Experiences of children with special educational needs and disabilities and their families in the United Kingdom during the coronavirus pandemic

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Abstract

Purpose – The purpose of this paper is to outline the experiences of children with special educational needs and disabilities (SEND) and their families during the coronavirus pandemic.

Design/methodology/approach – This paper draws on research gathered and collated by three different organisations working with families of children and young people with SEND.

Findings – There were a number of common findings across all three surveys. In particular: the rapid collapse of external support for children and families; the reduction/withdrawal of support exacerbated the stress and exhaustion already experienced by many families; it proved very difficult to establish home learning and get adequate support from schools; there was little government recognition of families’ vulnerability and need for support; and, paradoxically, a significant minority of children and families reported increased well-being.

Originality/value – Findings carry clear implications both for the provision of child and family support during any further lockdowns and, more generally, in respect of government policy and funding of family support.

Keywords Children, Family support, Coronavirus, Lockdown, Parent carers, Special educational needs and disabilities

Paper type Viewpoint

Introduction

It is in rapid waters that we report on the experiences of children with special educational needs and disabilities (SEND) and their families during the coronavirus pandemic. Writing as we do in August 2020 when children and parents are bracing themselves for the enormous challenge of returning to school, we can offer little more than a moment in time snapshot of the impact of coronavirus on our community thus far.

This paper is based on online surveys carried out with parent carers on the impact of COVID-19 and the associated lockdown on children and young people with SEND and their families. The surveys were carried out by three organisations:

1. Reaching Families (RF) (www.reachingfamilies.org.uk/), a small grassroots charity who provide information, training and peer support to parent-carers in West Sussex in the South-East of England;

2. Disabled Children’s Partnership (DCP) (https://disabledchildrenspartnership.org.uk/), a coalition of more than 80 organisations campaigning on behalf of children with SEND and their families across England; and

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3. *Special Needs Jungle* (SNJ) ([www.specialneedsjungle.com](http://www.specialneedsjungle.com/)), an online magazine for the SEND community in the UK.

Between them, these organisations surveyed almost 5,500 parent-carers over the period April–June 2020.

While there is obvious divergence in the focus of each survey – SNJ, for example, concentrated entirely on the challenges around education – there were also clear areas of consensus, most notably regarding the speed and scale of the collapse in external support for children and families, the mental and physical exhaustion of both parents and children, the challenges in home learning and getting support from schools, the need for government recognition and the paradox of those children and families whose well-being increased during the lockdown.

### Speed of collapse

Ten years of austerity has left support services for families of children with SEND diminished and threadbare. The DCP estimated in 2018 that the funding shortfall for these families was £1.5bn ([Disabled Children’s Partnership, 2018](http://www.disabledchildrenspartnership.org.uk)). In 2019, a survey by the DCP found that just 4% of parent carers got the support they needed to care safely for their disabled children ([Disabled Children’s Partnership, 2019](http://www.disabledchildrenspartnership.org.uk)). An unforeseen national emergency such as COVID-19 was, therefore, always likely to place huge strain on those support networks and expose underlying weaknesses, as has been the case for so much health and social care provision.

It took a matter of weeks for parents to reach breaking point. As schools closed and resources in health and social care were redirected to meet the looming crisis, the walls began to close in on families of children and young people with SEND. By late March/early April, RF was already receiving posts and commentary on their Facebook group that pointed to this strain. In early April one of the authors of the current article, a parent-carer and Director of RF, wrote an article for the Guardian headed “We’re on our own” which focussed on the speed of disintegration in the support systems on which our families depend ([O’Hagan, 2020](http://www.guardian.co.uk)). The article was published just three weeks after lockdown in England but quoted parents who said they were already at breaking point. One parent had developed insomnia, another said her child had started self-harming and, owing to the extreme social isolation, was questioning her own existence. Other parents in West Sussex at the time talked of children behaving violently towards them and their other children. One mum said she could only manage her son’s anxiety by staying at his side all his waking hours.

In late April, RF conducted their local survey into the effects of the pandemic and associated lockdown and found patterns of experience that would be picked up again and again in other surveys. Carried out the week of the 21–28 April, the survey was completed by 415 parents, a level of response the charity was not expecting. Responses included 650 comments across three open questions. Results included the following:

- 65% of parents described being physically and mentally exhausted;
- 51% said they were experiencing increased anxiety and depression;
- 43% said their children were also experiencing increased anxiety;
- 67% said they were struggling with home schooling their children;
- 12% of families used to receiving external support were still receiving it; and
- 34% of parents said their children were still receiving support from school.

“I am exhausted and feel like I have nothing left to give. Our family feels like it’s falling apart to be honest” said one parent. “Trying to manage a demand avoidant child and work from home has caused me to have panic attacks. I am failing as a parent and I am failing at work. It is soul destroying” said another.
When the DCP carried out their survey with over 4,000 parent-carers in May, the findings demonstrated that RF’s survey was not a localised early anomaly but part of a wider national picture. DCP findings included:

- 72% of parents said they were providing more care than prior to the pandemic;
- 68% said their non-disabled siblings were also providing more care;
- 24% of families used to receiving external support were still receiving it;
- 70%–80% of parents said their children had worsening mental health;
- 68% were still receiving support from their child’s school; and
- 50% said external therapies had stopped.

The overwhelming message was that families felt “abandoned by society” and left to cope on their own, including dealing with often complex care and medical procedures without support. As one parent said: “It’s like living in a pressure cooker. It’s constantly and endlessly exhausting”.

**Guidance and acknowledgement**

The SEND community were not alone in being confused and disappointed in government guidance during the lockdown and early stages of the pandemic. From the confusion over vulnerable groups to later vagueness in the government message of “Stay Alert”, the issue of clarity of message has persisted. But for parent-carers the issue was also one of acknowledgement, recognition and understanding of the additional challenges they face. We are the “great unseen” observed one parent.

The weekend before the lockdown started the government released guidelines on shielding for older people and vulnerable groups. There was little mention of children with SEND. To many of us who work with families of children with SEND and who understand their vulnerabilities, the absence of specific guidance was alarming.

Little more was said in the first few weeks of the lockdown other than in the COVID-19 Bill which controversially suspended the requirement of local authorities to meet the provision detailed in Education, Health and Care Plans (EHCPs), alongside regulations that relaxed legally binding timescales for statutory assessments. While children with EHCPs were identified as a group who could still attend school, removing the duties around their provision made that harder. SNJ would later find almost one-third of families (32%) said the suspension of these duties prevented them from sending their children to school during the lockdown. In response to questions about support for disabled children, the government often responded that schools remained open for children with EHCPs. But the reality was that the large majority were not in school – mainly because either parents or schools (or both) did not feel that the right support was available to care safely for them.

In their survey, the DCP found that the vast majority of parent-carers (68%) agreed or strongly agreed that government guidance was not relevant to the needs of families of children with SEND. In total, 77% found that government guidance on shielding was confusing. The SNJ survey noted that, of the 80% of parent-carers who were aware of government guidance, only 5% were happy with their advice. In total, 59% described themselves as “very unhappy”.

In total, 90% of parents in the RF survey said they felt the government should classify families of children with SEND as a vulnerable group. For many they hoped this would lead to priority support with challenges that at the time included shopping. But for other families acknowledgement from government would have been an outcome in itself. “Just acknowledging I guess that it is harder if you have children with SEND issues”, said one parent from West Sussex. The DCP described it as a “recurrent theme” in their surveys and
not surprisingly, in their report – *Left in Lockdown* (Disabled Children’s Partnership, 2020) – their first recommendation begins “the government must better recognise the specific needs of disabled children and their families”. “They feel forgotten” they added.

### Mental health

Measuring the impact of COVID-19 on the mental health and well-being of children with SEND and their families begins with firstly acknowledging where they were before the pandemic. We know for example, that over 72% of parent-carers reported suffering from stress, anxiety and/or depression – far higher than national averages (*Contact a Family*, 2011). This is the baseline against which current findings should be considered.

In April, 65% of parent-carers in the RF survey said they were suffering from “significant mental exhaustion” whilst 43% said their children were having significant problems with mental health. In May the DCP found that 70%–80% of parent-carers reported worsening emotional and mental health for both themselves and their children.

The pandemic’s impact on mental health is rooted in issues parent-carers are long used to – social isolation, overwhelming caring responsibilities, pre-existing behavioural and mental health issues, paucity of external support and so on. But these have been exacerbated by the sudden loss of the support that some did have; the lack of a break from caring when children would have been in school; the pressures of home schooling; and worries about their families’ health.

### We happy few

While we report on the negative impact of the pandemic on mental health it is important to note that the surveys presented a nuanced picture worthy of further investigation. In all three surveys, there were many children and families for whom the pandemic and the associated lockdown seemed to offer a release from the stresses and burdens of normal life. In total, 38% of families in the SNJ survey, for example, reported their children’s anxiety had improved since the lockdown (37% said it had got worse).

This positive impact on a significant minority of families of children with SEND initially seems paradoxical but is open to fairly ready explanation. While lockdown for most people meant social isolation, cabin fever and stress, for this minority, it meant an oasis of peace and calm. “My daughter is a square peg and society is a circular hole. She is so much happier in her own world” said a parent from West Sussex. SNJ reported that the change in some children was such that some parents were now considering making home education a long term option.

Sadly, however, what these “positives” highlight are the issues children and families faced before the pandemic. For many children the pressures of “normal life”, in particular the routines, structures, demands and challenges of school, are a major source of their anxiety. Overnight the lockdown removed these pressures and, in doing so, highlighted, for example, how the education system is failing many disabled children. Now might not be the time to debate the issue through the lens of the social and medical models of disability, but the findings do point to the mental pressures SEND children face in adapting to a world not nearly as forward in making its own adaptations to their needs.

### Schools and home learning

From the outset parents described significant struggles in supporting their children’s home learning. In total, 67% of parents in the RF survey said this was a challenge, 68% reported the same in the SNJ survey carried out in June. In the DCP survey, 64% of parents said they were worried about how much home schooling they were doing with their child. “I’m a secondary school teacher. Even with 15 years of experience, I am struggling to teach my
two children with special needs” said one parent from West Sussex. Again and again, the challenge of home schooling and the emotional pressure it placed on both children and parents were raised in our surveys. For many families, the overlap between home and school was a source of distress for children. One parent said her child had “collapsed his safe zone entirely into this house”. Asking him to then focus on school work was out of the question. Getting him back to school in September would be an even greater challenge.

While the government ruled that local authorities were temporarily relieved of the legal duty to meet the provision detailed in EHCPs, and parents understood the practical barriers to normal provision, they also did not expect it would mean they would be cut off from schools during lockdown. After all schools had been asked to apply “reasonable endeavours”. However, in April, the RF survey found that only 34% of children were still receiving support from their school. In June, just 28% of respondents in the SNJ survey would report their child receiving “good support” from their school during lockdown.

Of the three surveys cited, SNJ was alone in choosing a specific area of focus – education and learning. Their motivation started with reports by parents that risk assessments (needed to establish whether children were safer in school or home during lockdown) were being used by schools to prevent children with EHC plans from attending, despite their eligibility. They found that 75% of parents said their child had not been risk assessed (or if they had they did not know of it) and in less than 10% of those who had, were parents consulted during the process. “My input was added once the decision that my son had to stay home had already been made” said one parent. SNJ went further and measured levels of support across independent, special and mainstream schools. They also measured amount of work set, levels of differentiation and access to therapies and teaching assistant support. What they found was significant variance in quality of provision based on the type of setting. While 19% of parents in independent or non-maintained special schools, for example, agreed their child had received very good support from their school, just 7% of parents in mainstream and 8% in special schools were in agreement.

A similar pattern emerged on other topics. Almost half of parents of children in independent schools said their child had an appropriate amount of work compared to 16% in mainstream settings and 26% in special schools. The same pattern was also true of differentiation and access to learning assistant support. Not surprisingly, Special Needs Jungle (2020) has called for an independent review into the suspension of EHCP duties and “how the relaxations were used or abused, both before and after the announced easements were put into force”.

Return of support and returning to school

Over the summer, lockdown measures have eased and NHS staff who were redeployed during the pandemic have returned to their normal roles – but has this led to a return of support for families? There have been encouraging signs that government has listened to the concerns of parents. Ministers and officials have told the DCP that they have been strongly influenced by their survey findings. This has begun to show through into action. Government guidance to local authorities and providers has called on them to prioritise the reinstatement of short breaks and respite care for disabled children and their families. The changes to EHCP law have come to an end. But we do not yet know how this is translating into changes on the ground. A quick – and unscientific – poll on twitter by the DCP found that, for around half of parents, short breaks had either continued, restarted or were planned to restart. This suggests some progress, but still a long way to go.

The most immediate and pressing concern for SEND families is the challenge of children returning to school in September. Fear of returning to school has preyed heavily on parents during the lockdown. By the time schools open again in early September, some children will have had close to 26 weeks at home. For those for whom lockdown and holidays have been a welcome respite from the pressures of school and who have settled into more relaxed
routines, going back is an enormously daunting prospect. As early as April, over half of parents surveyed in West Sussex were prioritising the need for information and resources on preparing children for returning to school. Many fear for their child’s health, others worry about the process of transition (particularly if their child is due to move school), the need for time for their child to settle, the damage done by the lockdown to their mental health and social and communication skills.

The DCP found that parents believe a staggered, phased return to school will be necessary for children with SEND. The government’s insistence of a full and immediate return to school in September (backed by possible fines for non-attendance) does not suggest they are listening and aware of the challenges SEND children will face. The return to school – and school routines – after such a long break and with schools operating very differently than before, will be very challenging for some children. In some cases, this will inevitably impact on behaviour. It is vital, therefore, that schools recognise this in devising and applying their behaviour policies. Children with SEND are already disproportionately excluded and illegally off-rolled by schools; the pandemic must not be allowed to make that situation even worse.

Longer term policy implications

As we write, there is no scientific consensus about how long COVID-19 will last. The World Health Organisation has recently suggested the virus can be beaten within two years, whereas a former government scientific adviser suggests it is here to stay. Six months into the course of the pandemic may allow us only a marginally more advantageous view than we had in March. We do know, however, that the pandemic is changing our world and may have a seismic impact on society for years to come. The social and economic fallout has barely begun and as children return to school, wage support schemes stop or reduce and rent protections are withdrawn, the worst may yet be to come. The government must learn the lessons from the spring when dealing with any local restrictions or lockdowns and any second wave. They must ensure that support to families with disabled children is not cut off and that where children are unable to go to school, additional support is put in place both to support their education and to support their carers. This will require a joined up response across education, health and social care.

But the pandemic does offer an opportunity for real change. For the first time in years, the government’s educational focus has broadened beyond academic achievement. There has been increased recognition of the need to support families and the importance of services such as respite care. Lockdown has actually given families without disabled children a small glimpse of some of the realities of life for disabled children’s families. At the same time, the government is carrying out reviews of both the SEND system and of children’s social care. Taken together, these may prove fertile soil in which to propagate real change. At the upcoming Comprehensive Spending Review, the government must use this opportunity to invest in support for disabled children and their families and close the funding gap identified by the DCP. The DCP is also calling on the government to establish a Disabled Children’s Innovation Fund to support transformational change in the way support is delivered. An innovation fund would be an ambitious commitment to deliver real change for disabled children and their families.

References


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