

# Ask Research – Written Evidence (CPF0007)

## The experiences of families of children and young people with SEND

### Introduction

ASK Research have undertaken research on children with special educational needs and disabilities (SEND) registered at special schools and colleges in England during the Covid-19 pandemic, with Rob Webster (Associate Professor, University College London Institute of Education) and funded by the Nuffield Foundation.

There are approximately 354,000 children and young people in England with Education, Health and Care Plans (EHCPs)<sup>1</sup>. Around half of them are educated in special provision (i.e. special schools or specialist post-16 colleges)<sup>2</sup> and nearly all pupils in special provision (97.9%) have an EHCP. Special schools can provide education for pupils from as young as three and up to 25 years of age, depending on their offer. The percentage of pupils with an EHCP who are eligible for free school meals is 34.6%, more than double that for pupils with no SEND (14.9%)<sup>3</sup>.

76% of special schools and colleges we surveyed have pupils requiring personal care such as help getting around, eating, going to the toilet or with medical monitoring. 98% of special schools and colleges provide one to one support, where a personal assistant or other adult helps pupils to access learning or regulate their behaviour. 51% provide this support to more than half of their pupils.

In lockdown 1 (March – June 2020) we surveyed over 500 parent/carers of children with EHCPs who usually attend special schools and colleges and interviewed 40 in depth. We also carried out a representative survey of special school and college providers<sup>4</sup>.

In lockdown 2 (January – March 2021) we interviewed 40 parents and 40 special school or college leaders.

Our publications to date can be found [here](#), with more to follow shortly. This report summarises findings from all of our data collected from parents of children with EHCPs at special schools and colleges to date (May 2021).

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<sup>1</sup> Department for Education (2019) *Statements of SEN and EHC plans: England, 2019*. [Online] Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/805014/SEN2\\_2019\\_text.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/805014/SEN2_2019_text.pdf)

<sup>2</sup> Department for Education (2019) *Special Educational Needs in England 2019*. [Online] Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/814244/SEN\\_2019\\_Text.docx.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814244/SEN_2019_Text.docx.pdf)

<sup>3</sup> Department for Education (2020) *Academic Year 2019/20 Special educational needs in England*. [Online] Available at: <https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england> (Figures from July 2020)

<sup>4</sup> ASK Research was supported by the National Foundation for Educational Research for provider survey data collection and analysis

## **Our findings**

Families of children and young people with EHCPs who would usually have been attending special schools and colleges detailed how the reductions in school attendance and implementation of social restrictions during the pandemic had affected them.

There were several reasons why the pandemic proved especially difficult for families of children and young people with EHCPs. These include:

1. Special schools and colleges had reduced capacity meaning that most pupils with EHCPs were not in school or college for significant periods.

The Government stated that all children with an EHCP could access a place in their special school or college during the lockdowns and throughout the pandemic. However, our research with special school and college Heads in the first lockdown (March – June 2020) showed that, on average, they were able to offer around 30% of their usual number of in-school places. This was due to limited staff availability, limited space, the need to maintain social distance and understanding of how to adhere to the DfE guidance. In the second educational lockdown (January – March 2021) capacity was again restricted in similar ways, with DfE data showing attendance for these pupils at 35%<sup>5</sup>. The majority of pupils with EHCPs were therefore not in educational settings during the pandemic.

We found that in lockdown 1 a small number of pupils were offered full-time places. In lockdown 2, to balance reduced capacity with high family demand, a larger number of pupils were offered part-time places.

Even when education 'returned to normal' in September 2020, one in four pupils were still not back at their special setting<sup>6</sup>. This has meant that parents have had children with EHCPs at home, not accessing school or college, for prolonged periods of time.

2. Usual activities and support were disrupted, meaning children's needs have increased.

Special schools and colleges usually offer a wide range of activities to support pupils' development, meet their needs and deliver the support set out in their EHCP. Although most special schools and colleges are now back to their pre-pandemic capacity, they are still not able to provide their usual full support offer (such as hydrotherapy, horse-riding, trampolining, visits to local amenities), due to ongoing Covid-restrictions, interpretation of guidance and resourcing issues.

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<sup>5</sup> <https://explore-education-statistics.service.gov.uk/find-statistics/attendance-in-education-and-early-years-settings-during-the-coronavirus-covid-19-outbreak/2021-week-4>

<sup>6</sup> Sibieta, L. (2020) *School attendance rates across the UK since full reopening*. Education Policy Institute. [Online] Available at: <https://epi.org.uk/publications-and-research/school-attendance-rates-across-the-uk-since-full-reopening-november/>

As parents pointed out, these activities are not just 'nice to have's', 'add ons' or enrichment. They are a key requirement for pupils with EHCPs. Many of these activities are used to deliver the legally required health, care and social support. They are also key to pupils' physical and mental well-being, development, regulation, quality of sleep, behaviour and preparation for adulthood. Since March 2020 children with SEND have missed out on activities that support their development and help to regulate their needs and behaviours.

*"We chose this school because it is all practical, which suits our daughters' needs. Her SEND means she cannot, and would not benefit from, sitting at a desk all day. She benefits from going out and meeting people in the college cafe, burning off energy on a trampoline or horse-riding, learning about plants from gardening. Since she's returned she is sat in the same four walls all day, looking at a screen. It's boring, it's damaging her mental wellbeing. And it's the same for all the kids, so the noise and behaviour issues in her class are absolutely going through the roof."*

*Parent Interview*

Parents described how they normally accessed a range of social support for their child and family, such as play groups, holiday clubs or SEND family support events and how valuable these were to their family's functioning. All of these had stopped. Additionally, many of the other activities that families would do – which provided fun, engagement and activity for their child as well as respite and support for their family – were unavailable due to Covid restrictions. This meant usual strategies for managing children with EHCPs were not possible for families.

*"Our strategy for managing (our son) is to be out and about doing all the things he loves all of the time. Usually at weekends we are swimming, at the climbing centre, trampolining, go-karting. It's fun for all the family, a bit of normality, and a way for him to manage his behaviours. But none of this has been possible for over a year." Parent interview*

3. Support required in EHCPs was not provided, meaning aspects of pupils' development have stalled or regressed, increasing their support needs.

The duty to meet support needs set out in pupils' EHCPs was temporarily suspended from 1<sup>st</sup> May - 25 September 2020<sup>7</sup>. This meant there was very little speech and language therapy (SaLT), physiotherapy, occupational therapy (OT) or mental health support delivered during the first lockdown. Likewise, social services generally all switched to 'working from home', which in practice meant many could not deliver services, carry out assessments or visit families over this period. Parents and

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<sup>7</sup> Department for Education (2020) *Guidance: Education, health and care assessments and plans: guidance on temporary legislative changes relating to coronavirus (COVID 19)*. [Online] Available at: <https://www.gov.uk/government/publications/changes-to-the-law-on-education-health-and-care-needs-assessments-and-plans-due-to-coronavirus/education-health-and-care-needs-assessments-and-plans-guidance-on-temporary-legislative-changes-relating-to-coronavirus-covid-19>

Headteachers also detailed how difficult it was to contact or get a response from these professionals.

- Healthcare support was not provided at all, or only to a small extent, for 65% of pupils attending school or college and 83% of those at home during lockdown 1.
- Social care and support (including respite care and home help) was not provided at all, or only to a small extent, for 57% of pupils attending school or college and 77% of pupils at home during lockdown 1.

Parents reported that in practice these services had not been reinstated since September. Health and Care professional guidance, along with interpretation of DfE guidance, meant that many of these professionals are still unable to resume in-school work, face to face delivery or home visits.

The types of issues this lack of input has led to for families includes:

- Equipment not provided for the child to be at home. This included home adaptations (e.g. a hoist to get the child out of bed, or door widening to allow wheelchair access)
- Equipment not updated (despite the fact children had outgrown it and/or it would ordinarily have been updated). This meant children went without standing frames, wheelchairs, or splints, or were in ill-fitting medical boots or walking boots.
- Increased child anxiety, frustration or withdrawal as usual therapeutic strategies were not being used
- No support or check-in from professional services
- Regression or loss of progress in key areas such as mobility, communication and wellbeing.

Special schools and colleges tried to 'plug the gaps' but they are clearly not professionally qualified to carry out others' jobs and this has led to stress and workload issues for school staff, and the inability to maintain support now in-school provision has increased.

#### 4. Respite has not been available meaning families lost the support services that give them a break from care-giving duties and help to relieve stress.

Some of the families interviewed usually receive respite care for their children in the form of short-breaks, weekend family events and overnight care. For many during the first lockdown this stopped completely. Over Summer 2020 respite services started to reopen but they have remained restricted, in terms of what they can offer and how much.

- Most respite providers have limited the number of children that can attend at one time, so the amount of time each family gets is reduced.
- Some have stopped overnight provision.
- Some are only offering one-to-one care and no activities, so the way families use respite (and the benefit to their child) has reduced.

- Some providers have ceased to offer respite services to families because their business had not been sustainable over the lockdown periods, or because demand was so great that they had had to raise the threshold for who could get their support, or they would no longer take private referrals, meaning some families are no longer entitled to their services.

School leaders have identified limited respite services as a major issue for many of their families. They also highlighted how more families were now in need of respite care as the pandemic period had left parents exhausted and in need of more help to care for their child.

In addition over this period many families had also lost their informal childcare, such as that provided by grandparents, family and friends. This resulted in parents having to care 24/7 for their children, many of whom cannot be left unattended, require constant care (including feeding, medicating, toileting and regulation) and do not sleep very much. Loss of valuable in-person contact with family and friends meant many parents were feeling isolation and the need for a break acutely.

##### 5. Parents were trying to manage competing demands

Pupils with EHCPs by definition have special learning needs. Parents often did not feel equipped to appropriately support their children's learning at home and some received little support from schools or colleges to do this. Specialist providers reported that around 30% of families had IT access issues. Many parents also detailed how, due to their child's learning and cognitive disabilities, it was not possible to engage their children with learning on a screen, or maintain their engagement in other learning tasks. Support for home learning improved for many during the second lockdown but was still considered difficult for parents to deliver and in some cases leading to increasingly challenging child behaviour.

Parents reported how difficult it had been to try and work at the same time as having children at home, caring for them and attempting to home learn. Even if their child was in a setting part-time, parents still had them at home part of the week. Education start and finish times and transport arrangements had often altered and afterschool clubs had stopped, meaning parents were not able to work their usual hours.

*"I cannot cope. I must have break. I cannot go on. I just cannot keep on working and caring like this when both are so hard." Parent interview*

Many had used their annual leave or unpaid carers leave in the first lockdown, so were required to be working during the second. Parents in employment and with their children at home certainly reported that they had a more difficult time than those who were not working. Some had had to leave their job, reduce their hours or switched to a role with less responsibility. These changes had affected families' incomes at a time when their outgoing costs had often increased (due to the family spending more time in the home).

Most parents did not only have their child at home from their special school or college. Many had other children at home (some also with SEND) who needed care or helping with remote learning. They felt guilty at not being able to support all of their children in the way they needed and were upset about the perceived effects this period had had on their other children with no SEND. These children had:

- Been less able to engage in home learning
- Received less input, support or time with their parents
- Witnessed and had to endure behaviour issues of siblings with SEND

*"It's just been too much for his little brother. He's seen things he should never have seen. He's struggled with his home learning because we've not had time for him, we've been busy with [son with SEND]. He's not had any fun, he's just been stuck here with us in chaos." Parent interview*

A small number of parents said that in lockdown 2 siblings of children with SEND were offered places at their settings (as a vulnerable child and/or young carer) because providers realised how difficult being at home was for them.

### **Effects of the pandemic on families of children and young people with SEND**

These issues overall meant that many parents of children with SEND had to support their children at home either full or part-time, without much of the usual support for their child and them, and the stress of competing demands on their time, which they found very difficult. Many pupils with EHCPs really need the routine provided by going to school, are not able to adapt well to change, and require the specialist intervention and full support their settings provide. The lack of regular school attendance, reduced engagement in activities and required support, and the general disruption and anxiety of this time are reported to have increased children's needs and challenging behaviours at home.

Parents acknowledged that there had been some benefits to their family of the past 12 months (especially lockdown 1). Some had:

- Spent quality time together
- Learnt new skills and developed new interests together
- Developed ways of better understanding and supporting their child's needs
- Found out about new support options (when looking for services to access).

Parents told us how the combination of the removal of their support structure, the implementation of lockdown measures, the increased requirement to be working and expectation to be engaging children in learning at home over the past year had overall resulted in their deteriorating mental health, increased anxiety, exhaustion and concerns about the future of their children and family. Several parents reported how this time and the need to manage their child with an EHCP had put a

strain on their relationships. Some parents had separated; several had considered it.

Parents described how the experience of the last 12 months had left them emotionally scarred, heartbroken at the effect it had had on their children and family, and angry and resentful about the loss of support and consideration for families like theirs. They felt that the Government displayed a lack of understanding or care for families with disabled children.

After the Jan-March 2021 lockdown parents reported that they now require more help for themselves and their family, that they were on medication for anxiety and depression; that they had had to reduce their work, and that they now needed more input from support services (such as respite, and specialist support to address the negative effects and increased needs of their children – both with and without SEND).

It became apparent from our interviews with parents and Headteachers that there were many cases of services not being available for families even when they reached crisis point. This situation appears to be ongoing as social and support services try and manage a backlog of work, reduced capacity and an increase in demand.

Owen normally attends a special residential school, but was not offered a place during lockdowns as his parents are not keyworkers.

*"His behaviour took a real nose-dive. He attacked my husband, beat him black and blue, we had to call an ambulance. I rang social services for the area and said we really need some respite, just a break for us all. The lady on the phone said 'what message does it give your son that you don't want him with you?' I rang again after he'd attacked my other son. This time I was told if I really needed to I could apply for a Section 17 (Child in Need) assessment, it could be 6 weeks before it could be arranged and then only if he was deemed unsafe could we make a claim to get a place in school. They knew what was going on in this house. They knew we couldn't cope. They did nothing."*

Stanley is a 6'1", 20 stone 17-year old. He has issues with socialising and is frequently violent towards his single mum. Mum felt she was reaching crisis point by Christmas 2020 as the changes to his routine, lack of full-time school place and limits on his activities were making his behaviour issues worse.

*"My mum and dad live close and usually help me with him but I hadn't seen them since March and I was finding it really hard. I tried to access Children's social services, I had a Child In Need meeting and then was allocated a social worker, but they never got in touch and I wasn't offered any other help. The Disabled Children team said I didn't meet the criteria for any respite. I was frazzled. I just had enough. I think I'd heard 'no' one too many times. So I just took myself off one day."*

Stanley's mum was found and taken to A&E by the police and assessed by a social worker. She told them all she could not cope with her son. Later that night she was discharged with no support offered, back to care for her son.

*"They said because mum and dad were near they could keep an eye on me. But the closest they could be was outside the kitchen window. It terrified me how much of a breakdown I had so quickly and yet that wasn't enough to trigger any help."*

## **Recovery needs of families of children and young people with SEND**

When asked what families felt they needed to help them and their children recover they said:

### **A. Get back to normal**

Pupils need access to their full educational and wider support. They need the stability and consistency of usual schooling. They need all of the activities in school and community to reopen. They need to be getting all of the support their EHCP legally entitles them to. Many parents felt that return of their full support would be all that was needed to 'recover'. Parents felt what their children need more of now, to assist recovery, is for more input for their wider needs and a way of catching up on all the experiences lost over the year – social, developmental, and independence. They need chance to develop social skills, mix, play and get back to where they were. Most were very keen to see additional activities for their children and families available over the Summer holidays. Many were desperate for the promised 'dropping of restrictions' planned for June 21 2021.

### **B. Resource better health and care support services**

Parents and providers highlighted the need for improved services in health and social care. All services need to be reinstated to their pre-pandemic level, although many parents highlight that these were already not sufficient to meet their child and family's needs. Waiting lists for vital services, such as social care assessments and CAMHS, were frequently said to be too long. Thresholds for accessing services were felt to be too high and despite a push for joined-up professional working, many parents felt they were not getting the support their family needed.

*"Far from thriving, we're now barely surviving" Parent interview*

Some parents stated explicitly that what is required to support recovery is for pupils to be reassessed and new support packages implemented which meet their child's new needs. It was identified by many that there are now backlogs in the EHCP process, getting education placements for next year agreed and receiving panel verdicts as well as accessing specialist services, health consultants, respite and holistic family support, and that the longer these children go without the right support, the greater their needs will get.

### **C. Support families with children and young people with SEND**

Families said they need extra help to recover including reinstatement or increase in respite care. Several also suggested that as part of the Recovery Plan they should be given funding directly to spend on the activities their child and family would enjoy, to have quality family time. This was a suggestion echoed by many service providers. Families with children with EHCPs often struggle to find provision in the holidays that



can accommodate the needs of children with SEND, also takes siblings, provides children with opportunities for social experiences but also provides parents the opportunity to get peer support, relax, or have time to themselves. It was identified that these are needed now more than ever before. Parents said they need a break and some time to themselves (not caring, working or worrying) in order to be able to properly care for their children and family.

*"Families cannot be expected to just get on with all this and remain unscathed. We now need ongoing and extra support." Parent interview*

*27 May 2021*