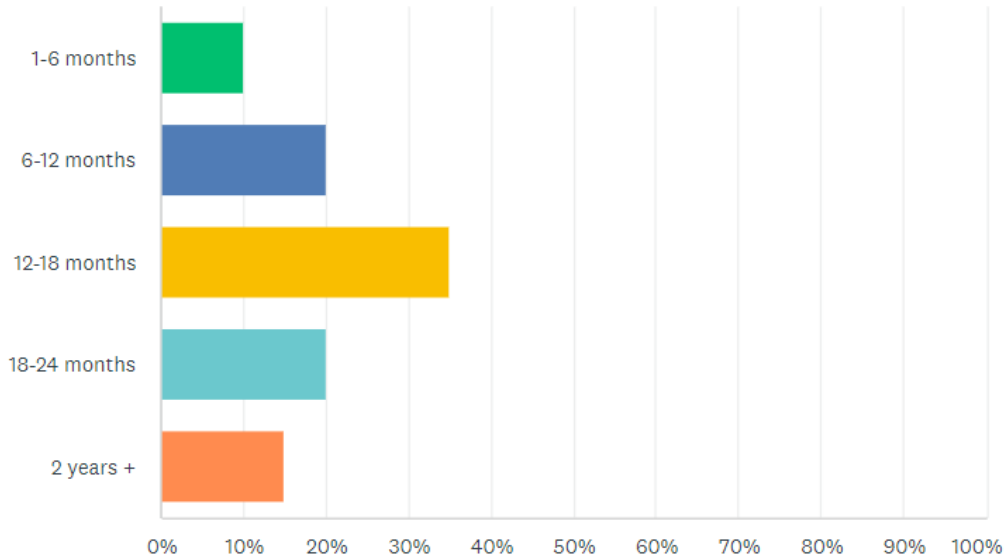
If your child is in a mainstream school but is waiting for a special school placement via EHCP, how many hours per week do you consider that your child is engaged in learning, as opposed to simply being supervised/kept safe?



ANSWER CHOICES	RESPONSES
1-5	30.00%
6-10	5.00%
11-15	0.00%
16-20	0.00%
21-25	0.00%
26-30	0.00%
Not applicable	65.00%

Q8

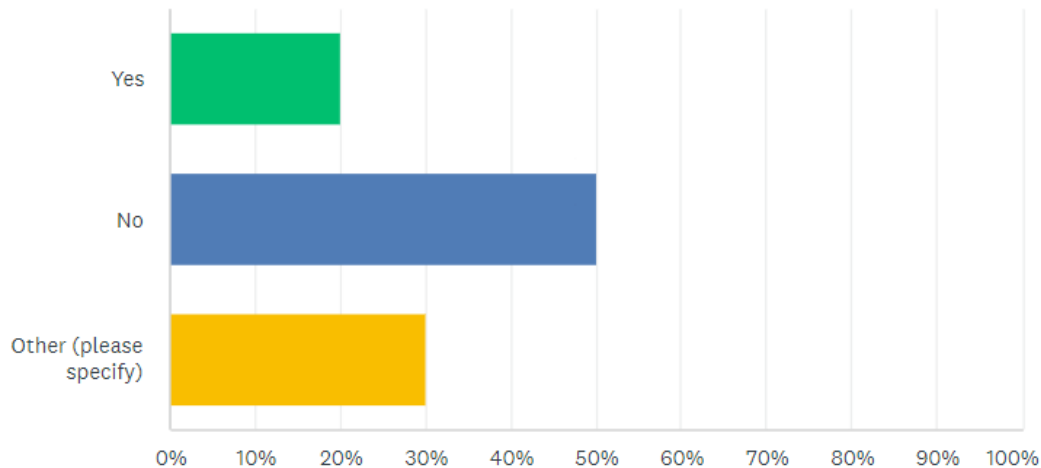
For how long do you consider that your child has not received a full time education?



ANSWER CHOICES	RESPONSES
1-6 months	10.00%
6-12 months	20.00%
12-18 months	35.00%
18-24 months	20.00%
2 years +	15.00%



Do you/did you feel supported by your child's current or previous school setting? Please elaborate under 'Other' if you have a mixed experience



ANSWER CHOICES	RESPONSES
Yes	20.00%
No	50.00%
Other (please specify)	30.00%

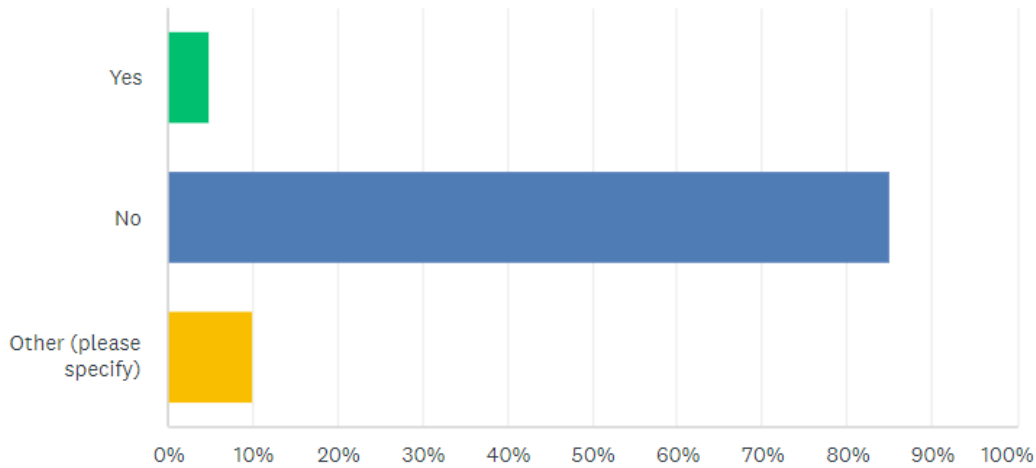
Answers given as 'Other' included parent's experiences that:

- School had been supportive but the parent felt that they were the 'driving force' behind getting a 'tiny amount' of alternative provision in place
- School is supportive, but not 'appropriately proactive'
- School is 'trying hard' but cannot meet need and has 'unofficially excluded' child as a result on multiple occasions, which has now progressed to formal exclusions
- They have felt the need to move schools in order to access a 'more supportive Head and SENCO'

Q10



Do you feel supported by the Local Authority? Please elaborate under 'Other' if you have a mixed experience



ANSWER CHOICES	RESPONSES
Yes	5.00%
No	85.00%
Other (please specify)	10.00%

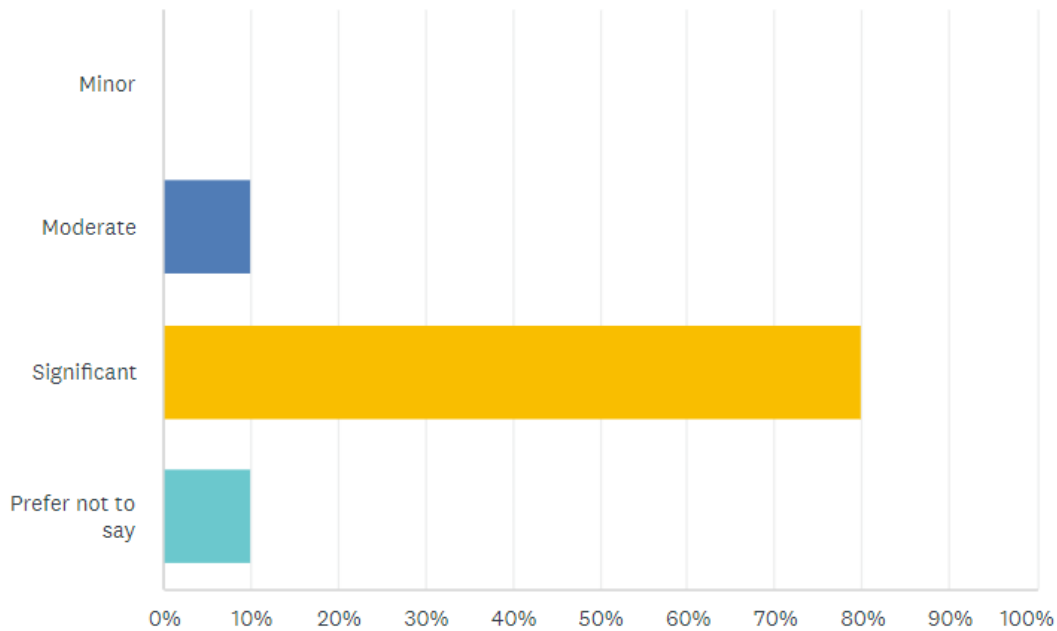
Answers given as 'Other' included parent's experiences that:

- They consider the local authority to be 'totally understaffed' for the number of children and families needing support
- Some support was available, but that it was 'bitty' or not the right support at the right time
- That timescales and processes have not been made clear, which has led to a lot of time spent chasing for updates that cannot be provided

Q11



Would you say the impact of not receiving a full time education on your child's mental health has been:

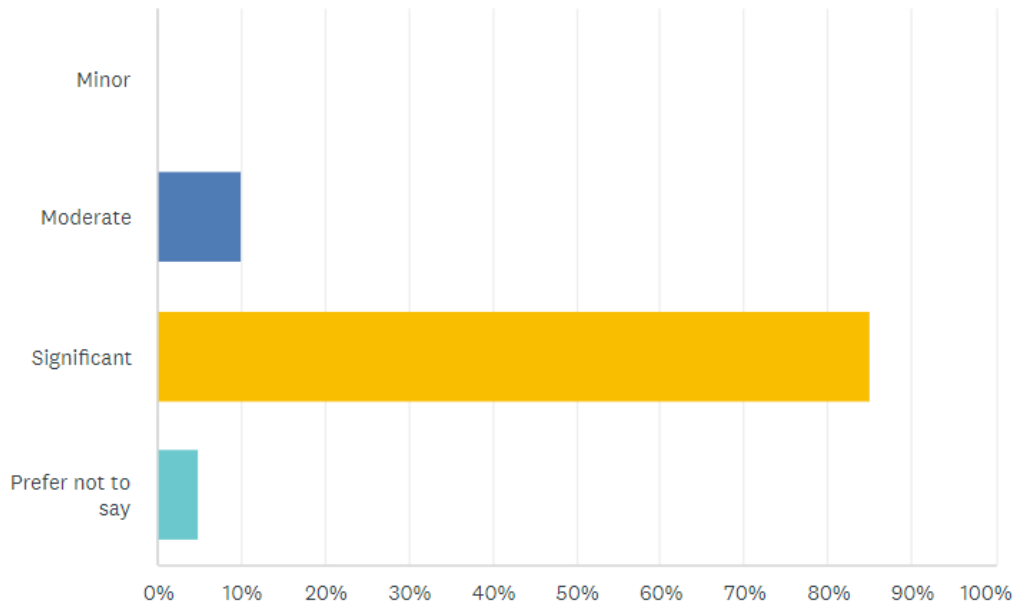


ANSWER CHOICES	RESPONSES
Minor	0.00%
Moderate	10.00%
Significant	80.00%
Prefer not to say	10.00%

Q12



Would you say the impact of your child not receiving a full time education on your mental health has been:

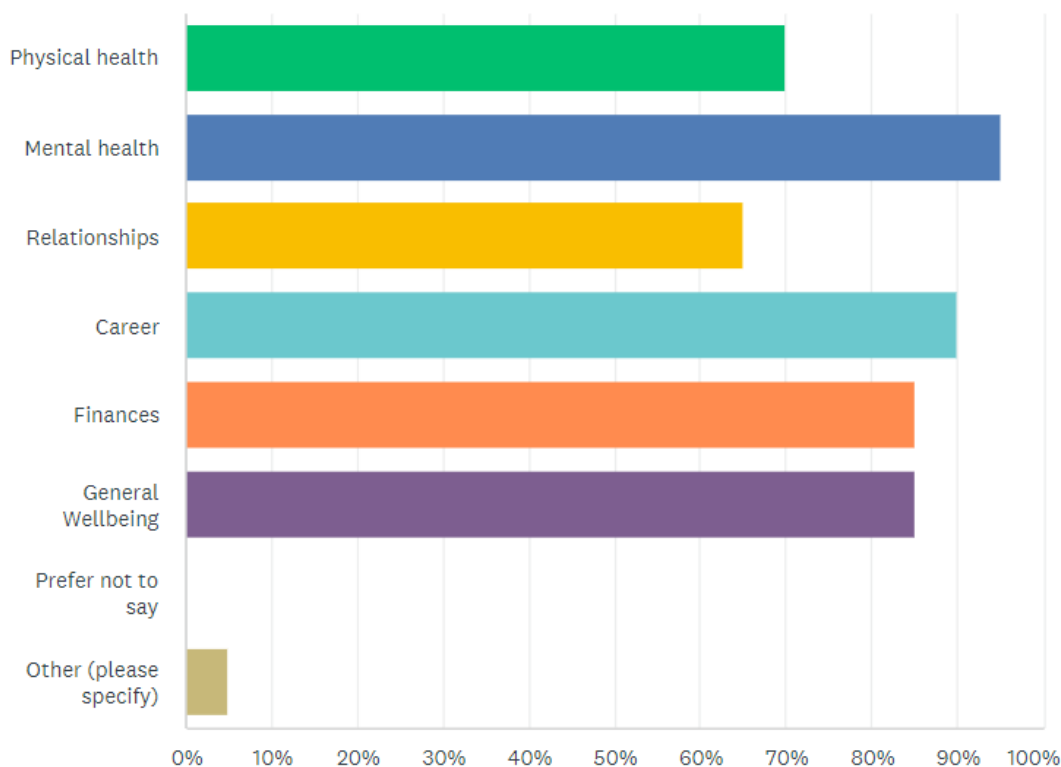


ANSWER CHOICES	RESPONSES
Minor	0.00%
Moderate	10.00%
Significant	85.00%
Prefer not to say	5.00%

Q13



Would you say that your child not receiving a full time education has significantly and negatively impacted any of the following areas for you? (Please tick all that apply)



ANSWER CHOICES	RESPONSES
Physical health	70.00%
Mental health	95.00%
Relationships	65.00%
Career	90.00%
Finances	85.00%
General Wellbeing	85.00%
Prefer not to say	0.00%
Other (please specify)	5.00%

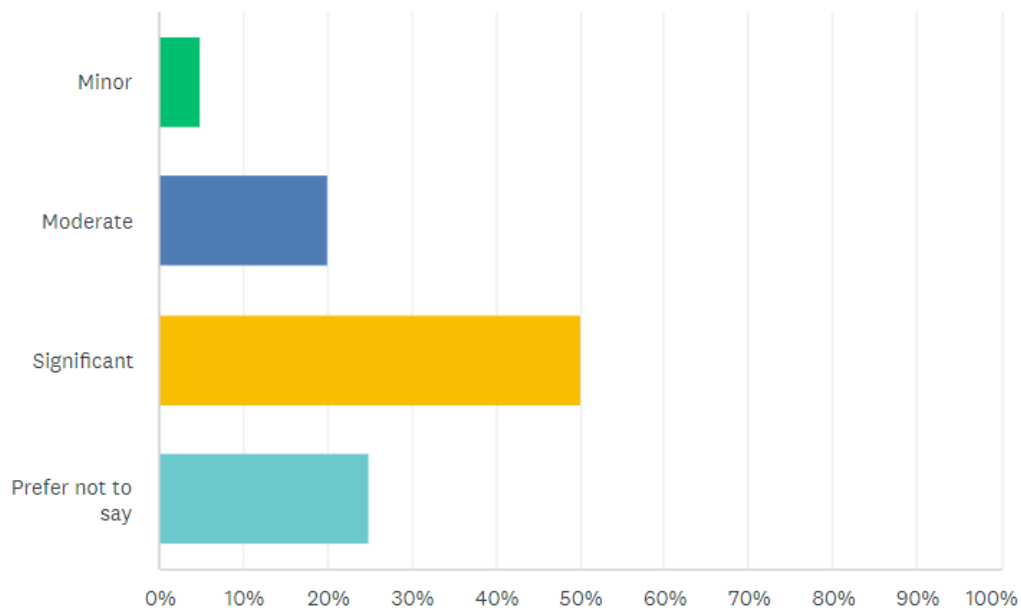
Answers given as 'Other' included parent's experiences that:

- They have been unable to seek new employment
- They have been unable retrain or even complete free of charge courses

Q14



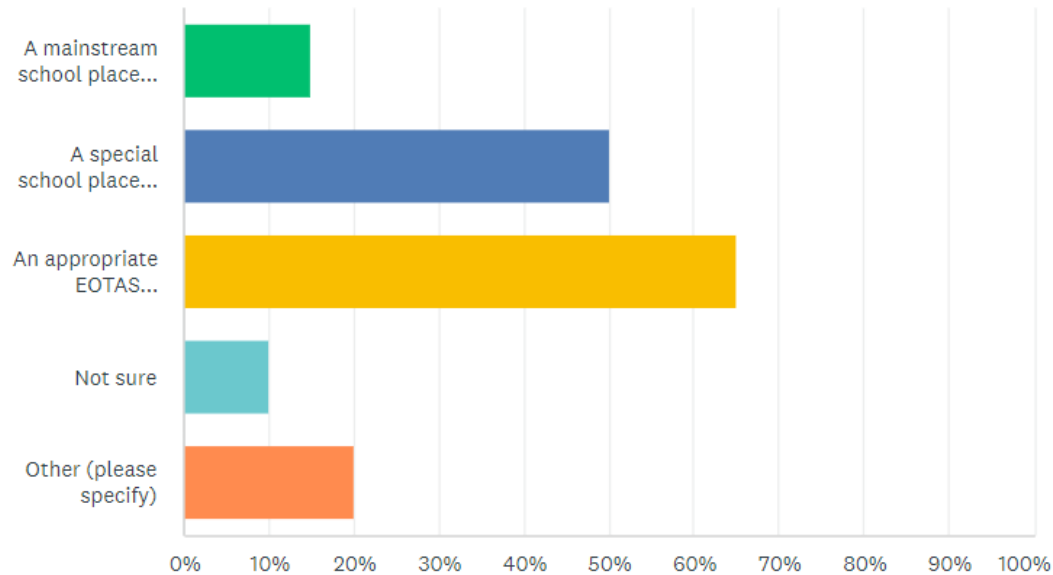
If your child has siblings, what would you say the impact has been on them?



ANSWER CHOICES	RESPONSES
Minor	5.00%
Moderate	20.00%
Significant	50.00%
Prefer not to say	25.00%



What would improve the situation for your child?



ANSWER CHOICES	RESPONSE
A mainstream school place where my child's needs are met	15.00%
A special school place where my child's needs are met	50.00%
An appropriate EOTAS (Education Other Than At School) package	65.00%
Not sure	10.00%
Other (please specify)	20.00%

Answers given as 'Other' included parent's views that the following could be useful:

- More readily available information on different schools, including more open days so that parents are fully informed and more easily able to identify a school that can meet their child's needs
- For the local authority to name a specialist placement if required without the need to go through the Tribunal process
- Smaller sized mainstream schools locally with appropriate support in place

Interpreting the Survey Data

Parents with children across a range of ages and stages responded to our survey. Almost half of our respondents have children who are Key Stage 2 age, with Key Stage 3 and 4 ages making up 25% each. Just 7% of respondents had children in Key Stage 1.

The results indicate that as children reach mid-primary school age the issues that they are experiencing become more pronounced, and continue into their teens.

40% of our respondents confirmed that their child's assessment was carried out after progressing through the CAMHS NDC (Neuro Developmental Conditions) pathway. This was followed closely by 36% who were assessed via an Independent (sometimes known as Private) provider. These providers are extremely costly with, for example, a combined child Autism and ADHD diagnostic package is priced at £2650 at a well-regarded clinic in Oxford (price correct as of 12th October 2022). There are variations in cost, dependant on the provider. The one used as an example provides the required NICE compliant level of testing (known as 'the Gold Standard') and Diagnostic Report. 24% of respondents obtained their child's assessments via the NHS directly (for example via the Community Paediatrics Department).

Over a third of our respondents felt the need to access expensive Independent diagnostic assessments for their child.

When looking at confirmed diagnoses, respondents were able to select all conditions that were applicable to their child, considering that a child may have multiple diagnoses or co-occurring conditions. 88% of our respondent's children have a diagnosis of Autism. This is followed by 48% having a diagnosis of Anxiety, and 32% having a diagnosis of ADHD. 16% of children have diagnoses of Dyspraxia or Sensory Processing Disorder and 8% have diagnoses of Profound and Multiple Learning Disability or Global Development Delay. 8% are still awaiting assessment and 4% have a physical health condition. Notably, most 'Other' responses mention Pathological Demand Avoidance which is a presentation profile of Autism, and one that is not currently 'officially' recognised as a diagnosis in its own right in Oxfordshire.

It is abundantly clear that Neurodivergent conditions make up the diagnoses for a significant majority of children who are experiencing difficulties accessing education. It is well known that clinical Anxiety is a key feature of Neurodivergent conditions such as Autism and ADHD. Sensory Processing Disorders are also extremely commonplace with these diagnoses.

Respondents were able to select multiple answers when asked why they considered that their child was not receiving a full-time education. 59% of respondents stated that their child was unable to attend school because the school could not meet their child's Special Educational Needs. This was followed by 50% of respondents confirming that their child's anxiety is at such a level that they could not attend school. 23% have children who are

attending a mainstream school but are of the view that their child is not receiving full time education because it has been confirmed that the mainstream school is unable to 'meet need' (which indicates an inability to educate the child as their needs require) and are waiting for a place to become available at a specialist placement. 9% of respondents are experiencing Transport issues which prevent their child from attending and 5% of respondent's children do not have a school place at all.

The survey responses indicate that a significant majority of children whose parents do not consider them to be receiving their education feel so because their children are enrolled at schools which are unable to meet their child's Special Educational Needs. Their children's anxiety levels as a result of not having their 'needs met' have escalated to crisis point and they are now unable to attend school at all.

Concerningly, particularly when considering the responses to the previous questions, 73% of respondent's children already have an EHC Plan in place. 14% have applied for a Needs Assessment but the local authority has declined to assess the child. 9% have never applied for a Needs Assessment and 5% have Needs Assessments currently in progress.

Almost three-quarters of respondent's children whose parents are of the view that their child is not receiving their education have an EHC Plan in place. The EHC Plan clearly sets out a child's Special Educational Needs and the corresponding Special Educational Provision that is required to fully meet these needs. The local authority has an absolute duty in law to ensure that all children who have an EHC Plan receive the Special Education Provision that meets their Needs, as specified.

We asked respondents how many hours education they considered that the setting (usually a school) named on their child's EHC Plan was providing. 27% felt their child was receiving between 26-30 hours per week. 18% stated 'None'. 9% felt that it was 21-25 hours per week and further 9% said 1-5 hours per week. 5% said 11-15 hours per week and a further 5% said 16-20 hours per week.

Just over a quarter of respondents whose children have an EHC Plan feel that their child's named setting is providing 26-30 hours education a week. Almost a fifth feel that the setting is providing no education to their child at all.

65% of respondents were unable to answer our question regarding children who are currently placed in a mainstream school but waiting on a special school placement to become available because it was not applicable to their situation. 30% of parents surveyed whose children are in this situation feel that their child is receiving between just 1-5 hours of education per week. 5% opted for between 6-10 hours per week.

The responses indicate that parents of children with SEND who are currently in mainstream schools whilst waiting on a special school place to become available are of the view that the education being provided to their child whilst they are 'in limbo' is minimal.

We asked respondents to confirm how long their child has been not been receiving their education. 35% said 12-18 months. 20% stated both 6-12 months and 18-24 months. 15% said over 2 years and 10% said 1-6 months.

It is indicative that the lowest percentage is also the shortest time period. It is clear from these results that respondents feel that their children are not receiving their education for extended and excessive periods of time. 70% of respondent's children have, in their parent's view, not received the education to which they are entitled for over a year.

50% of respondents said that they did not feel supported by their child's school, with 20% feeling supported and 30% appearing to feel mixed, opting for 'Other'. The responses given in the 'Other' category were also mixed.

85% of respondents said that they did not feel supported by the local authority, with just 5% disagreeing and 10% selecting 'Other'. The 'Other' responses pointed to understaffing issues, lack of resources, lack of transparency, delays, and parental frustration at constant chasing for updates only to see little progress.

Considering these two questions combined it is evident that the overwhelming majority of respondents are experiencing a lack of support from the professionals involved in and responsible for their child's education.

80% of our respondents reported that the impact of not receiving education on their child's mental health has been significant. 10% opted for 'Moderate' with 10% preferring not to say. No respondents reported that the impact was minor.

We asked respondents what the impact has been on their own mental health. 85% felt that the impact was significant, 10% felt it was moderate and 5% chose not to say. None said that the impact was minor.

We looked at the impact on the child's siblings. 50% shared that the impact on siblings was significant. 20% said moderate and 25% opted not to say. 5% said the impact was minor.

We also asked respondents which areas of their lives were significantly and negatively impacted by their child not receiving their education, with them being able to choose to select multiple issues from six areas listed. Mental health was the biggest area of impact, scoring 95%. Career followed, at 90%, with Finances and General Wellbeing scoring 85% each. Physical Health scored 70% and Relationships scored 65%.

Considering these questions together it is evident that the impact on children, the parents and the family unit's mental health and general well-being is significant. There are severe implications to be considered for the whole family when a child does not receive the education that they are entitled to as a result of their Special Education Needs and/or Disability.

Summary

The Oxfordshire Parent Carers Forum is committed to our responsibility of ensuring that parent carer voices in Oxfordshire are heard. We proactively communicate and engage with families of children with SEND daily, and where we identify patterns in experiences or common themes, we collate that information and convey it to the local authority. This helps to shape future improvement initiatives. We work co-productively with the local authority to drive these improvements.

All local authorities have a duty to provide an education to all children of compulsory school age. They are required to meet the specific needs of children with Special Educational Needs and/or Disabilities (SEND), a requirement that becomes an absolute duty when these children have an EHC Plan in place.

The family experiences documented in this report are current, gathered in September 2022. Fifteen parent carers have shared their stories with us to highlight the impact that their child or children not receiving the education to which they are entitled is having. Their stories are alarming, distressing, and indicative of widespread unlawful practice.

We have heard from parents and carers who have spent years fighting for their children to be understood and helped only to find themselves on seemingly never-ending waiting lists. There are examples given of children who have experienced multiple highly traumatic attempts to get them to 'fit' into a setting that clearly (often by the setting's own admission) cannot meet their needs. Children whose mental health has been so affected by these failures that they may never be able to access a school setting again.

We have heard from parents who face the prospect of their child not having a school place at all, in future. This is because they are enrolled at an officially acknowledged unsuitable mainstream school, and are now waiting years for a special school place to become available. The mainstream school, in the interim and for various valid reasons, may no longer be able to accommodate their child. For some families, this is already a reality. Their child has no place, and remains 'unallocated', long-term.

The survey data evidences that a significant majority of the children of the respondents have diagnosed Neurodivergent conditions, and high levels of diagnosed Anxiety and Sensory Processing Disorders. Nearly three quarters of our respondent's children already have an EHC Plan in place. Despite this, these children are still not receiving the provision and/or education that they are entitled to and their families are having to pick up the pieces with little support. This is having a devastating impact on the children and the entire family unit. We have heard from parents who have lost or had to leave their jobs, suffered relationship breakdowns, encountered financial difficulties, and become very unwell themselves directly as a result of the situation.

No parent, child or family asks or deserves to be in this position. The impacts described above can, and do, have lifelong effects.

Proactive action must be taken acknowledge these experiences and resolve these issues. Support must be provided to families and steps taken to transition the children back into the appropriate education for their needs, whatever form that may take.

What does this mean in practice? It means matching children to schools that can meet their specific needs. It means a much greater focus on early detection and intervention. It means carefully reviewing the law – not local policy – and ensuring that all legal duties are met without fail for every child.

It means investment in training for all school staff so that they are more empowered to begin the process of identifying children with SEN, as well as providing a deeper understanding of their needs and behaviours and how to support them in the classroom. It means that teaching staff will have greater knowledge to able to make their classrooms more inclusive in terms of environment, with even small, inexpensive adjustments making a difference. It also means embedding a positive culture in all schools where such children are welcomed, nurtured, and supported and where parents are always given the courtesy of transparency, respect, and the opportunity to work positively with the school rather than in opposition to it. Nobody wants to be 'that parent' or would choose to be seen as such. It is unacceptable that the reality seems to be that in order to obtain help for their child, in many cases, that is what it takes.

It means accepting that for some children with SEND, a traditional school setting may never be the right place for them and funding an EOTAS (Education Other Than At School) package before they reach the point that they are so traumatised by education that they're unable to engage with it at all.

It means actively listening to families, taking on board their views and concerns and acting on them. It means recognising that whilst the families may not the experts in education, teaching, law, policies, the various processes and difficult to understand systems; that they are *the* experts in their own child.

This report is not representative of every child in Oxfordshire with SEND. There will be many, many children in the county who are receiving the right support, who are in supportive schools, with exemplary staff and who are flourishing. However, it is evident, during a short exercise to collect experiences that there are children who are categorically not in this position. Those children, and their families, are floundering.

Recommendations

In order to see meaningful improvement in the long term, we recommend that the local authority:

- ❖ Commit to improving communication with families, to ensure that they receive transparent and accurate information at all stages of the process including regular updates and responses to telephone calls/emails
- ❖ Commit to actively listening to and engaging with families, taking into account their views and wishes and using them to construct positive outcomes wherever possible
- ❖ Commit to adherence to statutory timeframes for EHC needs applications, assessments, plans and subsequent annual reviews and plans amendments
- ❖ Review current local policy and procedure to ensure compliance with SEND law, followed by an annual audit and other measures such as regular quality-monitoring spot checks to ensure continued compliance by all staff
- ❖ Review SEND training provided to schools to ensure its adequacy and make improvements where necessary. All teaching staff and teaching assistants should receive comprehensive SEND training with additional more specialised sessions which are targeted, based on the needs of the child or children in the classroom
- ❖ Commit to a longer-term project to promote a culture change in schools to include a shift towards positive early intervention and more inclusive environments. Evidently, there are too many schools who demonstrate an outdated and unhelpful attitude to children with SEND. This must change
- ❖ Commit to providing comprehensive training to Senior Leadership Teams and SENDCos in schools to ensure their full understanding of the statutory obligations placed on them, and the local authority, to children with SEND
- ❖ Review the support offered to children and families where they are in the position that the child is not receiving or participating in education for whatever reason. At present, there does not appear to be any readily available
- ❖ Review the education provision provided by the local authority when a child is unable to attend their school. At present, some children are entirely without any education for extended periods if they are not able to attend. This is unacceptable, unlawful, and catastrophic for the children

- ❖ Improve access to specialist provision. If a child must remain in an 'unsuitable' mainstream setting whilst they wait for a place to become available for them, then a commitment must be made to ensure that 'above and beyond' measures are taken to meet their needs in the interim. Additional support by way of further funding, training, outsourcing and assistance in the recruitment of specialist staff if needed should also be provided to the setting

- ❖ Accept that for some children, alternative provision or EOTAS is the best outcome for them and where this is the case act swiftly to ensure they are being educated in the way that works for them, as soon as they can be

Comment

Oxfordshire Family Support Network:

"We welcome this report and would like to thank OXPCF for highlighting the current situation for far too many families in Oxfordshire. The lack of appropriate education for SEND children and young people has an enormous negative and long-lasting impact on the whole of the family. The distress to families is being compounded by parents not feeling listened to or believed and through sometimes careless and often poor communication - something we hear about all the time at OXFSN.

While the SEND 'crisis' is not unique to Oxfordshire these case studies are real and from here, they are distressing to read and it is highly likely there are more families struggling with the same or similar issues. It is imperative therefore, that officers and Councillors act now to address these failings."

Support and Advice Services

Oxfordshire Parent Carers Forum

The Oxfordshire Parent Carers Forum offers support to parent carers in the form of our closed peer-to-peer Facebook support group, The Oxfordshire SEND Room. All Administrators, Moderators and members are parent carers of children and/or young people with SEND.

Website: www.oxpcf.org.uk

Email: info@oxpcf.org.uk

Telephone: 07394 735666

The Oxfordshire SEND Room: www.facebook.com/groups/oxsendroom

SENDIASS Oxfordshire

SENDIASS Oxfordshire provides free of charge impartial information, advice and support to parents and carers of children with SEND.

Telephone: 01865 810516

Text: 07786 524294

Email: info@sendiass-oxfordshire.org.uk

Website: www.sendiass-oxfordshire.org.uk

Oxfordshire Family Support Network

Oxfordshire Family Support Network have a small team of Family Support Workers who are all family carers of people with learning disabilities and/or SEN. They can offer free of charge advice and support.

Telephone: 07891 734987 or 07821 987080

Email: info@oxfsn.org.uk

Website: www.oxfsn.org.uk

SOS!SEN

SOS!SEN offers a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs and Disability (SEND). They also offer regular in person drop-in centres in Oxfordshire.

Telephone: 0300 302 3731

Website: www.sossen.org.uk

IPSEA

Independent Provider of Special Education Advice offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND).

Website: www.ipsea.org.uk

Autism Family Support Oxfordshire (AFSO)

AFSO is a local charity which supports families, children and young people in Oxfordshire who have a diagnosis of Autism. Their support is free of charge. They also offer chargeable training courses and various supervised activities for autistic children and young people.

Telephone: 01235 754700

Email: info@afso.org.uk

Website: www.afso.org.uk

Oxfordshire MIND

Oxfordshire MIND are a local charity which can offer free of charge support to anybody who is experiencing difficulties with their mental health or well-being.

Telephone: 01865 247788

www.oxfordshiremind.org.uk

Samaritans

Samaritans is a national charity which offers free of charge support 24 hours a day, 7 days a week to anybody who is experiencing difficulties.

Telephone: 116123

Email: jo@samaritans.org

Website: www.samaritans.org

SHOUT

Shout is the UK's first and only free text messaging support service for anybody who is struggling to cope. Text 85258 for support.