



**Reaching
Families**

Coronavirus Survey



Empowering families of children and young people with special educational needs and disabilities in West Sussex

About our Survey

Our survey was carried out in order to better understand the challenges experienced by families of children with SEND in West Sussex during the coronavirus lockdown. It comprised of 25 questions (22 closed, 3 open) covering a range of subjects – income, mental health & well-being, physical health, home schooling, returning to school, shopping, etc. The survey ran from the 21st to the 28th April. 415 responses were given by parents representing children with a wide spectrum of needs.

- 24% of parents had more than one child with SEND
- 63% of parents said their children had Autism
- 39% of families said their child had a learning disability
- 12% said their child had a physical disability
- 69% of parents said their child did not meet the government definition of clinically vulnerable
- 20% of parent-carers are lone parents
- 31% described themselves as full time carers.

Key Findings

- 48% of families have lost income since the lockdown
- 43% of children with SEND are having significant problems with mental health
- 65% of parent-carers described themselves as suffering from significant mental exhaustion, 51% say they are physically exhausted
- 51% of parents say they have had a significant increase in anxiety and/or depression
- 67% of parents said they are having significant struggles with home schooling their children
- 34% of families say they are receiving support from their child's school
- Of those families who usually have paid carers, 12% are still receiving support
- 47% of children who were due medical appointments have missed these as a result of being in self-isolation.
- 67% of families are having significant problems with online deliveries, click and collect and accessing vulnerable time slots
- 90% of parents think the government should classify SEND families as a vulnerable group.

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Executive Summary

It says a great deal about the need for parent-carers to speak out over the challenges of the coronavirus pandemic that 415 of them responded to our week long survey on the virus and the impact of the lockdown. Parent-carers are often asked to complete surveys, to do so now in these circumstances and in such large numbers, is exceptional.

Parents also provided their own written feedback in large numbers, 652 comments in all across three open questions. The need to speak is therefore clear from both the quantitative and qualitative results of the survey.

Two thirds of parent-carers told us they are suffering from significant mental exhaustion as a result of the pandemic – more than half said they are suffering from physical exhaustion, the same again with increased anxiety and/or depression. Almost half are struggling to sleep.

“ I think the government need to help the vulnerable with mental health issues that are now arising. ”

Families of children with SEND are long used to surviving on little sleep, they are long used to chronic stress and anxiety. It is worth remembering therefore that their baseline is significantly higher than national averages. In our 2019 annual survey of 324 parents 78% of them said their greatest challenge was emotional stress. For them now to say they are suffering from mental exhaustion is to plot their fatigue somewhere off the map.

“ We are strong, stronger than people who don't experience our lives. We have better coping mechanisms. But after all of this I have no idea how we as parent-carers will be... ”

The impact of the lockdown on children has been tumultuous, for some a practical dismantling of their daily life and routines. It has resulted in significant anxiety, behavioural problems and concerns for their mental health. Some children have become verbally and physically aggressive since the lockdown, which in turn has had a negative impact on siblings, some of whom also have additional needs.

Not surprisingly, home schooling and preparation for returning to school are major concerns for families. Over two thirds of parents said they are struggling with home schooling their child, in many cases the result of children seeing home and school as entirely separate zones that do not overlap. The sanctuary of home also presents a challenge to children being ready to return to school. Given that for many families school itself is a major cause of anxiety, getting their children back into that zone will be a considerable challenge they cannot meet on their own.

Many parents in our survey expressed surprise families of children with SEND are not already classified by government as a vulnerable group. 90% think they should be. The single biggest advantage for families in government doing this would be their improved access to shops.



“ I obviously understand completely the need for lockdown and support it wholeheartedly, but it has a massively detrimental effect on my child's well-being. Mental health and behaviours have been impacted in a very negative way. ”

Even families who do meet the government definition of clinically vulnerable have experienced significant problems with shopping whether online or in person. For some families this causes problems in giving their child a specific diet, in other cases a financial drain as they are forced to use smaller more expensive shops.

It is comforting to know that for around 20% of families, the lockdown has brought with it a respite from the pressures of normal life. Parents report their children being more relaxed, spending more quality time together as a family, having the time to take life at their own pace and focus on supporting their children with things like life skills. The challenge for these families will come in the period of transition back to school when children will need to readjust to the structure and demands of school life.

Little has been said by government or the national media about the needs of our families during the pandemic. We hope in some small way the following report adds to those voices raising the need for additional support to children with SEND and their families. Their vulnerability to the social and economic consequences of the pandemic is clear, their need for government support, urgent and pressing.

About SEND Families

Measuring the impact of the pandemic on families of children with SEND cannot be done without first reference to the baseline information we have on the challenges they face in normal times. They are a community used to chronic stress, isolation and little support. Further stresses and trauma caused by the pandemic and lockdown should therefore be measured using information like the following as our starting point:

- It costs three times as much to raise a disabled child as it does other children (Joseph Rowntree Foundation)
- 40% of disabled children are estimated to be living in poverty (Disability Rights UK)
- 65% of families of disabled children report feeling isolated either frequently or all of the time (Contact)
- 72% of families of disabled children experience mental health problems like anxiety, depression or breakdown (Contact)
- 78% of parent-carers in West Sussex say their greatest day to day challenge is emotional stress (Reaching Families)

Parental Exhaustion

Parent-carers are commonly known to suffer from stress, anxiety and depression. Numerous studies have demonstrated their experience of mental ill health is exponentially higher than national averages. Now, in the age of coronavirus parents tell us they are at breaking point. “Totally and utterly exhausting, parent-carer burnout” said one respondent.



“ 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. ”

A number of obvious factors are combining and contributing to parental exhaustion – their child’s mental health, social isolation, home schooling, shopping, the pressures of work or other caring responsibilities and lack of respite - all playing their part in creating a highly intense environment that is wearing away at parental resilience. That so many parents are mentioning mental exhaustion just six weeks into the pandemic is grave cause for concern.

“ I am exhausted and feel like I have nothing left to give. Our family feels like it’s falling apart to be honest. ”

- 65% of parent-carers report significant mental exhaustion since the lockdown
- 51% of parent-carers report significant physical exhaustion
- 51% of parent-carers report a significant increase in anxiety and/or depression
- 47% of parent-carers report significant problems with sleep.

“ As the weeks have passed behaviours, anxiety, frustration, lack of normal routine, mental health, etc, is spinning out of control. ”

Children’s Mental Health

“ The children are so angry and stressed all the time and as a parent without any respite my resilience is wearing away so home is not a happy safe space, lots of shouting and arguing. ”

For families of children with SEND consistency, predictability and routine are basic management tools for maintaining well-being. It is not surprising therefore that the greatest source of anxiety to children with SEND during the pandemic is the enormous disruption to their normal way of life. 57% of parents said their children were struggling with the changes in structure and routine. This extends to their isolation from friends and family (58%), commonly a significant element in our children’s support networks.

“ Massively affecting my eldest’s behaviour. He is very verbally aggressive and becoming very OCD. ”

Parents also told us that their children were suffering from significant anxiety (47%), with mental health problems (43%) and with behavioural problems (42%). In some cases it was leading to children being violent. Two parents confirmed the police had visited. Many were concerned their children’s behaviour was having a significant impact on the mental health and well-being of other siblings, some of whom also have SEND.



“ We have gone from a confident, easy going, independent child to one that cries or lashes out in anger (both verbal and physical) at the drop of a hat. ”

- 57% of children having significant problems in change of routine
- 47% of children have significant anxiety since the lockdown
- 43% of children have significant problems with behaviour
- 42% of children having significant behavioural problems
- 51% of parents say they're having significant problems managing their child's behaviour

Shopping

Over two thirds of parents in our survey told us they were having significant problems with the various shopping options available to them (67%) – click and collect, online deliveries and vulnerable time slots. As illustrated above even families of children who meet the government definition of vulnerable are struggling to access shops. Again and again, parents commented on the need for vulnerable status in order to gain better access to food shopping.

Current policy towards vulnerable groups appears to vary amongst supermarkets and there is evidence from our survey that some shops are demonstrating poor understanding of the needs of SEND families. One parent commented that when she tried using her sunflower lanyard to join the front of a queue with her son, the

security guard laughed and told her to join the back of the queue “like everybody else”. Meanwhile, some children with Autism for example cannot tolerate the sensory overload that comes with shopping whilst others are too vulnerable to be left at home. Other families contain medically vulnerable adults, which of course compromises their ability to shop. Struggling to access larger supermarkets has also forced some families to use smaller local shops, which are more costly. For families who have already lost income since the lockdown, the extra costs involved in shopping this way is doubly punishing on household budgets.

“ We are on the extreme vulnerable list and he only managed one click and collect and one delivery during our 5 weeks out of the 12 which was capped at 80 items (wish this could be increased for extreme because we can't just pop to the shops) with over 10 items out of stock and 10 substitutes. ”

One other finding of note in the survey was the small percentage of families who are receiving external help with shopping. Neighbours and friends accounted for the most common support (11%) whilst community volunteers represented 4%. We know that through the NHS volunteer recruitment drive and the community hub established by the local authority that there are a significant number of volunteers able to support families. Perhaps the challenge is making families more aware of that support.



- 67% of parents said they were having significant problems with click and collect, online deliveries and accessing vulnerable time slots
- 77% of parents said they received no external help with shopping (4% had received support from community volunteers)

“ I think the government should issue children with SEN/additional needs a letter to give them priority for online food shopping, because of their extreme food restrictions. This letter should also allow them to purchase more than two items. ”

Home Schooling

We asked parents what their greatest challenge has been since the lockdown and more than two thirds of respondents said home schooling (the highest ranked issue). The percentage of parents struggling with home schooling (67%) is almost identically inverse to the percentage of parents who say they are still receiving support from school (34%).

For many children the struggle with home schooling is a result of a change in structure and routine that has turned their world upside down and caused significant anxiety. Almost half of parents (48%) said they are

“ I'm a secondary school teacher. Even with 15 years of experience, I am struggling to teach my two children with special needs. ”

“ My son finds it really hard to home school. The work being set is generic and does not take his EHCP or individual needs into consideration. My mental health has been low owing to home schooling pressures. ”

struggling to put the structure in place to facilitate home learning. Their children have struggled to make the transition to learning at home and see each as entirely separate zones.

Problems with home schooling have led to other challenges for families including anxiety, conflict, demand avoidance, withdrawal and sometimes violence. For parents with more than one child to home school, perhaps dependent adults with care needs of their own or who are working from home, the pressure is intense.

“ Trying to get any school work done with a school refuser is hugely difficult, and it is turning the child's safe place into a nightmare for them. ”

- 67% of parents said they are having significant problems with home schooling their child
- 57% of children are having significant problems with change in routine
- 48% of families struggling to create structure and routine for their child
- 34% of parents said they are receiving support from their school SENCO or LSA.



Returning to School

Over half of parents in our survey (53%) said they would like information and training from Reaching Families on how to prepare their children for returning to school. After managing anxiety in children (54%) it was the highest option chosen. The two issues are closely linked.

“ I think my biggest challenge is when we come out of lockdown as my eldest son will have collapsed his "safe zone" entirely into this house. Stretching that once we are out is likely to be challenging for some time. ”

For many children for whom school is a highly pressurised environment and/or who need significant support to build up to or maintain a regular school week, being at home has come as a great relief. However, for parents it presents an enormous challenge in their child making the transition back to school. They worry their children's social and communication skills will be impaired by the lockdown, their trust and connection with staff, their willingness to let go of what for them has been an oasis. Many worry that the process of their children readjusting will take several months.

“ I am so worried about the impact on my son starting school in September. It was always going to be difficult. I really don't know how to help him prepare. ”

Happier Homes

“ My daughter is a square peg and society is a circular hole. She is so much happier in her own world. ”

For around 15-20% of families in our survey, the lockdown has proved a respite from the pressures and strains of normal life. 21% of parents said their children are significantly more relaxed since the lockdown started, 15% are sleeping better. Parents reported benefits too – 21% say they feel significantly less pressure, 15% say they feel significantly more relaxed. Poignantly, one parent said their daughter had stopped self-harming, whilst another said their son is starting to eat as home gives him the confidence he is not being watched.

“ The lockdown has helped my son have less meltdowns and anxiety, as we usually have this every morning before school and when he comes home from school, and without this it has made a huge difference to his well-being. ”

Of course for families of children who are happier and more relaxed since the lockdown, the lifting of social distancing measures and the return to school may bring with it significant challenges in terms of their transition back to normal life, or the “new normal” we all anticipate.



Key Recommendations to Government

Parent-carers overwhelmingly agree that government should classify families of children with SEND as a vulnerable group. 90% of them answered in the affirmative to this question. For many parents this alone would represent acknowledgement of the additional struggles they face, for others that it would simply mean improved access to shopping.

Many parents in our survey said they felt abandoned or forgotten by the government. "We are not even on their radar" said one respondent. Many could not understand why families of children with SEND are not already recognised as a vulnerable group.

In addition to vulnerable group status parents repeatedly emphasised the need for increased investment in mental health support for both children and parents and the pressing need for support in children making the transition back to school.

1. Classify families of children with SEND as a vulnerable group

This move would provide parents with the acknowledgement the government recognise the additional challenges they face and all importantly, should mean improved access to shopping whether online or in person. We suggest the government should instruct supermarkets to make the necessary changes to improve access to families of children with SEND.

2. Increase DLA payments during the pandemic

With almost half of families reporting lost income as a result of the lockdown, and baseline data demonstrating their underlying financial vulnerability, an

“ Classify SEND children as vulnerable so we can get the support we need. ”

increase in DLA would help cover some of those losses plus the additional costs associated with shopping, educational resources and expenses associated with caring for disabled children and young people.

3. Increase funding to support the mental health and well-being of families of children with SEND

A crisis in the mental health and well-being of both children with SEND and their families is mounting and significant investment in mental health services for both is needed to help families stay together, return to school and adjust to a new normal way of life.

4. A home schooling and back to school strategy is needed to support families of children with SEND

Whenever schools open, we can expect some children with SEND to be attending on a part-time basis, needing significant time to adjust to returning to school and an ongoing need for parents to manage and deliver home learning. A government led strategy for home learning and returning to school is therefore needed to support both children and parents through this period of uncertainty and adjustment.

“ Children will need massive support in place returning to school, some children will also need a lot of extra help with learning support. ”