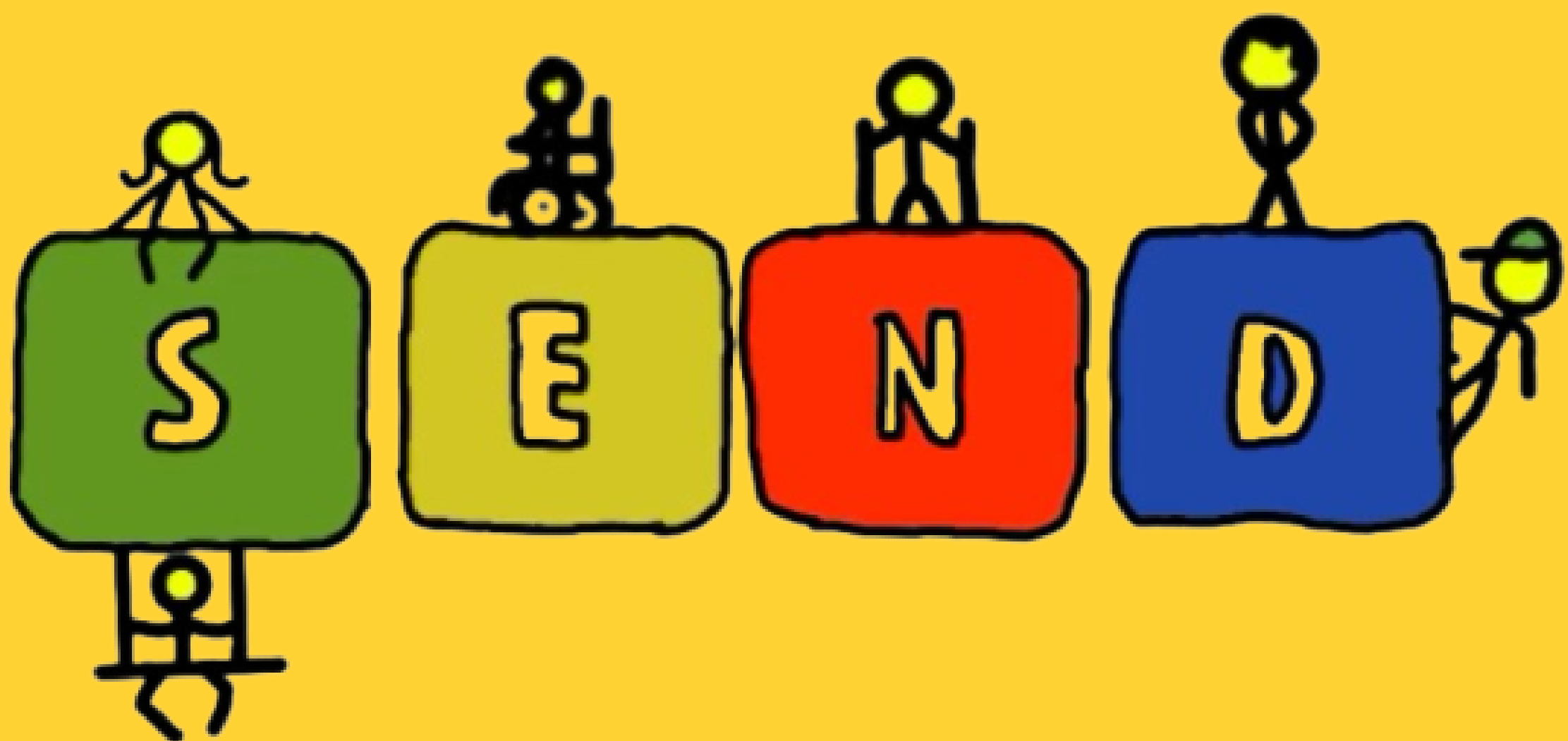


Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability (SEND) support for children after the COVID-19 pandemic.

The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study

Evidence briefing 2: Qualitative interview data; Children with SEND, parent/carers and professionals' perceptions of the impact of the COVID-19 pandemic



**Dr Emma Ashworth, Liverpool John Moores University,
Dr Joanna Kirkby, Liverpool John Moores University,
Prof. Lucy Bray, Edge Hill University,
Prof. Amel Alghrani, University of Liverpool.**



Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability (SEND) support for children after the COVID-19 pandemic.

Executive Summary

Background to the Study

This study was funded by the National Institute for Health Research's (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2021. The work aimed to examine the perceptions, experiences and lessons learnt in order to scope, understand, and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children with SEND.


In the United Kingdom (UK), the Department for Education and the Department of Health (2015) states that a child that has special educational needs and disabilities (SEND) if 'they have a learning difficulty or disability which calls for special educational provision to be made for him or her' (p. 16). They then expand on this definition by stating that a child has a learning difficulty or disability if he or she 'has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions' (p.16). To ensure that each child receives the support they need, some children with SEND have an Education, Health and Care plan (EHC Plan) drawn up by their Local Authority. An EHC Plan is a legal document that describes a child or young person's individual special education, health and social care needs and the additional support that will be given to meet those needs.

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in the provision of services for children with SEND (CQC & Ofsted, 2020; Harris & Davidge, 2019; Byrne, 2020; National Autistic Society, 2021; Alghrani & Byrne, 2020). In March 2020, the UK Prime Minister implemented the first national lockdown to slow the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and COVID-19. The lockdown involved those who were not key workers staying at home, not mixing with other households, and social distancing when in public. Schools were closed except for the children of keyworkers and vulnerable children. NHS staff were redeployed to respond to COVID-19 related pressures (Special Needs Jungle, 2020), and education, mental health and social care services were rapidly withdrawn (National Autistic Society, 2020). In May 2020, children with EHC plans had their educational rights formally downgraded (Byrne, 2020; Children's Commissioner, 2020) by the Coronavirus Act.

Study Design and Methods

The research was a rapid cross-sectional multiple phase mixed-methods study. The three phases of the study were:

- Phase 1: A rapid scoping review of the evidence related to children with SEND during the pandemic.
- Phase 2: An online survey and interviews to gain the perspectives of children with SEND, parent/carers and professionals (health, social care, education and local authority).
- Phase 3: Stakeholder workshops to co-develop priorities for 'going forward' for children with SEND, parents/carers and professionals to promote recovery and renewal.



This report focuses on the qualitative interview data from Phase 2, which examined the reported impact of the COVID-19 pandemic on children's education, health and social care. Semi-structured interviews were conducted via online platforms, and interviews with children used creative methods to facilitate the conversation. Data was analysed using thematic analysis.

Key Findings

Four children aged 8-14 with SEND, ten parent/carers, ten health and social care professionals, three education professionals and two local authority professionals took part in the interviews. Interviews were conducted between August and September 2021. Participants were distributed across the UK, and a range of multi-disciplinary health and social care, educational and Local Authority professionals took part. The key findings are presented according to participant type.

Children with SEND's Perceptions of the COVID-19 Pandemic

Children with SEND told us that lockdowns had been “lonely” and “boring”. They could not go out of the house as often and lacked the opportunity to socialise. Children took part in activities and played games inside the home, and they did not like remote learning. Children preferred coming out of lockdown and going back to school. We recognise that some of the themes are not necessarily SEND specific, however, the lockdown compounded existing SEND, e.g. children with Attention Deficit Hyperactivity Disorder (ADHD) were unable to do the activities that allowed them to expend their energy, children with Autism Spectrum Disorder (ASD) struggled in particular with the change in routine and friendships and for many it exacerbated underlying social and communication difficulties. Participants noted that these issues amplified difficulties already disproportionately experienced by children with SEND, and negatively impacted on their social, emotional and physical development and health.

Parents/Carers of Children with SEND's Perceptions of the COVID-19 Pandemic

Parents/carers told us that there was already a pre-existing lack of support for their children with SEND, and this was exacerbated during the pandemic. Health care, health appointments and therapies were cancelled, delayed or moved online. Parents/carers reported that the pandemic negatively impacted their child with SEND's mental health.

School places for children with SEND were reported as not being available during the first lockdown and there was a lack of support and communication from school during periods of online learning. Remote learning for children with SEND was extremely challenging, if not impossible, as it was inaccessible and schoolwork was not differentiated for their child's needs. Parents also told us that their child had little support with transitioning back to school after national lockdowns. Parents described how the requirements outlined in their child's EHC Plan needs were not met. The pandemic was reported as also impacting on their child's friendships and social interaction, as activities and clubs for children with SEND completely stopped. Parents also spoke about a lack of respite and short-breaks and how this impacted on a decline of their own mental health.





Health, Social Care and Education Professionals' Perceptions of the COVID-19 Pandemic

Professionals told us that children with SEND were not taken into consideration during the pandemic. Those interviewed reported that the services that support children with SEND were prevented from operating and that guidelines were unclear, inconsistent, and rapidly changing. Professionals identified challenges in being able to work directly with children and concerns this raised about safeguarding and social care provision. Professionals told us about increased demand for services, increased waiting lists, staff shortages, and increased workload and burnout. Despite many challenges, professionals described supporting and reassuring parents during the pandemic and trying to maintain support to families in crisis. Professionals also commented on the accessibility of remote support and how online working had facilitated improved inter-agency collaboration.

School places were reported as being not available for children with SEND as well as the many challenges encountered in engaging children in remote learning. For those children who had been able to access in-person schooling, small classes were reported as working better for children with SEND. Professionals reported that over lockdown, some parents had gained a greater understanding of their child's needs.

Conclusion

In conclusion, the needs of children with SEND were perceived by those interviewed to have not been given (any) appropriate consideration during the pandemic. The health and social care services, clubs and activities that support children with SEND were prevented from running face-to-face, and most children could not go to school during the first lockdown, despite government guidance stating that those with an EHC Plan should be deemed 'vulnerable' and able to attend. Online appointments and remote learning were deemed not to be a sufficient alternative for most children with SEND. Children with SEND were bored and lonely and their mental health declined. Parents /carers of children with SEND received no respite or support and consequently their mental health also declined. During the pandemic, professionals encountered many more families of children with SEND in crisis and had concerns over safeguarding due to not being able to 'see' children in person. There has been an increase in demand for services, longer waiting lists, staff shortages and burnout among staff who support children with SEND.



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Introduction

In the United Kingdom (UK), the Department for Education and the Department of Health (2015) stated that a child has special educational needs and disability (SEND) if 'they have a learning difficulty or disability which calls for special educational provision to be made for him or her' (p. 16). They then expanded on this definition by stating that a child has a learning difficulty and disability if he or she 'has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions' (p.16). To ensure that each child receives the support they need, some children with SEND have an Education, Health and Care Plan (EHC Plan) drafted by the Local Authority in consultation with the parents/carers. The purpose of an EHC Plan is 'to meet the special educational needs of the child or young person, to secure the best possible outcomes for them across education, health and social care and, as they get older, prepare them for adulthood' (DfE & DoH, 2015, p.142). This EHC Plan identifies each child's individual needs and the additional support required to meet those needs. Currently, 3.3% of children in English schools (or 294,800 children) have an EHC Plan because of their disability, while 12.1% of children (or 1,079,000 children) receive additional special educational needs (SEN) support (DfE, 2020).

Children with SEND are some of the most vulnerable children in the education system (Byrne, 2020) and are disproportionately exposed to poverty. Government statistics show that more than twice as many pupils with an EHC Plan get free school meals (35%) than pupils without SEND (around 15%) (Skipp, 2021). Children with SEND are also more likely to have a diagnosed mental health condition. For example, just over a third (36%) of children with a mental health condition also have a SEND (compared to 6% of children without a SEND), and 72% of children with a diagnosed mental health condition also have a physical health condition or a developmental disorder (NHS Digital, 2018). Furthermore, in 2018 children with SEND comprised 45% of all children who had been permanently excluded from all state-funded primary, secondary and special schools (DfE, 2019; Byrne, 2020).

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in provision for children with SEND (CQC & Ofsted, 2020; Harris & Davidge, 2019; Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020). Support for children with SEND was described as already diminished, threadbare, and chronically underfunded (O'Hagan & Kingdom, 2020; National Autistic Society, 2020; Boesley & Crane, 2018; Byrne, 2020), with an estimated funding shortfall of £1.5bn (Disabled Children's Partnership, 2018). In 2019 the Disabled Children's Partnership found that only 4% of parents and carers could safely care for their disabled child(ren) with the amount of support they received. On top of this, the framework for the provision of services for children with SEND is 'characterised by confusion, unlawful practices, bureaucratic nightmares, buck-passing, and a lack of accountability, inadequate resources and an overly adversarial process for parents' (Alghrani & Byrne, 2020, p. 2).

In March 2020, the UK Prime Minister implemented the first national lockdown to slow the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; COVID-19). The lockdown mandated that all except key workers stayed at home, to not mix with other households, and to socially distance when in public. Schools were closed except for the children of keyworkers and vulnerable children. NHS staff were redeployed to respond to COVID-19 related pressures (Special Needs Jungle, 2020), and education, mental health and social care services were rapidly withdrawn (National Autistic Society, 2020). In May 2020, children with EHC Plans had their educational rights formally downgraded (Byrne, 2020; Children's Commissioner, 2020) by the Coronavirus Act 2020. However, on the 28th April 2020, the Secretary of State for Education issued the relevant notification as required under paragraph 5 of Schedule 17 of the Coronavirus Act 2020 to modify section 42 CFA 2014 which meant the Local Authority only had to make 'reasonable endeavours' to provide children with EHC plans with the support they need.

Thus, from 1 May to 31 July 2020, the absolute legal duty conferred upon Local Authorities to deliver the special educational and healthcare provision set out in a child's EHC Plan under section 42 of the CFA was modified to a 'reasonable endeavours' duty to secure the provision. Whilst the relaxation was intended to balance the pressures that councils and others were under, the term 'reasonable endeavours' was vague, lacked specificity and left little room for accountability when vital services were not provided.

Study Overview

Dr. Emma Ashworth (Liverpool John Moores University), Prof. Lucy Bray (Edge Hill University), and Prof. Amel Alghrani (University of Liverpool) were funded by the National Institute for Health Research's (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2021. The research was a rapid cross-sectional mixed-methods study to scope, understand, and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children with SEND.

The research aimed to engage with children with SEND, their parents/carers, and key stakeholders across three phases;

1. Phase 1: A rapid scoping review of the evidence related to children with SEND during the pandemic, to examine the existing evidence and policy.
2. Phase 2: An online survey and interviews to gain the perspectives of children with SEND, parent/carers and professionals (health, social care, education and local authority) to capture the impact and lessons learnt, experiences and reported impacts of the COVID-19 pandemic on the long-term development and wellbeing of this generation.
3. Phase 3: Stakeholder workshops to co-develop priorities for 'going forward' for children with SEND, parents/carers and professionals to promote recovery and renewal.

This report focuses on the qualitative interview data from phase 2, which examines the reported impact of the COVID-19 pandemic on children with SEND's education, health and social care. Ethical approval was gained through the lead researcher's institutional research ethics committee (UREC Ref: 21/PSY/024, 21/PSY/026).

Methods

This phase of the study utilised a qualitative approach to data collection and analysis.

Recruitment and Participants

At the end of the online survey in phase one, parents/carers and professionals were asked if they would like to participate in an online interview. Participants who registered an interest were contacted via an email with an invitation to participate (for parents/carers this was both for themselves and/or their children) and were provided with participant information sheets. If potential participants responded, written opt-in consent was then sought from parents/carers and professionals, and opt-in assent for children. If children wanted to participate, they were offered a 'quick hello' meeting via the online platform to talk about the study, meet the researcher, ask any questions they may have, and allowed the researcher to ascertain their communication needs.

Data Collection

Data was collected using semi-structured online interviews. Interview schedules were designed with patient and public involvement from children with SEND, parents/carers of children with SEND, and steering group guidance. Separate interview schedules were designed for children, parents/carers, education professionals, health and social care professionals and Local Authority staff. The interview schedule followed a semi-structured format to ensure that certain topics highlighted by the survey were covered, but that participants had the flexibility to lead the interview direction and talk about issues of importance to them. Questions were open-ended, and prompts were used to elicit more detailed responses. Questions for parents/carers, children and professionals covered topics such as the positive and negative impacts of the COVID-19 pandemic on children with SEND, experiences of education, health and social care provision during the pandemic, and the priorities for moving forward out of the pandemic. An activity worksheet was provided to children before the interview so that they knew what to expect and could have a think about the questions beforehand. Questions were tailored for children so that they were appropriate for different ages and abilities. The data were collected between August and September 2021.

Data Analysis

Interviews were transcribed, read, checked and 'quotable quotes' (Hunter, 2010) were identified. The 'quotable quotes' were then analysed by the research assistant for each participant group using thematic analysis. Coding was conducted using NVivo. Final themes were then checked by the research team.

Findings – Children with SEND

Participants

Four children aged 8-14 (all male) with SEND (including autism, ADHD, blind, deaf, dyslexia, anxiety and 'medical conditions') took part in an interview. The interviews lasted between 9 and 15 minutes. One child took part in a 'quick hello' meeting and expressed a preference to type their answers to the interview questions and send these through to the team.

Findings

The main themes identified in the data included: Lockdown was "lonely" and "boring"; not being able to go out; lack of opportunity to socialise; activities and games; remote learning; and coming out of lockdown and going back to school. We recognise that some of the themes are not necessarily SEND specific, however, the lockdown compounded existing SEND, e.g. children with Attention Deficit Hyperactivity Disorder (ADHD) were unable to do the activities that allowed them to expend their energy, children with Autism spectrum Disorder (ASD) struggled in particular with the change in routine and friendships and for many it exacerbated underlying social and communication difficulties. Participants noted that these issues amplified difficulties already disproportionately experienced by children with SEND, and negatively impacted on their social, emotional and physical development and health. The participants have been allocated pseudonyms.

Lockdown was "lonely", "boring" and it stopped me going out

One child, reported how he had been *"very lonely"* during lockdown. When asked what being at home during lockdown was like the children described being bored, Jamie (who is dyslexic and has ADHD) told us that lockdown had been *"a bit boring"* and had made people sad:

"You just basically do the same thing over again... I didn't really have anything to do, a bit boring... There was nothing really good about being locked down, we can't really do anything or go out or anything, and it does make people sad."

When asked how lockdown had affected his wellbeing, Matthew (who is autistic) commented:

"I feel like it wasn't too bad because obviously, the lockdown was there for a reason. So I obviously obeyed it. But it wasn't nice, but you have to do it because it's the law and also to stop infections. So it was for a purpose. So it didn't really hurt me that much."

Nick (who is blind and has a speech disorder) commented on a positive about lockdown: *"It was calm and quiet. I am finding the world very noisy. The air was unpolluted."*

Children spoke about not being able to go out. Jamie said: *"You can't go out with your parents or whatever because my parents had online work"*. Similarly, Matthew noted: *"You can't go outside. So really, there's not much you can do"*. Jamie spoke about still not being able to go to some places because of COVID-19:

"I mean, there are still some places now I haven't even been still because of the virus... Like places where you go just to have fun and stuff, and the park, back then you couldn't even go to the park."

Children told us that throughout lockdown, they did activities at home. Liam (who has autism and ADHD) told us: *"Made stuff! Made loads and loads and loads of stuff!"* Nick commented: *"I learned to read and write. I did lots of maths. I played board games and piano."*


Liam's advice to other children about how best to manage the lockdown was to *"get a trampoline"*, and Jamie told us that playing games on a console helped him: *"Well basically, I just went on my Xbox... It helps me get through general life."*

"I could not use zoom like other children": Lack of opportunity to socialise

During the pandemic, the children who took part told us they lacked the opportunity to socialise: *"I had no social contact with other kids"* (Liam) and they missed seeing extended family members: *"It was kind of like not nice not being able to see like my Nan or somebody for ages and I could only see them through the window, that wasn't nice and probably made me feel a bit sad."*

Matthew talked about how important it was to keep in contact with people over video call:

"I would say my advice would be to just make sure you're just talking to someone like through a video call or just have some contact because it would be very boring if I didn't have my phone to video call people, I wouldn't like it. I always just had my phone fully charged just because I was able to ring someone."



However, this was not possible for all children with SEND, who could struggle with this type of communication as Nick explained:

"I could not use zoom like other children. I cannot see, and the sound is not enough. I could not follow the conversation. I really need to touch people to know what they are paying attention to."

"I don't think I learnt much": Remote learning

Children spoke about their experiences of education and learning over lockdown. When Liam was asked about schoolwork over lockdown he replied: *"Oh no, I didn't have any"*. Jamie told us about the challenges of engaging in online learning:

"No, I don't think I learnt much. It was just not good... Online school did not really do anything, I'd say, because loads of people could just skip the lessons, have the video playing, and they're never even there. I mean, in mine, it was muted, and you couldn't even see their face."

Matthew described how the lack of contact with school meant he did not really engage in the online lessons:

"I didn't really like trying to do the online work because that was just horrendous... The school, which I went to specifically, they didn't ring us up. We never did any lessons where we had, what's it called? Be on a zoom call... We didn't really have that many calls. We rarely ever actually rung the teacher... I feel like it could be massively improved, you kind of have to just try and do it by yourself. That kind of put me off. It was really annoying just trying to Google it."

When asked how remote learning could have been improved, Matthew responded:

"They need to improve it [online learning] massively, because it's really inadequate because, as I said, the teachers don't message you that much, and when they do message you, it's more of a message to everyone. Not you specifically."

"It was better when we went back to school": Coming out of lockdown and going back to school

The children involved described positive feelings associated with coming out of lockdown. Jamie spoke about how he was able to socialise when restrictions started to lift:

"You could actually go out. You could actually go to a few places and still be there. You actually could socialise. It was a lot better because people are generally meant to socialise."

When asked about going back to school, Liam said: "Fun" and Matthew described how;

"It was better when we went back to school... because you can actually speak to the teacher and you're actually getting taught it in class rather than through a video."

Some of the children, described issues with feeling safe when returning to school and the application of the COVID-19 restrictions in school. Jamie's school had experienced high levels of infection:

"My school was not too good with the COVID restrictions, I'd say, because once it got shut down for not having good COVID restrictions, and a second time, a bunch of people had gone and had the virus, and on the last day of school before summer, there was there was only a few people in there. There was only about five people, maybe even less in some of my lessons."

Matthew mentioned the use of bubbles as part of the COVID-19 restrictions in school:

"Basically, what it was like, we had our own different classes. Like, because we had nine A, B, C, D, we had our bubbles, and we weren't allowed to leave our bubbles. So yeah, we couldn't leave our bubbles, but we did our lessons, but I didn't really see the point of the bubble. So it didn't really work because when it was like break time everyone just saw each other anyway so it defeats the entire purpose of having bubbles."

Findings – Parents/Carers of Children with SEND

Participants

10 parents /carers (all female) of children with SEND (including autism, ADHD, sensory processing disorder, anxiety, Global Development delay, attachment disorder, dyslexia, chromosome deletion syndrome, epilepsy, and learning difficulties) were interviewed. The online interviews lasted between and 18 and 55 minutes.

Findings

The themes identified were organised into five overarching categories: 1) the pre-existing lack of support for children with SEND, 2) health and social care, 3) education, 4) children's activities and social interaction over the pandemic, and 5) parent support. Themes for each category are listed below:

- 1) Pre-existing lack of support for children with SEND** which was exacerbated over the pandemic.
- 2) Health and social care:** health appointments and therapies being cancelled, delayed or moved online; the impact of the pandemic on children with SEND's mental health.
- 3) Education and learning:** challenges in school places for children with SEND during the first lockdown; lack of support and communication from school during remote learning; remote learning for children with SEND; inaccessible technology; no differentiated work; the transition back to school; attending school; the Government guidelines did not work for children with SEND.
- 4) Friendships, activities, and social interaction:** friendships and social interaction; the cessation of activities and clubs for children with SEND.
- 5) Parent support:** lack of respite; mental health of parents of children with SEND during the pandemic.

1. "We had a battle to get what is needed": Pre-existing lack of support for children with SEND exacerbated over the COVID-19 pandemic

Several parents/carers framed their accounts by descriptions of how they had to struggle to try and get their children the support they needed even before the pandemic began. Parents/carers described at length how they had to ask for support and access to services "time and time again" and despite this often still did not receive any support.

This lack of support was reported as having a detrimental impact on both the child with SEND and their family. Nicky, whose son has autism and co-morbidities, described the impact on her and her son of not being listened to and the process of trying to get the appropriate support for her and her son:

"There was very little support to start with. We already couldn't access any support so we weren't getting any... So as Mum, I've had a breakdown because of it all because you just feel like you've failed your child. My husband and I separated last year because it just became too much for me to handle everything... But I don't think that would have all happened had we had support from the start. Yeah, it's a long and complex story of lots of letters back and forth and phone calls... Following that, we do now have a traumatised child with complex SEND needs... No true support, it needed to be a lot earlier, and I needed to be listened to."

Steph, who has one son with autism and co-morbidities and another son with ADHD and "numerous medical conditions", described her ongoing battle to get continued support for one son:

"So there wasn't enough [support]. There certainly wasn't adequate amounts prior to lockdown, and there certainly isn't enough now... They'll do a block of interventions. Once that blocks over, they will discharge, and then school have to re-refer in. So we had a battle trying to get school to re-refer in, when they finally did it they said 'No, we've already been out in the past'... It was frustrating because there was things that were required at school that school wouldn't put in place, even though I was telling them that's what is needed."

Marie, who has a 7-year-old daughter with multiple conditions and an eight-year-old son who is on a pathway to being diagnosed told us that it has always been a challenge to access support:

"The system itself is in such huge knots. Accessing health has been always been a challenge but it is a lot worse now because the NHS overstretched. It's not so bad if you can afford to fund it privately which historically I could, but now I can't."

2. Health and Social Care

"Everything stopped, I mean literally everything": Health care, health appointments and therapies were cancelled, delayed or moved online

During the pandemic, much of the little support that had been previously available completely stopped. Nicky's response to the question 'Was there anything that supported you as a family over COVID?' was as follows:

"No is the simple answer. No, there wasn't, and I think this is what brought everything on to its knees... I think that was the difficulty, even if we would have just been validated and just checked on once a week, just a phone call... So we were very alone. Very very alone."

Many parents told us that their children's 1-to-1 care, health appointments and therapies completely stopped once the pandemic began. Mel, whose 6-year-old son is deaf and has a developmental delay, explained:

"It was frustrating because everything stopped, I mean literally everything. We've not seen as many professionals... It took away any kind of support that there was."

Another parent, Marie, talked about how their therapies had been cancelled and still have not resumed:

"We were receiving Occupational Therapy pre-lockdown, but that obviously stopped, my son was receiving Psychology, but that obviously stopped... The waiting lists for the therapists are all very long. I don't know when they're going to be back up and running. Even the therapists they were seeing are too busy to take them back on again."

Parents told us that although some appointments went ahead online, the cancellation of in-person physical health appointments was very worrying, especially if their child had a progressive condition. Julie, whose 15-year-old son has a rare genetic condition, explained:

"Because he's planning to have his operation, a lot of those sort of pre-op discussions continue, just differently online, but any other kind of key physical health appointment just stopped, and for somebody like him with a progressive condition that changes, it's been very worrying not to have had physical appointments."

For one parent, Steph, the delay in a health appointment was described as impacting on her 9-year-old son's plan for surgery:

"Then COVID came along, and they weren't scanning anybody whose conditions were stable. So within that time, three years had actually passed because of the lockdown. They did the MRI scan in January, and we had to wait until the March to have the appointment with the consultant for him to say everything had got quite bad, and he needed major spinal surgery. So obviously, we don't know whether he would have needed that surgery, or surgery that extreme if we had to have the scan within the proper timeframe."

At the time of the interviews (August/September 2021), parents told us that they were still experiencing delays in accessing services for their child with SEND. One parent, Lauren, whose son has genetic and medical conditions, told us:


"I've asked for an assessment of the house just to see what we need to alter, and I asked for that in July, and they're not coming 'till October. So everything is just a lot slower, but I don't know why it's so delayed."

Several parents accounts highlighted how the cancellation of speech and language therapy during the pandemic led to the regression of their child's speech and language ability. Marie told us about the effect the lockdowns have had on her children:

"They've both got good vocabulary. Instead of using it, they've gone back to baby speak. My daughter often says that she's a dog and will just bark at me."

As well as delays in accessing speech and language services, mask-wearing was described as difficult for some children with communication issues. Julie commented on the effect that everyone wearing face coverings when in public areas had had on her son who lip-read:

"The whole COVID situation for young people with communication issues has been really difficult because of wearing masks, and I think that's had a massive impact on him... He used to lip read, and that was the same even when he was admitted to hospital. I found that was such a big challenge that staff were still speaking to him with masks on. He couldn't hear."



However, the pandemic was not described as having a negative impact on all children's speech and language development. Lauren suggested that the lockdowns might have had a positive effect on her son's speech development:

"Interestingly, I think because he had more 1-to-1, his speech has actually started coming on. So I think that's a positive thing. I'm not saying it wouldn't have happened anyway, but I actually don't think it would have happened as good as it is."

"The anger and violence escalated a lot": The impact on children with SEND's mental health

Many of the parents shared accounts of their child's declining mental health during the national lockdowns. Nicky commented on what it was like for her autistic son during the pandemic:

"Being very sad, saying he didn't want to live the next day. He stopped eating for three days last autumn, and we ended up in A&E because he wanted to die... He didn't understand what was happening."

Natalie, whose son has autism, ADHD and anxiety, told us about the effect lockdown had had on her son's emotions and behaviour:

"He went through a stage he had night terrors every night... It was very difficult, and [he] had some very dark times with his violent behaviour and anxiety that that was mostly aimed at me when I got home... The anger and the violence escalated a lot, so I had a black eye, and we had a lot of breakages at home and things like that because I suppose he couldn't vent his stress anywhere else because we were at home all the time."

Many parents told us about how they had struggled to access support from Child and Adolescent Mental Health Services (CAMHS). When asked what support had been available from CAMHS for their child, Natalie told us:

"Nothing. We've been referred through to them, I want to say three times... But there was nothing else they could do but refer back if we needed. So each time we have referred back, we have been rejected... So it was like every point, we never quite met the threshold... I don't know how bad it would have to have got to actually get support."

Nicky told us that she felt mental health support needed to be offered earlier for autistic children:

"We need healthcare to understand what it's like to be autistic, and to actually offer these services earlier than when kids are self-harming of, you know... I know the suicide rate is a lot higher in autistics because of trauma, but even knowing all of that... The money isn't put in place."

3. Education and Learning

"They refused to have him in school": School places for children with SEND during the first lockdown

Many of the parents interviewed were not automatically offered a place in school for their child with SEND during the first national lockdown. Kate, whose daughter has autism and learning difficulties, gave an example:

"So they refused to have them in until the May when my eldest's school actually phoned them and said, 'you've got a duty of care, and their mum is really struggling, so you need to take them.' Even then, they only agreed again part-time for three days."

Natalie also told us about her battle to get her son a school place during the first lockdown:

"We had a bit of a battle, and in the end, the educational board was contacted because even due to my job, and even with him being on the SEN register... The school didn't want to have him back during the lockdown because they said they couldn't staff it, but in the end, a social worker contacted the educational board. He said yes, he ticks every box to be in the educational setting full time, but in the end, it was done that he was on a reduced timetable."

Even for those parents who were keyworkers, their child with SEND was not always allocated a place at school. Lauren described a similar experience whilst trying to get her son with complex needs a school place:

"So the last headteacher... I had to ring her up and say we're both keyworkers, he needs to come into school, and she was still refusing... So that was hard in itself, even getting him into school... She was saying because he is more complex, the rest of the children in his class are on the spectrum, so they can walk and eat and do other things. So obviously, because he needs a lot more support, she decided that he would be the one that wouldn't be in school... I emailed back to say he's got a legal right to be in school, but then she didn't get back to me after that."

"School pretty much ignored her": Lack of tailored learning, support and communication from school during remote learning

A perceived lack of support from school was a common theme discussed by parents/carers interviewed, with several parents/carers feeling that their child's school had not provided adequate education for them during the pandemic. Amy, whose daughter has ADHD and co-morbidities displayed this in the following comment:

"The teacher that we had at primary school didn't really want to engage or send any homework back. He was looking after the majority of the classroom and seemed to ignore [her], which is one of our big upsets. They got homework and tests and, you know, all the fun things as well. And communication, she wasn't offered anything by him, he pretty much ignored her... We did feel very let down by the school's provision for her and her needs. So as a Mum, I just felt, again, just having the child with a disability and coming at the back of the line, really. So it was a big disappointment for us."

Likewise, Kate talked about a lack of support and communication from school to facilitate her daughter's education during periods of remote learning:

"There was no communication or no support for her from when she wasn't in the building. So you know, nobody would contact me and say, 'how are you getting on? Is anything we can do?' I even said, 'can you send homework in a paper format? So at least when she's not in school, she can still do something.' But no, they wouldn't do that. Point blank refused. They could have been a lot more supportive and adaptable."

In a similar fashion, Lauren talked about how staff in her son's school could have been more supportive and communicated with her better during periods of remote learning:

"They could have actually taken that time to ring the parents and say how are things going? Is there anything that we need to help on? Because communication was a massive issue last year, and these are the times that I think the teachers should be helping and supporting more."

Amy, reflected that she had maybe been too accepting of the situation and spoke about wishing she had made the school more accountable to provide education and learning for her child with SEND:

"Make the school accountable. And I think at the time, you know, thinking about it, I was probably a bit too quiet. I should have been probably banging on the door and going to the local press about it... I know it was a very unusual situation for everybody. But there's no excuse for ignoring the child with SEND just because you don't really get it."

Parents/carers told us that their children were often unable to do the work set by the school during periods of remote learning as the work was not differentiated and did not meet their child's needs. Steph described her son's experience of remote learning:

"We literally only logged into the, they had like a class assembly thing for 10 minutes a day. There was nothing. Because of his needs, it would be impossible to try and get him to do it. They used set work, just standard work. It wasn't individual for him."

"It was hell on earth": Remote learning for children with SEND

Children with SEND who were not in school during the lockdowns were offered remote learning by their school. Many parents/carers told us how they had initially tried hard to implement remote learning with their children but soon stopped when they realised remote learning did not work for their children. Marie described how her children had been unable to cope with home-schooling:

"There is absolutely no way we could home-school. We tried it during the periods of isolation, and it was just hell on earth... As soon as my attention is diverted to one trying to do the set work, the other is just bouncing off the walls, running across the furniture... In the end, I'll be honest I abandoned it... Our kids, they do schoolwork at school, and home is for home, and they just can't cope with the concept that the two mix."

Kelly, who has one autistic son, and one son with dyslexia, ADHD and medical conditions, told us how difficult home-schooling was both for her children with SEND and the family:

"Oh my god, so hard, so hard. [He]'s capable of doing work, really capable, but he can't self manage. So he would never think of just logging on and doing work. We'd be constantly telling him, and then it'd be arguing, and it was very, very hard work... So we just gave up, and he didn't do anything. If we really, really, really moaned and moaned, he would do a little bit of work."

Other parents/carers told us how distressing her child had found remote learning. Nicky told us that her autistic son had found learning at home very upsetting:

“Accessing learning in the home, he just shuts down, gets really distressed and upset.”

An element of home-schooling that was particularly raised by parents as challenging was the technology needed to access remote learning. This technology was often inaccessible for children with SEND. Julie provided an example:

“I think they set up like a teams thing once a week, but he can't access that. Technology, I'd say for a lot of young people with SEND, would be a big massive barrier. They'd expect him to know what his email and password was, he doesn't even know what an email is... He didn't really get anything sent for him. Because it's, you know, it's different for kids in a mainstream school, they could access stuff on technology, be supported and understand, but we didn't really get anything for [him] until I had a call with a teacher and he sent me some like colouring sheets, and I mean, stuff like that just wasn't really helpful.”

“Nothing was put in place”: The transition back to school

Several parents/carers spoke about how hard their child had found the transition back to school after periods of remote learning/staying at home, Marie commented:

“We've had loads of meltdowns for the last couple of days because of the transition back to school.”

Nicky explained how her son struggled with the transition back to school:

“So, of course, [he] goes back to school in September, and everything changed. It was just too much for [him] to really cope with... His mental health has been really bad, up until about two weeks ago, he didn't even want to see this one friend because he couldn't cope with that transition.”

Parents also described how their child had not received any support with the transition back to school, moving to a new year group, or starting a new school. Kate stated:

“She didn't get any of the transition. She didn't get any sort of support on the run-up to starting a new school, and then even though she's got an EHCP, nothing was put in place to support her when she started. Then obviously we had lockdown, she coped quite well considering, and then we had lockdown, and again she was refusing, she wasn't coping.”

A number of parents/carers told us that any disruption due to the pandemic was particularly problematic for children with SEND due to the reliance on carefully constructed daily routines. Steph explained:

“So I think it affected them more so, especially the one with the autism because he likes routine.”

Nicky told us that her son needs to keep a rigid routine to prevent him from dysregulating:

“We try and keep things in a really rigid routine when he is here, and when he is at his Dad's so that he doesn't dysregulate.”

As such, 'bubbles' in school also had a negative impact on children with SEND when one child in the 'bubble' tested positive for COVID-19. When this happened, all children in their 'bubble' (usually a class or a year group) had to go home and self-isolate (not leave home for ten days). This caused further disturbance to the daily routines of children with SEND. Kate explained how disruptive this was for her daughter who could not do schoolwork at home:

"Every time there was a COVID case or a COVID contact, they were home again for ten days. That was really disruptive because she didn't know from one day to the next if she went in whether she'd get sent home again. I think twice she was then sent home, which again just disrupted everything. Because she wouldn't do her education while she was at home, even then. So I think the important thing for her and us is that continuity, that she settles back in school, goes consistently, gets the support, and is back with her friends."

"School was probably the only thing that saved everybody's sanity": Attending school

Some of the parents/carers described how their child had been 'allowed' to still attend school over national lockdowns. Marie spoke about the importance of her children being able to continue attending school:

"So the fact that they were in school was probably the only thing that saved everybody's sanity. Without that, I don't think we would have coped at all. So thank goodness they don't have health issues that prevented them being in school. If they'd have been clinically vulnerable, I don't know how we would have isolated for nine months. I don't think we'd have survived it."

Whilst attending school was described positively by parents, some elements had been challenging. Whilst attending school during lockdowns, some parents described how their child had not always got the support they needed as they were not able to access 1-2-1 support and work was not differentiated. Kate told us:

"Especially in the second lockdown, there was no kind of differentiated learning... It was all very much one size fits all. Even when she was going into school, and I did challenge them and say that 'She needs somebody just to sit and explain this work to her'. 'Oh, we can't do that because of COVID, because we can't get that close to her.'... I think that was the hardest thing as well, knowing that she was struggling, not only being in school and the pandemic, but having to do the work that everybody else was doing."

Despite being in school, parents told us that there were fewer opportunities for their children to learn through practical activities during the pandemic. Julie stated:

"It's that kind of holding on to skills and things in remembering stuff that stopped. So even though they were going to school, you know, they weren't allowed to do things like cooking, all of those sort of therapeutic type activities that are really good stopped because of the rules and regulations of cooking, for example, you know, equipment and handling. So the things like that stopped, so even though he was maybe accessing school, it was very different."

"Absolutely went out the window": EHC Plan needs and annual reviews

Some parents/carers told us that their children's needs, as outlined in their EHC Plan, were not met. Here was Amy's response to the question, 'In relation to her EHCP, do you think her needs were met over the pandemic?':

"No. Absolutely not. It went out the window entirely. There was there was nothing. Nothing. Nothing at all... There was no even consideration that we had an EHCP, or that provision should have been put in place. It was just no, nothing. But I'm sure I'm not the only person that's said that."

Here is Kate's response to the same question:

"No. Initially it was down to COVID. Now they're sort of saying, well, if she needs that level of support, you know, we're a mainstream school we don't provide it."

Steph commented on how despite having an EHC Plan, her son did not receive any meaningful education:

"He could still attend [school]... But the problem with him was because he's so far behind, so he's like three school years behind. He doesn't have any 1-2-1 or anything, despite having an EHCP. A lot of the time, it was literally a babysitting service, which school even admitted. There was no education as such. It was mainly colouring-in and playing. So I think in regards to that, he's probably fell back more."

As well as her daughter's EHC Plan needs not being met during the pandemic, Amy spoke about the delay in the annual review of her daughter's EHC Plan:

"Well, she had her annual EHCP meeting in July of 2020. I only just got it back this week, literally over a year later. Which I think is just appalling. COVID or no COVID... So that was one thing that the LA, you know, completely and utterly failed on... Sorry to get emotional. She didn't ask to be born with these things that she needs. She needs what she needs to support her, you know? I shouldn't have to keep arguing for it, to be honest."

4. Friendships, Activities, and Social Interaction

"He was devastated he couldn't see his friends": Friendships and social interaction

Parents in the study described how not being able to see their friends affected their children with SEND in different ways. Marie explained these differences even between her two children:

"My daughter doesn't really have what I would class as close friends because she finds making any form of friendship very challenging. She tends to orientate towards other autistic children. So she didn't really miss her peers. But my son, he has three close friends, they don't see each other at school, but outside of school, and he was devastated that he couldn't see them, and it showed in the deterioration of his behaviour and his confidence, or lack thereof. It just increased his anxieties."

Amy told us how much her daughter (who has ADHD) was impacted by the lack of social interaction and not seeing her friends, as well as the difficulty her daughter had in communicating with her friends online:

"I just feel like socially it was a big problem for [her] because, of course, she learns from her peers how to act socially. A great big part of her development has gone now... She did miss them. She loved it when we did have the opportunity to take part and look at them all on-screen when we were doing a Zoom call. To see all her friends, she got very excited. But again, having the lack of speech or confidence to speak, she didn't really speak to anybody, but she saw them, and she listened."

Kate spoke about how her daughter became reliant on just one friend during lockdown and how this has affected her ability to interact with other friends:

"Her best friend had to then come into our bubble because I was doing a lot of childcare and things for them. But she has been very restricted to that one person, which has just kind of deepened that dependence on her. But she hasn't really been able to interact with other friends, and I think that has contributed to the reliance on a particular child."

“We lost the lifeline for the parents and for the kids”: The cessation of activities and clubs for children with SEND

During the pandemic, activities and clubs that children with SEND attended were described as suddenly stopping. Nicky commented:

“He was always a boy that enjoyed going to soft play, going out, cycling, swimming and things like that... Monday was the first day he had access to home education, out of the house activity for 18 months since March the 10th last year. We went on a home-school holiday to Wales on a history holiday. That was the last thing he did.”

Julie offered similar reflections on how clubs and activities suddenly stopping removed a lifeline for many families:

“It was really difficult in terms of all the, my biggest thing I think, was all these slightly extra things that are really hard to find and do for children and young people with special needs and learning disabilities stopped. And they're often like a bit of a lifeline for the parents and for the kids because they can't access, you know, as a young person, his kind of social world will be kids at school who are on a similar wavelength and maybe like an inclusive club that he does.”

Marie spoke about her children who had not had access to the physical activities they needed over lockdowns and the adjustments she had had to make to the family home to try and compensate for this:

“My whole house is like Fort Knox to try and keep them safe, but it's also things like making sure they can hang, climb, run, jump, spin safely. Because they need that sensory input to help them regulate, and they're not getting it. Normally outside of COVID they would swim, they'd go to gymnastics, they would do lots of physical activity. They couldn't do that, and we had to recreate it at home.”

Kate spoke about how hard her daughter has found it to restart activities after almost a year:

“She missed, really missed, she does care farming and horse riding, and she'd literally had her first lesson the week before we were put into lockdown. So that was a big disappointment. Then obviously, she missed the care farming, which she was really settled well into, she had made friends... Then it was almost a year again before he was able to go back, and after she went back, her sort of anxiety is now increased, and it's sometimes challenging to get her in. So much she's regressed now back to the beginning.”

5. The impact of the COVID-19 pandemic on parents of children with SEND

“We need breaks to fill our buckets back up again”: Lack of access to respite and short breaks

Many of the parents /carers shared accounts of how a lack of respite for children with SEND during the pandemic had impacted on family members and their ability to support their child with SEND. Nicky told us about how a lack of respite affected her family:

“I am [his] support, and his Dad is his support, and when we suffer, he suffers more. So it's not only the direct effects that COVID has had on him. It's the effect that COVID has had on his support network, his family. We just can't connect as good and have the same patience and resilience that we've always been able to have because we got our social breaks and things like that to fill our bucket back up again.”

Pre-COVID-19 parents would get some access to respite when their child went to school. If their child was not attending school during the pandemic, parents found they had no opportunities for respite or a short break from their caring responsibilities. Lauren, whose child has a chromosomal deletion syndrome described her experience:

"I think the whole thing is challenging because having a child as complex as [him] is hard and challenging anyway. Then you add in the fact that you've got less support because of (not going to) school. You don't get any respite because that's my only respite... It's exhausting, to be honest."

Some parents also spoke about how before the pandemic they got respite when they went to work. During the pandemic, if parents had to work from home, any respite from leaving the house to go to work also stopped. Lauren spoke about her experience of working from home whilst looking after her son:

"Obviously, I go to work for a break, so I was never having that break... It was just it was just more difficult, obviously, when I was trying to work from home and sort [him] out... I'd have to feed him, and sometimes I was having meetings at work and with my colleagues. So obviously, they knew that he couldn't understand, and I'd be feeding him while I was doing that."

Natalie explained how working from home had been stressful for her husband, when her son's behaviour would impact on online meetings:

"So for him, it was very stressful. A lot of his work is over the phone and all the meetings via Zoom, and that was with people from all around the world at all different times. One of his bosses has a child with autism, so understood a bit more, but obviously, when you have [him] kicking off and swearing in the background, it can become very stressful. So it was really stressful for my husband. He then started smoking again and things like that, the impact it had on him."

One mother had made the difficult decision to stop working over the pandemic as she was not able to manage working from home and looking after her children with SEND:

"I had to make the decision to give up my 25-year career... During lockdown, trying to work from home with the children around... I couldn't do it competently. So I've ended up having to take the decision that trying to work doesn't work for my family."

"I've had a breakdown because of it all": Mental health of parents of children with SEND during the pandemic

Several of the parents/carers interviewed spoke about the struggle with their own mental health during the pandemic. Kate gave us her experience of the challenges of trying to juggle everything:

"It was chaos. My husband and I are both working for the NHS. So we're both still doing shift work. Both of us work alternate shifts... The first lockdown, we coped until May when everything just had an impact on my mental health. I ended up walking out of my job, having to leave, and after that, the schools then agreed they would have the children in part-time because up until then, they'd refused."

Natalie, whose son has autism, described how difficult it had been for her trying to support her son during the pandemic:

“So I did have a bit of a mini-breakdown just after Christmas... I don't know if that was a whole connection from COVID or, a lot of it was stress related to trying to support [my son], trying to sort the school out, the EHCP, talking to the SENDCo, appealing, all of that happened all just after Christmas. It was a really hard, really hard process.”

Nicky also spoke openly about how the situation had led to her experiencing a breakdown:

“You know, we really got caught in a catch 22 situation. So as Mum, I've had a breakdown because of it all because you just feel like you've failed your child.”

In some families, the stress of trying to home-school and work had led to the need for formal help for mental health issues. Steph told us that her husband had to go and seek medical help:

“To the point that he actually, it was a whole mix of things, it wasn't just that, but he did have to go to the doctors because he got that down, because he wasn't used to working from home, wasn't used to trying to home-school.”

Findings – Professionals

Participants

15 professionals who work with children with SEND were involved in online interviews. The semi-structured interviews lasted between 19 and 54 minutes. Professionals were from health and social care, education, charities and Local Authorities. Three SENDCo's participated and these have been labelled as SENDCo (1), SENDCo (2) and SeNDCo (3) for identification purposes.

Findings

There was consistency across the professionals of key themes. The themes identified were organised into three overarching categories: 1) the recognition of children with SEND during the pandemic, 2) health and social care, and 3) education and learning. Themes for each category are listed below:

- 1) Recognition of children with SEND during the pandemic**
- 2) Health and social care:** Services were prevented from running; unclear, inconsistent and rapidly changing guidelines; supporting and reassuring parents during the pandemic; concerns over not being able to 'see' children; safeguarding and social care provision; accessibility of remote support, collaborative online working; demand and waiting lists; workload; burnout and staff turnover.
- 3) Education and learning:** School places, remote learning; parents understanding their child's needs.

1. “Everything just reversed”; Recognition of children with SEND during the pandemic

The professionals we interviewed, described how SEND were not taken into consideration during the pandemic. A service manager for a regional SEND charity commented:

“It was frustrating, really frustrating. I didn't feel like SEND or disability was taken into consideration. It was one rule for everybody... I just think that maybe there should have been exceptions to the rule from day one, being allowed to go out and access your support.”

Professionals reported that in addition to considerations not being made for SEND in pandemic management, the national guidelines were seen to protect adults rather than children. One consultant paediatrician explained why the SEND system did not work during the pandemic:

"I found myself having to email supermarket chains to get people on the list so that they could get their groceries delivered because nobody was doing that for them. The system did not work. So it didn't work in terms of identifying the correct children, and it didn't work in terms of mobilising the required support... I don't think we're very good at the type of pandemic we've had where it's very much geared towards adult services of what works for grown-ups."

The lack of provision for children with SEND in the pandemic was reported as resulting in children with SEND regressing. A physiotherapist spoke about this:

"The second the pandemic came in... everything just reversed 30 years, and there was a danger it could get stuck there."

Professionals reported that they were redeployed to COVID-19 orientated services, often not linked to paediatric care. One consultant paediatrician was redeployed away from providing care and support for their caseload including children with SEND:

"So when the pandemic started, we all went onto a COVID rota, which meant that all of our daytime work got scratched out... I was told I couldn't do any of my clinics... But I felt very unhappy abandoning my patients who still have needs, who I knew if I didn't proactively manage their epilepsies, their constipation, their reflux, everything else, they would end up in hospital."

This professional decided to work, against guidance, and carry on supporting children with SEND on top of their redeployed role:

"I was naughty, I'm afraid. I carried on contacting the families of vulnerable children I support... So I basically spent lockdown when I wasn't covering the ward, ringing families either to provide direct clinical care or to complete a triage exercise to sort out who needed ongoing care. So I was actually phoning about 60 families a week... Most of whom would have had diddly squat if I'd not been ringing them."

2. Health and Social Care

"We wanted to, but were told we couldn't": Services prevented from running

Many services for children with SEND reported being prevented from continuing to go into schools and homes. One SENDCO (3) who works in secondary education told us that health and social care services (e.g. physiotherapy, occupational therapy, speech and language therapy) stopped attending the school she worked in: *"That stopped completely, everything stopped."*

Professionals discussed a range of reasons why services were prevented from going into schools and homes. A service manager for a regional SEND charity told us that it was the Government guidelines that prevented them from going into schools and homes:

"We did keep referring back to the Government and saying 'You know, this is not us making the rules'... The young people felt that they were abandoned because everything that they had around them disappeared overnight... As soon as the restrictions started easing, it meant that we were able to be in people's gardens, that meant we were able to offer that service a bit more."



A sensory support professional told us that the service he worked for was prevented from doing face-to-face visits due to Local Authority guidance:

“The Local Authority, they went into panic mode, which is ‘You can't go anywhere’... Quite a lot of schools... were getting fairly irritated with us because I was having to say ‘I'm sorry, we're being told we can't come and visit.’”

Another health service was prevented from doing face-to-face visits with children with SEND due to their service “taking a cautious approach” due to the small size of their team. A CAMHS practitioner explained:

“Some parents made complaints about our service not going out at certain points, especially when other services started to go out with regards more physical needs, like OT and Physio, and we still weren't... So that's been difficult because we wanted to, but we've been told we haven't been able to... The health service, in terms of our particular service, have just been incredibly cautious... We're a very small team... If we got ill, the service would be not there at all, which would be even worse. So that is the main reason.”

A SEND professional working for a Local Authority told us that some schools were also cautious about allowing services into schools:

“When schools did go back, they were very nervous about bringing people in, so our services were a bit like, it took a while before they enabled us back into schools because of the worries.”

One physiotherapist described how they had to negotiate with schools to deliver their service:

“Going through the risk assessments with the schools, the schools were kind of saying, ‘well, that can't be done because of x’, and you physically have to get your tape measure out and go round the classroom and say ‘well, this is another way that it can be done, it has to be done, they need to come to school, so how can it be done?’ That's the question. Not, can it be done?”

“They would literally change overnight”: Unclear, inconsistent, and rapidly changing guidelines

One of the most common themes evident across the interviews with professionals was the difficulty professionals had with navigating the Government guidelines. A service manager for a regional SEND charity spoke about how the guidelines changed so quickly:

“The constant changing of guidelines as well like, are we allowed to be in? Are we allowed to be out?... You'd get an email two hours later saying, ‘It's changed again, it's changed again.’ So by the time you've disseminated that down to the rest of the team, you were like, ‘Okay, scrap that now’... So we'd say to a family, ‘Yeah, we can come back out and see you’, and then all sudden we'd be like ‘Oh actually no, no we can't.’”

As well as rapid changes, there were also inconsistencies reported in the way guidelines were applied across the different lockdowns. A SENDCo manager spoke about a lack of consistency and how difficult it was to get clear information:

“Just consistency in what we were expected to do across the different lockdowns... It was the risk assessments. They would literally change overnight, you'd get the DFE email, and your heart would sink before you open it. What are we expected to do tomorrow now? What's changed? It was difficult... Just trying to get clear information from the DFE and the Department of Health. That was just incredibly difficult.”

One consultant paediatrician told us about how problematic it was to receive different messages from different Government sectors:

“The other thing that was really bad was the lack of communication between the Department of Health, Public Health England, and the Department for Education, about what constituted an aerosol-generating procedure, about how those should be managed, and because different messages were going out through different sectors, all the confusion was there, I think that was terrible.”

The lack of consistency between the guidance from different departments and services was also raised by a designated clinical officer:

“Clear, consistent guidance across all sectors [was lacking] because there were some instances where DFE were following one pathway and health were following another, it has to be consistent.”

The lack of clear consistent guidance was reported as massively adding to workload over the pandemic and the ability of professionals to offer any services to children with SEND. SENDCo (1) reported these challenges from the perspective of an education professional during the pandemic:

“Really clear guidance from the Government... I know for a fact that our SLT team have spent evenings, weekends, up till midnight, having meetings, getting the information, the information is not clear, and then they've got to cascade that down to the rest of the school. The amount of time that's spent, you're getting emails at 10 o'clock at night from the head saying we've got to do this.”

The rapidly changing guidelines resulted in trying to interpret and implement changes over weekends and evenings, as reported by SENDCo (3):

“More time to plan things that were being put into place, the amount of change that we were expected to just adapt to and do... The headteachers will get an update on the Friday for something that's got to be implemented on the Monday. It's absolutely ridiculous... and a clear timeframe, but being given the time to actually do it because you're already doing a job.”

“Parents having someone to talk to”: Supporting and reassuring parents during the pandemic
Professionals told us that during the COVID-19 pandemic, an important part of their role was to provide support and reassurance over the telephone to parents of children with SEND. A service manager for a SEND regional charity stated:

“So we would just be talking through the anxieties around COVID, around the impact of not having a routine of going to school, giving them ideas about what they could do, and how they can access other support that was maybe going online as well. You know, just kind of being there and reassuring them more than anything and having someone to talk to.”

This role, whilst not always acknowledged within workloads, was reported as being really appreciated by parents of children with SEND who were struggling over the pandemic. A CAMHS practitioner said:

“Generally, parents have said to me that just having that someone to talk to, someone to kind of talk through the difficulties... has been helpful.”

Sometimes support could be more specifically needed for parents' mental health. One SENDCo (2) told us how they had spent time "trying to keep families afloat" during the pandemic:

"It was about trying to keep that family afloat, and it was about support for the parental mental health."

Professionals reported that they did not always have the skills to provide the level or type of support that was needed by parents. One consultant paediatrician mentioned:

"It's been difficult to access mental health services during COVID. Certainly, in the first lockdown, they just stopped altogether, and they discharged people from waiting lists because they said they'd have to be re-referred afterwards, and yet there was nobody. So I found I was treading water with families without the skills to provide what they needed. Just to be there for them whilst they were waiting."

A paediatrician described the challenges associated with providing support beyond what the service he worked for was commissioned to do:

"Our service for ADHD feels quite compromised because we're not there to provide behavioural support... We're only there to do medication reviews, but the reality is, it is very hard when a parent phones up in crisis and struggling. You end up doing both."

Many of the professionals described how more parents than usual had come to them or been referred to their service as 'in crisis' over the pandemic. A paediatrician attested:

"That first lockdown we put the nurse helpline on, and we seem to be dealing with more parents in crisis, families in crisis."

The lack of support and services available was seen to have directly impacted on parents' ability to manage during the pandemic. A therapy manager for a national SEND charity described the extent of one family's crisis:

"I had a family, who essentially the behaviour of their child has got so bad that they were going to just drop him off at social services because they couldn't cope, there was no support. He wasn't in school, so they had him 24 hours a day, seven days a week. There was no one there to support him."

"I know we're missing things": Concerns over not being able to 'see' children

Many professionals talked about how problematic it was not being able to see children with SEND face-to-face as this impacted on professionals' ability to assess, care for, and keep some children with SEND safe. One SENDCo (2) explained how they felt they may be missing potential safeguarding issues by not seeing children in person:

"I know we're missing things. We're missing things by not being able to do the face-to-face because we're not picking up on the nonverbal communication... I've been doing much less direct work with children. Observations tend to be standing at the doorway."

The importance of seeing children with SEND face-to-face was also described by a CAMHS practitioner who felt it was essential to be able to pick up subtle cues which could be lost online:

"I was no longer able to go out and about to see families and children directly and had to move everything online... Direct observations of the children to aid my assessment and interventions was very much more difficult. I mean, the children I work with just weren't able to be online... It's the more subtle stuff that probably gets lost when you can't see somebody directly... Just ethically, I think that it's right to actually meet the child and see the child."

The lack of direct interaction with children with SEND was reported as resulting in an over-reliance on parents' accounts. One SENDCo (3) described not being able to be 'there in the room' as problematic:

"Just not being able to be there in that room with them, to help them as we normally would... We can see when students are struggling. You can just tell, you can see it... We relied on parents a great deal to advocate for them."

Some professionals described high levels of concern over trying to work online with vulnerable children and families. An educational psychologist's account demonstrated how not being able to see a child could create an ethical dilemma for them:

"Seeing the child only head down, or only a parent if the child couldn't come to the screen, only head down, out of the context, so not seeing the context, not being able to see them engaging within the context, not being able to pick up on nonverbal signals and use all of the tools of my trade that really help me to make an informed judgement. I'm not sure how comfortable I would have been accepting a commission for a piece of work that I did not necessarily feel skilled or ethically able to deliver in a way that would have fulfilled my duty of care, or my sense of happiness, not happiness, but my sense of professional integrity."

Some of the ethical challenges encountered in practising throughout the pandemic were also described by a paediatrician, who had faced tensions in decisions around increasing a child's medication:

"We'll phone up ADHD and say 'My child needs more meds because I can't cope with them,' and we were saying 'Actually, it's not that they need more meds, the situation has changed.' An ethical consideration was for us then was there's actually nothing wrong with this child, but would we medicate more to try and alleviate that?"

The ability to judge online 'how things were really going' was described as limited in some cases and one professional reported that it was not clear how much families had been struggling until they were seen face-to-face again:

"We really only kind of got the sense of how some of these families have struggled by doing our home visits, again, meeting families face-to-face. It's as if the families didn't really feel able or willing to open up through those virtual contact points, you know, or weren't able to successfully engage with us anyway at that time."

"The families that really needed help were getting nothing": Safeguarding and social care provision

Some of the professionals talked in the interviews about concerns they had had around safeguarding children they could not see face-to-face. One SENDCo (1) raised the initial concerns around how effective online working would be to sustain contact with vulnerable children from school:

"We were concerned about safeguarding when Teams was set up. We were concerned about those students that we didn't hear from."

The nature of online engagement was described as making it more difficult in some cases to raise issues of concern, the following SENDCo (2) encountered disquiet over discussing domestic violence via online platforms:

"I have two parents, and I'm worried about domestic abuse. I'm not going to be able to have those conversations. I'm not going to be able to pick up the nuance online."

Concerns were also raised by a paediatrician, who commented that not being able to conduct a physical examination could reduce the chance of picking up safeguarding issues:

"From a safeguarding perspective as well, is that if you can't see a child, how can you physically see if they're well, do they look tired, have they got any bruises, any marks which we've got to be aware of? So that was one of our big initial concerns."

Some professionals reported a rise in safeguarding issues they encountered over the pandemic. A SENDCo manager described the challenging circumstances social workers were dealing with as a result of there being no support for families with children with SEND during the pandemic:

"The Social Care provision has been awful. Social workers have been working from home, but they've only recently started going out into the homes... The families that really needed help were getting nothing... Some of the homes we know that weren't great in the first place have deteriorated hugely. Domestic Violence has gone through the roof. Parents were coming to see me to talk to me about domestic violence, substance abuse. I never had that before in my job, and I have now."

"A new form of exclusion": Accessibility of remote support to children with SEND

Many professionals described how remote support had both positive and negative aspects with regards to accessibility for children with SEND. Remote support was described as working well for some children with SEND as it made some services more accessible. An example of how engaging with some children in their own homes made them more comfortable was reported by a SEND professional working for a Local Authority:

"It was great for the child because we found that we were getting far more involvement and participation from the children because they were in a safe space with their parents. We weren't bringing them into an alien environment."

Advantages of 'moving online' included professionals being able to offer appointments more quickly than face to face, this was described by a CAMHS practitioner:

"I think we were we were able to be really responsive, from that point of view, get back to people quickly, offer appointments really quickly."

In a similar way, a service manager for a SEND regional charity noted how virtual appointments could be offered more quickly, which had a positive impact on waiting lists:

"So what's been quite nice as we've been able to offer that virtual offer that and then say 'We can get you in quicker if we offer you virtual.' So then, we've been able to respond to some of the families that are in need, which has been quite nice. So our waiting list has calmed down slightly if you're on the virtual offer."

Working online also meant that parents did not have to travel to meetings, with the associated need to park and organise childcare. A SEND professional working for a Local Authority commented:

“The parents loved it because they weren't having to drive somewhere, try and find childcare for other children... Being able to just switch on their phone and sort of chat to somebody.”

This ‘easier, accessible way’ for parents to engage in appointments was also described by, a CAMHS practitioner told us:

“We were accessible to parents. They didn't have to travel. They didn't have to bring their children to a base or anything like that... Parents have been able to join from work... It doesn't take hours to have an hour meeting.”

Due to being able to conduct meetings remotely, some services were described as being able to offer more provision. A therapy manager for a national SEND charity described this:

“How it's changed our services is we now have more provision. So beforehand, we were just doing a two-day assessment, but because of course a lot of parents couldn't afford it... We now offer the second day of assessment via Zoom... and by developing the smaller services, the half-day assessments, all that sort of stuff, it made it accessible to parents.”

Professionals described how they had been able to organise online groups for children with SEND and their parents. A team leader for school sensory support explained:

“We've got students together remotely. We've created a peer group. So historically, you couldn't do that... That ability to get children together and families together to do new activities... They all turn their Teams on.”

However, this reported increased accessibility for some families to support through online appointments and meetings was not the same for all families of children with SEND. One SENDCo (2) warned that this new way of online working could exclude some families:

“One of the things which really, really worries me is that we're forming a new form of exclusion, on the assumption that people can understand and work technology.”


This digital literacy and ability to access and use technology was described as a big challenge by some professionals. The following sensory support professional described this as one of the biggest challenges they had faced:

“I think the biggest challenge of all was trying to keep in touch with the families who didn't really have decent digital connectivity.”

“It does allow for more cross-fertilisation and sharing of good practice”: Online collaborative working

Many professionals noted that being able to have multi-agency meetings online during the pandemic had improved collaborative working; this was highlighted by the following sensory support professional:

“Much more collaborative working... Being able to have a meeting like this, using technology has really changed the way that we work... I've sat in EHCP meetings with paediatricians who never would leave the hospital... But they've now attended the meeting and given much more nuanced information to assessments... I've had more conversations like this with EHCP coordinators in the last eighteen months than I've had in the previous four or five years.”



Being able to draw large numbers of professionals together online was described as a real benefit from developing online ways of working during the pandemic. This enabled the wider sharing of best practice as described by the following educational psychologist:

"I don't think I would have been had the privilege of being able to be in a group with seventy-odd representatives of headteachers and teachers and things, and collectively come together to think about topics that count if we had tried to arrange that in-person... It does allow for more of that cross-fertilisation and sharing of good practice between headteachers and teachers."

The time saved from using online methods rather than travelling to meetings was reported by a consultant paediatrician as increasing efficiency within the provision of services and improving meetings across and between agencies:

"The other positive thing I should have said was the online meetings and the online interagency stuff, which was fantastic... Just to be able to get good outcomes from meetings without having all that travel has been much more efficient and effective... and a willingness of partners to work across agencies has been good."

The use of online platforms to meet was also reported as increasing the number of meetings or appointments which could take place in a day. One SENDCo (2) told us:

"I would say for multi-agency colleagues, that is often a huge advantage because actually, you can get more meetings in a day. It's been much easier for people to drop in meetings for a half an hour meeting."

As well as increasing the number of meetings which were able to be held, a CAMHS practitioner told us about being able to organise meetings sooner:

"Meetings with professionals was much, much easier and much more effective, and you can make it happen within a day rather than weeks."

"Some waiting lists are unbelievable": Demand, waiting lists and staff shortages

A common theme throughout professionals' interviews was the increase in demand for their services over the pandemic. A paediatrician described the rise in demand for the service he worked for and how the referral numbers could not be met:

"I think our activity increased over one hundred percent during COVID... At one point, we're getting one hundred referrals a month for ADHD, and I think up to four hundred for ASD a month. The ADHD was originally commissioned for fifty a year. So a huge increase in demand... My worry is that will these kids receive everything they need? Just purely because the services are just so stretched at the minute, more than ever."

An education psychologist talked about the 'flood' of demand which their service was experiencing:

"I can only speak for colleagues who are continuing to plough through constantly coming requests. There's not really respite in the flood of the demand that's coming through."

The huge increase in referrals or requests for services was reported as resulting in long waiting lists for children with SEND. One SENDCo (3) commented:

"The waiting list is twenty-four months for an appointment to even see somebody, a specialist practitioner... Some waiting lists are unbelievable."

A therapy manager for a national SEND charity told us how the pandemic had exacerbated waiting lists, creating a massive unmet need for children with SEND:

"Our referral rate has increased, on average from the year previous by one hundred and sixty-seven percent... There's such long waiting lists now... It was like that before COVID, but COVID made it worse. So I've got families who are waiting just for an initial appointment with a paediatrician who can be waiting three, four years... and the whole process can end up taking you another two or three years on top of that."

A service manager for a regional SEND charity told us about being able to increase their workforce to meet the demand:

"Our referrals probably doubled during lockdown... We've increased our workforce by double. So that shows how much our referrals went up."

However, most workforces did not encounter new staffing. Some professionals described how they had experienced a loss of staff over the pandemic, and this had impacted on delays to accessing the service. A CAMHS practitioner told us how staffing and capacity issues impacted waiting lists: *"Because of our staffing issues, capacity issues, we've now got a really big waiting list."*

When asked what the biggest challenge was to him as a health and social care professional, one paediatrician also told us: *"Resource. Predominantly having enough staff to meet the capacity."*

A physiotherapist also told us how staffing was a challenge: *"We needed to redistribute our staffing a little bit, and staffing was still a challenge."*

Similarly, a deputy for SEND told us that staffing was difficult: *"Staffing was really difficult, because we had some staff who just did not want to come in, and that's fine."*

"We're often working into the night": Workload

Most professionals working with children with SEND reported an increase in their workload. An education psychologist described how the pandemic had been incredibly demanding:

"It's been an extraordinary year in terms of workload, extraordinary... it has been the most demanding time that I have seen so far... It has taken me to the brink of my coping and beyond."

A SENDCo manager spoke about how hard teachers have been working, but how in many cases this extra work would not directly reach children with SEND:

"Teachers were working three times as hard as they've ever worked, and that wasn't ever going to reach the SEND children."



Professionals described working 'over their hours' to ensure their service could remain running, one SENCo (3) talked about working these extra hours:

"So I was already doing a job, and then other things that you are asked to do... I haven't been given any extra time to do that. I am doing that as part of my job. So, you know, I work extra hours to make sure that's happening, but it's so vital at the moment that that happens."

In some cases, whilst online methods were reported as increasing the productivity of a working day, due to increasing caseloads the workload also increased, as described by a sensory support professional:

"What people have found is they're doing their two visits, but then they're still doing the remote contacts, and things as well. So they feel as though their workload has increased... I'm catching up at weekends. I'm doing Teams calls or telephone calls at the end of the day."

This increased workload meant that professionals shared accounts of having to work evenings and weekends. A senior educational psychologist provided another example:

"I don't think I ever worked as hard as during that first lockdown, if I'm honest... I was working through weekends very often, often working into the night."

"Resignation, frustration, fatigue": Burnout

As the pandemic went on, professionals described high levels of burnout and staff leaving their posts. One CAMHS practitioner told us how both parents and professionals had got more jaded and fed up:

"As people got more jaded, more fed up, more stressed. I'm talking about everybody, so everyone in the schools, the parents were more stressed, and under more strain, the children were struggling, and we were struggling."

Many professionals reported that they had observed an increase in burnout among staff. This was noted by a paediatrician who explained that working 'every hour' had resulted in staff becoming ill:

"We did see some burnout from staff... There was no endgame. I think people thought by Christmas we'll have this sorted, and Christmas came and went, and staff hadn't taken many breaks, and a couple of staff fell by the wayside because they worked every hour."

One education psychologist told us about high staff turnover and colleagues' low mental health:

"By the second time, there was kind of a little bit more resignation, frustration, fatigue... Like a marathon, like they'd started by sprinting, not realising it was a marathon... There was so much illness, so many people leaving... Seeing colleagues at a lower level of their mental health and wellbeing than I've ever seen before... We've also had a lot of disruption with incredible staff turnover... Some of the stripping back was not helpful and stripped us down to a point where, and then some people leaving because of, I guess, challenging work conditions."

3. Education and Learning

“Not many of our young people were given places in schools”: School places

Professionals reported that during the pandemic, most children with SEND were not in school. The following SENDCo (3) described the true magnitude of this: *“Sometimes, there were only 20 children in out of a 2,500 cohort. That was really small.”*

Health and social care professionals told us that it was often the more complex children who were not offered a school place and that they had to step in and ask schools if the children they worked with could have a place in school. One service manager for a regional SEND charity provided an example:

“It should have been made mandatory that special needs schools stayed open... Not many of our young people were given places in schools because they were trying to keep the numbers quite low... Those more challenging children maybe didn't get spaces, and actually, they were the ones that really needed the spaces... We did actually step in and say, ‘No, hang on a minute, this young person has an Education Health Care Plan, they meet all of the criteria, can you please just offer them even one or two days a week?’”

The following physiotherapist described how their service had advocated for children with SEND to be included in school and had emphasised their human rights:

“Some people sat around the table seemed to be taking the view that they just can't go to school. I felt our service was a driving force behind saying that's not okay, they are going to school, what needs to happen is whatever changes need to be made to accommodate that need to be made... So I think we were a massive advocate for getting our very complex children recognised in terms of their human rights to have an education and inclusion.”

One SEND professional for a Local Authority told us how the children she worked with have realised how valuable their education is to them:

“A lot of what the children told us about being desperate to get back, you know, a lot of realisation that they miss their friends and they really miss their teachers... Having that gap made them realise how important having good teachers was to them. So they probably hadn't realised that before. So that's been some of the learning from the pandemic about how they valued their education.”

Professionals told us that the children who did get a place in school during lockdown preferred the smaller class sizes. A service manager for a regional SEND charity noted:

“The children that did get a space, we have found that their needs were met better in school because it was a lot smaller.”

A SENDCo manager observed that children with SEND found going into school much better than staying at home, but also touched upon the difficulty some children had transitioning back to a busy school:

“They found it much better when they were in school. They really liked it in school when there weren't many children there. Our SEND children did really well when they were small groups and not many children. They really liked it. So they weren't very happy when everybody came back, that's for sure. That really did mess with them a lot... Some of them are still on a reduced timetable and still can't cope with everybody being back in school. That has been a huge problem for a lot of children. They can't cope with the noise and the crowds and the people.”

SENDCo (3) also noted how difficult it has been for some children to come back to school after lockdown:

"I'm still struggling to get some in. It still remains very difficult... So it is a case of very, very slowly, small, small steps. We've still got a couple of students who have not returned. We've got some that are coming in tentatively, even if it's twice a week, just for that morning, just to come into the inclusion department, and aren't ready to get back out into school yet."

"Different students react in very different ways": Remote learning

Professionals told us that children with SEND experienced remote learning in different ways. Some children loved remote learning, as SENDCo (3) explained:

"Different students react in very different ways. Some of the children with autism, I found actually loved it, and I've had great trouble trying to get them back into school. They loved not having anybody judging them. They liked the fact that they didn't have to get up and put themselves through that trauma of getting the bus and getting to school and going through the classrooms. So some children really liked it. Some children, usually the children with social-emotional difficulties or learning difficulties, couldn't understand without somebody being there. That's what I found the most difficult in the first lockdown."

Similarly, SENDCo (1) told us that in her experience, some children with SEND found it easier to concentrate whilst learning remotely:

"A lot of students with autism were saying that they could concentrate better because they used the chat, so they switch the microphones off... It was much easier to focus because they didn't have all of that stuff going on around the room."

However, some children with SEND struggled to access technology and engage with remote learning as the following SENDCo manager described:

"Children that struggled to use the computer, a lot of them their parents struggled to use the computer. They didn't have WiFi some of them, they didn't have good internet, we're in the middle of nowhere... To teach children with lots of different needs, whether it be emotional, or the children with autism. It was really hard to reach those children. They just would not log on. They wouldn't engage. We tried lots of different things to get them engaged, but they just didn't want to log onto a screen and see people on screen."

Similarly, a service manager for a regional SEND charity commented:

"The young people we support potentially have a lot of anxieties having the screen, like the focus being one hundred percent on them was a struggle. Some young people just didn't have access to laptops, or there might have been like three or four of them in the house and only one laptop, and obviously, they were trying to do online learning."

"Parents have noticed the difficulties": Parents understanding their child's needs

Professionals spoke about how parents have become more aware of their child's needs throughout the pandemic. A paediatrician told us:

"Lots of parents had never seen their children during the day, for any length of time, they'd certainly never had to try and implement schooling at home with them."

Similarly, a therapy manager for a national SEND charity said: *“I think because they've been at home, parents have noticed the difficulties earlier on.”*

Comparably, SENDCo (3) mentioned: *“We've had a lot of parents recognise that their child might have some form of SEND whilst they've been off.”*

A sensory support professional spoke about how lockdown had given parents an insight into their child's education and learning:

“The insight that it's given parents and carers into the impact of their child's disability on their learning, their ability to learn, but also at times how the support really needs to be ramped up by some of the settings as well. So schools were sending poorly photocopied worksheets home and things like that. Children we work with were saying, ‘Actually Mum, this is typical of what I get in class.’ So it was really good that parents felt as though they could go back to the school and say, ‘This isn't good enough.’”

SENDCo (1) suggested that children's struggles following the pandemic are not necessarily indicative of SEND:

“We've got families coming to us saying ‘We've been off with them for so long and we've noticed this and we've noticed that’, and I think as a professional, I look at it, and I think a lot of that is down to the situation. So parents are saying they're anxious to go out, they're staying in their bedrooms, and lockdowns have definitely impacted and made that worse, but now parents are looking for a reason for that, that's not lockdown and not COVID. So they're like ‘I want them referred for an ASD assessment’ or ‘I want them referred for ADHD’... For some of them, they're now refusing school, and parents are saying, ‘I want an EHCP’. It's not that simple. That's not what an EHCP is for.”

Conclusion

In conclusion, parents/carers, children, and professionals believed the needs of children with SEND were not taken into consideration during the pandemic. The health and social care services, clubs, and activities that support children with SEND were prevented from running face-to-face, and most children could not go to school during the first lockdown. Online appointments and remote learning were not perceived to be a sufficient alternative for most children with SEND. Children with SEND reported being bored and lonely, and their mental health declined. Parents of children with SEND received no respite and their mental health also declined. During the pandemic, professionals encountered many more families of children with SEND in crisis and had concerns over safeguarding due to not being able to ‘see’ children. Professionals also reported an increased demand for services, longer waiting lists, staff shortages and burnout among staff who support children with SEND.

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