



## **#LeftInLockdown - Parent carers' experiences of lockdown**

### **Summary**

#### **Our survey found**

- Parents reporting an increased caring load, both for themselves and for their disabled children's siblings. Parents feel exhausted, stressed, anxious and abandoned by society. In many cases, the support families previously received has now stopped. Many families are seeing declines in both mental and physical health
- Parents are particularly concerned about the pressure of children's behaviour and mental wellbeing; managing home-schooling; and what will happen to their children if they contract Covid19.
- the little support that had previously been provided for families has often stopped altogether
- Children's friendships; learning and communications; mental and physical health; and emotions and behaviour have all been negatively impacted.
- The lockdown is increasing financial pressures on families.

#### **Parents call for action now, including**

- acknowledgement and respect for their situation and the challenges they face; and for them to be prioritised
- increased support - both financial and services
- information and guidance more specifically at families with disabled children
- flexibility - including from employers, schools, and around lockdown rules to enable family and friends to provide support.

**As the country begins to move out of lockdown**, parents were greatly concerned about their child's return to school. The return of their children to school needed to be contingent on it being safe; and needed to be well planned; and carefully managed; with clear communication with parents and children. Those children with the most complex

health needs, and who are therefore shielding may continue to face these challenges for a considerably longer period of time and must receive additional support.

The right support - including mental health support - needed to be in place to support the transition back to school. Flexibility and understanding were key.

**Specific responses from parents included:**

- Most parent carers (72%) responding to our survey said they are providing a lot more care compared with the amount before lockdown.
- Just over two thirds (68%) said non-disabled siblings were also providing a lot more care.
- Prior to lockdown, many parents (62%) were managing without support such as short breaks. For those who had previously received support, the majority have seen it stop (76%)
- Half of parents whose children had been received therapies or other extra support have seen this stop.
- The lockdown has led to some parents not seeking necessary medical health for their disabled children (44%), themselves or their partner (54%) or their non-disabled children (17%)
- The majority (70-80%) report worsening emotional and mental health for both their children and themselves; although a minority report improvements. The impact on physical health is less marked, but still nearly half (45%) say their disabled children's physical health has declined; and just half say the same about their own (54%)
- Many parents whose children were eligible for a school place had not taken up places; mainly because of either concerns about their children's health or because the right provision was not available.
- The majority (64%) of parents were worried about how much home school they were doing with their disabled child; and nearly a third (32%) said they were receiving no support specific to their child's needs from school; on the other hand, a quarter were getting good support.
- The lockdown was impacting on statutory process - two-thirds going through an assessment process had seen it delayed; whilst approaching half (43%) of annual reviews had lapsed or been put on hold.
- Families are facing financial pressures, through either, or both, a reduction in income (39%) or increased costs (61%). One in five (21%) said they will go into debt as a result.

# Full Report

## Introduction

### About the Disabled Children's Partnership

The Disabled Children's Partnership (DCP) is a coalition of more than 70 charities set up to campaign to improve disabled children's services.

### About the survey

We set up an online survey to assess the impact of the coronavirus pandemic and lockdown on families with disabled children across the UK. The results will be used to assist government understanding and plans around support for disabled children both now and beyond lockdown.

The survey was promoted between 1 -17 May 2020 via social channels, direct emails to supporters of DCP charities, parent carer groups and networks.

The survey covers the following areas:

- Caring in lockdown
- Information and support
- Health and social care
- Education and learning
- Work and work
- What could government to do help now and with the transition from lockdown

## Findings

### Section 1: Number of responses

We've had the biggest ever response to a DCP survey with 4074 responses from across the UK.

- 48% of responses from South East, South West, East of England and London
- 39% from Midlands, Yorkshire and North of England
- 13% from Scotland, Wales and Northern Ireland

Responses relate to 4868 disabled children and under people under 25.

- 13% are under 5
- 64% are 5-15 years
- 10% are 16-18 years old
- 13% are 18-25 years old

### Section 2: About the respondents and their children

- 92% are responses from the mother in the family
- 26% are lone parents

- 35% indicate that either they or a partner has a disability or health condition
- 76.5 % have one disabled children, 18.5% have 2 disabled children, 5% have 3 or more disabled children
- 57% also have non-disabled children in the household

Breakdown by condition/disability of children:

- 68% Learning disability
- 66% Speech language and communication difficulties
- 62% Behavioural emotional and social difficulties
- 61% Autistic spectrum disorder
- 33% Physical difficulties
- 23% ADHD
- 20% Rare conditions
- 16% Life-limiting or life-threatening condition
- 16% Visual impairment
- 11% Hearing impairment
- 7% Undiagnosed

Other household characteristics:

- 25% have a household income under £15,000 per year (22% between £15,000 - £30,000)
- 72% have someone in the household in paid employment (including members who have been furloughed).
- 35% say that someone in the household is shielding

### **Section 3: Caring in lockdown**

#### **Levels of care and support**

- 72% say they are providing **a lot more** care compared with the amount before lockdown.
- 68% say non-disabled siblings were also providing **a lot more** care.

Prior to lockdown, only 38% say they were getting support from their local council or NHS such as a short break (respite) to help care for disabled child.

Of those,

- 76% say ALL support has stopped since lockdown
- 8% say support has stayed the same
- 16% say offered an alternative such as online or direct payment

#### **When asked about the impact of this change in support:**

Overall parents talks about extreme exhaustion, stress and sleepless nights. Families pushed to the limits.

There is an overwhelming feeling of 'being abandoned by society', to deal with often complex care and medical procedures on their own. Many are trying on doing therapies such as physiotherapy at home. With no end in sight.

Very often parents talk about non-disabled children having to take up the slack.

A lot of concern about increased behaviour/meltdown, children going backwards or falling behind and how support will return post lockdown

Quotes about the impact of not getting support in lockdown:

*It's like living in a pressure cooker. It's constantly and endlessly exhausting.*

*Impact is huge absolutely no break from caring. It's really, really intense and quite overwhelming and you're just left to it, no one seems to want to have the debate or talk about those with children with complex needs how they're dealing with it, it isn't just home-schooling it's living breathing physio communication lifting feeding stimulating interaction trying to keep yourself sane home-school another child the list is non-stop and endless and no one to help or make you feel like they actually care by checking on you*

*Huge impact. We now have no respite and have no break from 24/7 care needs plus we are expected to home school two children, including modifying home-schooling work for visually impaired child. We now have no therapy intervention at all. This has been detrimental to my SEN child's progress and health. We are all completely exhausted both mentally and physically*

*My son's mental health is suffering, he has been harming himself and others. I can't leave him alone with his brother because I don't know what he will do. He refuses to leave the house for exercise and he hardly sleeps*

*PA's have stopped working since lockdown and all overnight respite ceased. However Disabled Children's Team of Kent County Council have telephoned on regular basis.*

*Support worker in school has obviously stopped which has impacted on learning but not being in school has had positive effect on child's mental health*

*I feel physically exhausted with the constant personal care I'm giving to my disabled child and emotionally drained trying to avoid melt downs through change in routine and restrictions. I'm overpowered with guilt that I'm not supporting my other children as well as I should and feel isolated and anxious about the current situation & the future. I have no time to deal with my own thoughts and feelings*

*The disability social work team have not even checked in and paid lip service to see how we are coping or how they might be able to help - remotely or otherwise.*

*Confusion for my daughter, she had a support worker to take her out into the community twice a week but now that isn't happening she doesn't understand why. It also means I don't get a break at all*

## Dealing with lockdown

The following were rated as the top 3 things respondents are finding most difficult about being in lockdown.

- Additional pressure of child's behaviour or mental ill health
- Managing home-schooling
- Fear of getting the virus and who will care for children if I'm ill

Most (71%) of respondents think their disabled children are dealing with lockdown fairly to very well

- 49% fairly well
- 22% well to very well
- 29% badly to very badly

Most (82%) say siblings are dealing with lockdown fairly to very well.

- 50% fair well
- 32% well to very well
- 18% badly to very badly

Most (76%) of the respondents think they are dealing with lockdown fairly to very well

- 56% fairly well
- 20% well to very well
- 24% badly to very badly

When asked about what would be most helpful (from a pre- defined lists of options), the following things received the most votes:

- Increase in carers allowance or disability benefits (54%)
- Sensory toys and equipment (46%)
- Outdoor play and leisure equipment (46%)
- COVID 19 testing (39%)
- Tablets, computers and laptops (32%)
- Someone to talk to about my worries (31%)

## COVID 19 testing

84% think that unpaid carers should get COVID testing like other essential workers so the recent change in England to include unpaid carers in the list of essential workers will be welcomed. The online portal needs to be updates to include unpaid care in the dropdown menu

Home testing needs to be available as many of these families will be shielding. (Add the disabled young people leaving in care/residential homes/ATU needs also need to have access to testing).

#### **Section 4: Information about COVID 19**

When asked to rate a series of question about government information:

- 43.5% agree that government information on COVID- 19 is clear and consistent (56.5% disagreed).
- 68% agree or strongly agree that COVID-19 information isn't relevant to the needs of families with disabled children (32% disagree or strongly disagreed)
- 77% agree or strongly agree government information about shielding is confusing (23% disagree or strongly disagreed)
- 42.5% agree or strongly agreed that there is too much information about the pandemic/lockdown 57.5% disagree or strongly disagree).

The top places families are getting their information are from:

- government website/daily briefing
- media reports
- local council
- social media
- charities

57% didn't know about the DCP web resources on COVID, those that have seen it most found it useful.

38% said they are interesting in getting advice from a charity such as Contact about caring for their child at the current time (39% said they weren't sure).

#### **Section 5: Heath and social care**

Overall emotional mental health has been affected more in lockdown than general health for all family members. The parent carers' mental and general health has been affected slightly more compared to the other children in the family and the partner.

When asked to rate the *emotional and mental health* of their family in lockdown

- 30% say disabled child's emotional and mental health is a lot worse, (41% a little worse, 18% the same and 10% saying it's got better)
- 19% say a non-disabled sibling is a lot worse. (48% a little worse, 26% the same and 7% saying it has got better)
- Nearly a third (32%) say their own is a lot worse (47% a little worse, 14% the same and 7% saying it's got better)
- 19% say their partners general health has got a lot worse (43% a little worse, 30% the same and 7% saying it had got better)

When asked to rate the *general and physical health* of their family in lockdown

- Around 1 in 10 (11%) say disabled child's general health is a lot worse (34% a little worse, 45% the same and 10% saying it has got better)

- 6% say a non-disabled sibling is a lot worse.  
(27% a little worse, 58% the same and 9% saying it has got better)
- Nearly 1 in 5 (18%) say their own general health has got a lot worse  
(36% a little worse, 37% the same and 9% saying it had got better)
- 9% say their partners general health has got a lot worse  
(29% a little worse, 52% the same and 9% saying it had got better)

#### Negative impact of lockdown on disabled children

- 83% say the lockdown is having a negative impact on their disabled child's friendships
- 86% say the lockdown is having a negative impact on their disabled children's learning and communication
- 87% say the lockdown is having a negative impact on their disabled child's behaviour and emotions
- 78% say the lockdown is having a negative impact on their disabled child's mental health
- 67% say the lockdown is having a negative impact on their disabled child's general health
- 64% say the lockdown is having a negative impact on their child's disability or condition  
(others said no impact or positive impact)

#### Level of health and social care support

1 in 4 (25%) were getting no therapies or extra support from the NHS/council or school before lockdown.

Half (51%) of those that were receiving therapies or other extra support say this has now stopped.

Of those still getting support (912 responses), 12.5 % say they are getting support in full either at school, home or online. The rest of getting some support, mostly online.

68% say a health or social care assessment has been delayed due to the lockdown

#### Impact of change in support

Again parents are talking about frustration of being left to cope alone. Commonly used words included stress, anxiety and worry. Many sound like they are close to giving up.

A sense of a building up of health problems on carer and child. A sense parents are really trying their best, common reflect a sense of guilt that they aren't doing enough.

*Examples of quotes:*

*Son had just had an operation on his foot and needed to exercise his foot to try and get him walking again, all physical support was withdrawn and no visits and no support as not attending special school due to lockdown and have services that go in so couldn't access these. We were given exercises to do at home via email and one email contact to see how he's progressing, poor communication*

*My son is struggling to engage with phone or video calls. They seem to trigger some very difficult behaviour. Including destruction of property. He struggles with change. And the change of environment has a negative impact. So. The therapies aren't positive for us right now*

*Guilt and worry that important therapies are being missed - detrimental to her development. We spent all that time trying to get her EHCP right and now she has nothing except us*

*I've been given minimal support at home just to help with personal care issues. It doesn't help with the emotional health or physical and mental health sides of it all. Can be very stressful, draining and causing extra health problems to myself.*

*His respiratory physiotherapy is carried out at home by mum and I'm following speech therapy plan and occupational therapy plan in his home-schooling but he isn't having the professional input he has at school weekly or any assessment of progress.*

Seeking health support

Of those needing medical help in lockdown:

- 44% say that the lockdown has stopped them seeking medical help for their disabled child.
- 54% for themselves or a partner
- 17% for a non-disabled sibling

Impact of not seeking medical help

The main themes are worry and uncertainty about what not seeking medical help may lead to.

Concerns about delays in getting treatment such as dentist, specialist equipment, eye appointments and DIY medical help. Pain and discomfort are used a lot (in 25% of the responses).

A real sense that community health support needs to be back into place for this group of child and to keep their parents healthy.

Quotes from survey:

*GP surgery refused to allow me to get swab test done on stoma... ended up in hospital for just over 2 week on antibiotics.*

*My neurodiverse child has ongoing throat problems - we can't see a GP and their appointment with ENT specialist has been cancelled and we've been discharged without consultation as to whether this was ok with us.*

*Myself, I haven't been able to access clinic appointments for steroid injections for arthritis in hands. Consequently, experiencing flare-ups in pain, made worse by increase in caring role.*

*My son hasn't been able to access medical appointments for splint and shoe fittings. Consequently his cerebral palsy is getting worse. Have been unable to access opticians to get him some glasses.*

*Marcus's 3 monthly IV antibiotic prophylaxis has been suspended during our shielding period.*

*I've had pneumonia and pleurisy during shielding period and initially struggled to get a doctor to assess me properly and ended up in hospital for 4 days*

We asked families where they have sought help for mental health and wellbeing from (based on a pre-defined list)

- 43% from friends and family
- 38% school/college
- 32% from social media
- 27% from a media or mental health professional
- 26% from a local parent carer group or forum
- NHS or government website
- 25% from charity website/helpline
- 14% local council
- 6% church or faith group

We asked respondents if they would be interested in receiving information on any of the following for your child's mental health and well-being

Managing my child's emotions or behaviour	51%
How to prepare [my child] to return to school	49%
How I can support my child's condition or disability	32%
How to support my child to maintain their friendships/peer group	27%
Trustworthy sources of information on Mental health and wellbeing	27%
I don't need any more information to help look after my/my child's at this time	26%
How I can support my/my child's existing health needs	24%
Supporting family relationships	23%
How to talk to my child about their worries about CV19	21%

#### Response to open question about health and social care

Fear about having to shield for a long time with our support, getting support after lockdown with be even harder. Concern that limited service provision pre-COVID will effectively not recommence because of risk of infection

#### *Quotes from survey*

*They aren't really supportive with day to day life in a crisis like this they are hopeless. Weeks without help despite two disabled children and a parent undergoing chemotherapy... Who is prioritised for practical support?*

*Even though all our respite has stopped, we have had fantastic support from our son's CAMHS clinical psychologist. He calls twice a week to offer support and strategies to help current problems. He has made social stories using photographs we have sent him to explain why, for example, McDonald's is shut (!) and what Coronavirus is. He has even collected and delivered prescriptions.*

*Everyone is doing their best. It's now time for government to stop treating parents of disabled kids as a forgotten underclass. We need recognition. Big time.*

*We don't receive any help from social care. My son sees CAMHS. This is now phone call consultations only and I don't get space or time to have the call appropriately because my disabled child is there all the time just now. I'm not about to talk about him in front of him.*

*I was about to ask for a social work assessment in hope of getting some PA support but now feel it wouldn't be seen as a priority and/or it would be hard to carry it out so will delay applying until after Lockdown.*

*I do worry about when my son goes back to school as he won't have had any transition. He is due back in June but I won't be sending him until I'm happy with all the virus stuff. So looking at sept for him, which would mean he would go into year 2, so would be new teacher and classroom without any of his transition.*

*My biggest fears are about how this will continue longer term as our daughter is extremely vulnerable and unlikely to be able to return to school and the normal way of life any time soon. There needs to be a way to find a balance of receiving support and reducing risk of catching the virus but I don't feel the government have or will prioritise the needs of vulnerable and disabled children like our daughter to help us find adequate solutions. We also know that the social care sector has been chronically underfunded for years and this is inevitably not going to improve as we enter a recession.*

### **Section 6: Education and learning**

39% attend a mainstream school, 42% a day special school

30% not eligible for a school place in lockdown.

Of those eligible for a place, the following reason were given for not taking up the place

I am concerned about my child's health at school or someone in the household shielding	43%
The school or council have informally advised that my child should not attend	20%
My child does not wish to attend	14%
The offer of provision was not appropriate to meet my child's needs	12%
The school or council have formally risk assessed my child and advised that they should not attend	11%

Two thirds (64%) of parent carers are worried about how much home schooling they are doing with disabled child.

61% worried about the amount of home schooling they are doing with non-disabled siblings in household

#### Specific support for home schooling

Nearly a third (32%) say no specific support in relation to your child's additional learning needs, disability or special educational needs has been offered by the school to help with home learning.

- 1 in 4 (25%) are getting good support for my child's needs
- 1 in 5 (21%) are getting some specific home learning support but would like more
- 17% say support was offered but not relevant for child's needs.

Of those getting specific disability support for home schooling, a third (33%) rate the level it poor, 33% say it's good, the remaining third say it's average.

We also asked parents that were using a school place to rate the level of education and learning their disabled child was getting

- 43% say it's good
- 40% average
- 18% poor

#### Access to assessments and reviews

66% of those going through an assessment process for extra help with their child's learning say it has been delayed by the COVID -19 pandemic

43% of those entitled to an annual review say it has lapsed or been put on hold

#### Quotes from parents about education

*We have left completely alone. Not even a phone call. Child is unable to learn at home. Sees home as home school as school. Huge rows and meltdowns when attempted. I fear he will very very behind when school continues.*

*The best thing that has happened has been the school arranging for 1:1 music lessons to be delivered by video call - music really helps my child so this is great.*

*Home schooling is incredibly hard to do with an ASD child and a neurotypical child. The latter has to get on with it by themselves*

*Although my child has an EHC plan, they are not able to access school as they attend a special school and there would be too many pupils to make it safe. He is currently meant to be doing transition to secondary school. As a non-verbal child we cannot explain or prepare him for the change in September and are very concerned that lack of preparation will have a long term impact on his mental health and his ability to adapt to a new setting*

## **Section 7: Money and work**

- 39% say household income has dropped as a result of coronavirus pandemic.
- 56% say household income stayed the same
- 2% say household income has increased
- Reminder are unsure

The main reasons for the fall in income is someone being furloughed (20%), followed by other reasons mainly around being self-employed (15%) and needing to reduce hours of work due increase in caring (9%), pressures of home schooling (7%), loss of job 6%, benefits reduced 3%

Of those reporting a drop in household income, the monthly drop is:

- 23% by £250- £499 per month
- 14% between £500-£999
- 13% less than £250
- 12% between £1000 - £2999

The impact of a drop in household income

- 76% cause extra stress and worry
- 38% sleepless nights
- 27% say children going without treats
- 23% causing debt
- 21% causing arguments with family

61% say they are spending more in lockdown, of those 71% spending between £21-£100 extra per week.

Top things families are spending more on

- 88.5% on food/food deliveries
- 62% on utilities
- 36% costs of home schooling such as laptops
- 32% sensory/specialist equipment to care for my child at home
- 30% replacing items damaged due to challenging behaviour
- 15% on PPE

21% think they will go into debt due to the pandemic/ lockdown

8% have seen an increase in their benefits, most (76% stayed the same)

## **Section 8: Things that will help with transition out of lockdown**

The responses to this question showed a great deal of concern, worry and anxiety from parents about their children's return to school (although a minority of responses says that they would not need additional support).

Many respondents said that they would need to be sure that the return was safe and that they and their children would need reassurance on safety and support to feel safe. This

included appropriate hygiene and social distancing arrangements; testing and PPE and applied both to the school and to transport provision. For some, safety could not be assured until a vaccine was in place or COVID-19 otherwise eradicated. A handful of respondents said their children would not be returning to school or were considering continuing with home schooling. It was felt that fines should not be imposed for non-attendance.

Respondents were clear that any return to school would need to be well managed; with a clear plan communicated in advance so the child or young person knew what would be happening. The importance of social stories was a recurring theme.

The right support needed to be in place, with many respondents saying one to one support would be needed, and consistent staffing. The need for a phased return was reflected in many responses, with suggestions around visits (to home by staff and/or to school by the child or young person) prior to return, and a gradual return to full time provision. Some respondents said that mental health support would be needed, particularly to cope with anxiety or behavioural issues.

Flexibility and understanding were key themes – in particular on the part of school staff, but also from parents’ employers as they balance work and supporting their children. Schools should recognise that the upheaval might impact of children’s behaviour and make appropriate allowance.

Some parents called for a review of the existing provision and/or the making of an Education Health and Care Plan. These comments appeared to reflect dissatisfaction with the provision in place prior to the current crisis.

*Parent responses to this question:*

*Guarantees about health and safety for shielded children Understand how additional support will be put in place to help SEN children get up to speed with work*

*My child struggles with transitioning regularly, when returning back to school, my child will need a slow transition back to school, as fully returning straight away could cause anxiety, behavioural problems, and their mental wellbeing can suffer if not done correctly.*

*Parent carers to have conversation with school involved to give personal feedback on child at the time. Reassurance regarding school transport and social distancing (travelling to and from special school). Plenty of notice before return to school*

*Opportunity for a gradual introduction back to school Possibility of visiting before the new term begins, possibly during the summer Information about daily routine, designate transport well in advance and knowing which staff and children will be in class*

*I don't believe I will get him back to school now. My son has meltdowns and violent outbursts every time he leaves the house. The school will just send him home if he behaves like that.*

## **Section 9: What three things should the Government do NOW**

The survey asked parents what three things they would like to government to do now.

There was a wide variety of responses to this question, but some common themes emerged. The most frequent calls were for support – both financial and in terms of services. Respondents called for more financial support for families, such as through increases to carers’ allowances and other benefits. The need for financial assistance was the most common single response.

A significant number of respondents simply asked for more support in general, whilst others were more specific in the type of support needed. These included education support - such as support for home learning and specific support from schools –therapies, mental health and health support. Health support included re-instating services that had stopped because of the pandemic. Parents called for the provision of equipment and toys, including sensory toys, much of which would previously have been provided by school. The need for more (or any) respite care was also a common theme. Some parents called for more funding for services, particularly SEND support in schools; CAMHS and social care; and charities providing support. The need for proper monitoring of (and accountability for) the support provided was also a recurring theme.

The next most frequent call was for better guidance, more specifically aimed at families with disabled children and better signposting to support.

Another recurring theme was simply for disabled children, their families, and the challenges they are facing to be acknowledged and respected. There were calls for the needs of families to be prioritised. As with support, this included general calls and more specific suggestions. The most common specific suggestions were the availability of on-line deliveries; and dedicated access to shops and leisure/outdoor facilities.

Being able to call on family to provide support was important for many respondents. They asked for flexibility around the lockdown rules to enable families to be part of a wider ‘bubble’ to include extended family, PAs and others who could help care for their children.

Having access to testing was cited by a number of respondents, as (to a lesser degree) was personal, protective equipment. Shielding was also mentioned in a number of responses.

Schools and access to education was mentioned by a number of parents. Some called for schools to be re-opened, either in general or – more often – specifically for their children. Conversely, some parents said that schools should remain closed. In between, some stressed the need for a flexible return to school. Respondents pointed to the need for the right (and safe) school transport to be in place.

On the subject of flexibility, parents called for flexibility within their own jobs, both from employers and the government (in the operation of the furlough scheme) to enable them to balance work with the additional caring responsibilities under lockdown.

Other points raised included immediate reversal of the changes to SEND law; improvements to housing; assessment of families' needs; adjustments to examinations next year to recognise impact of lockdown; and arrangements for allocating school places for September.

### **Section 10: Positives that come out of life in lockdown, quotes from responses:**

Sadly, many respondents did not see any positives coming from the current crisis. However, others did and there were a number of common themes amongst their responses. The most quoted benefit was the opportunity to spend more time together as a family, and that their families had become closer and stronger as a result. The next most common area was a view that other people's experience of lockdown would have increased their understanding of the challenges that families with disabled children face; and a hope that this would increase empathy and that, in turn, this might lead to action by the government.

A significant number of respondents cited reductions in their children's anxiety. This was often related to them not being in school where the school environment had been a cause of anxiety. More generally, a slower pace of life was also seen as a benefit and contributing towards reduced anxiety. Home learning – and a more flexible approach taken by schools – was also seen as a positive; and a number of parents also welcomed different ways of working, including video and on-line appointments, from other services.

*I can only speak for our two, they have bonded well, they have been able to speak to friends on social media. They are looking forward to seeing friends. Learning that you can help others with sharing stuff*

*It's been positive for my boys anxiety isolation has been a positive experience for them so far, but as one of my son loves Eastenders it's been hard on me as we have to watch the same episodes every night!*

*The lockdown has made us realise that pressures from school have a dreadfully negative impact on my child's wellbeing and behaviour. Taking the stress of school out of the equation has improved her general health, both physical and mental.*

*We always appreciate our time together as a family and grateful that we are able to keep her safe. I hope society recognises how vulnerable some members of society are and continue to practise good hygiene. Also fantastic to see acts of community kindness and support*

*My twin boys have formed a fantastic bond since lockdown, something that has always been a challenge due to their differing needs and diagnoses. Society hopefully will understand how challenging and difficult life is for families with disabled children, they will be more patient and supportive*

## **Section 11: Policy recommendations**

### **Policy Recommendations:**

#### **1. Prioritisation of disabled children and their families:**

The Government must better recognise the specific needs of disabled children and their families and the additional pressures they are facing during the crisis. Financial difficulties, poorer mental health, and additional caring responsibilities mean that they will be facing lockdown in a different way and with a greater level of intensity than the majority of the population and the Government's approach should reflect this.

Many families with disabled children do not feel that Covid-19 information is relevant to their situation. They feel forgotten. Whether its uncertainty about shielding, daily exercise, or managing additional caring responsibilities due to service cuts, lockdown has affected the whole family and a similar holistic approach is required across Government to ensure that no-one falls through the cracks.

There needs to be a cross Government approach, involving multiple different departments, to provide clarity for families of disabled children and a recognition of their needs in any measures that are announced.

#### **We are calling for:**

- i) *Cross-departmental Government plans of support for families of disabled children. These should be co-produced with families to ensure they recognise the pressures of lockdown on them and should adopt a whole family approach to meeting their needs across education, health, social care and social security. They should also provide clarity about the flexibilities afforded to these families during lockdown, including the need for wider circles of support from family members and/or professionals.*
- ii) *Additional guidance on Government plans for those required to shield for longer periods, including:*
  - *a framework for identifying families who will be shielding for months*
  - *a set of standards the Government expects local areas to deliver*
  - *a requirement on local authorities and CCGs to explicitly set out how this will be delivered, taking into account requirements such as home care support, therapies, testing and PPE*
  - *the education, health, social care and financial support available to those in this situation*

#### **2. Rights and equalities during lockdown:**

Families are reporting cuts to the services they receive, delays in health and social care assessments and reductions in support as a result of provisions in the Coronavirus Act 2020. While local authorities' duties have been eased in some areas, they are still required to use

their best endeavours to meet disabled children's needs and many legal duties, such as parent carer assessments, remain.

This change in the landscape and the inconsistent way in which the new measures have been implemented has created confusion amongst many families of disabled children about what they are entitled to and has left them with a reduced ability to challenge decisions when they are unlawful and uncertainty around how to best meet their child's escalating needs.

In education, families face uncertainty about when and how to safely ensure their child can return to school. Some will continue to shield due to their child's health condition, others will want their child to return due to the additional support they might be able to receive and many will need further reassurance that a return is in their child's best interests. This creates a variety of different situations for disabled children and it essential that parents understand the options available to them and that support is provided across a variety of different settings to ensure no child is left behind or forgotten.

In social care, families tell us that they need support now more than ever, but they do not know how or where to go to get it. Short breaks have been almost entirely stopped and other provision has been cut for the majority of respondents. This puts additional caring pressures on already stressed families, with an increased risk of poor outcomes for disabled children including, for some, a risk of in-patient admission.

In health, redeployment of NHS staff has seen a drastic reduction in the availability of therapies and community support as they are not deemed to be critical. This means many children aren't getting the vital health services that they need, including mental health support and occupational therapy, and also has an impact on the health support that will be available for children when, for example, they return to school.

Families' finances are also being put under pressure during lockdown. Many report having additional expenditure to accommodate the change in their child's care and support and this is married with reduced income as a result of either reduced income from work or from having to give up work to meet their child's needs. This creates an unsustainable set of circumstances that are disproportionately falling on families of disabled children, especially those who have to shield over a long period of time.

There needs to be urgent clarity on what families with disabled children are entitled to in lockdown, how community support will be put back in place and how those who shield for longer will be supported.

**We are calling for:**

**Education**

- i) *Additional schools guidance for children with SEND on:*
  - *The rights of families to choose the best schooling options for their child's circumstances, including to continue to home school or return to the classroom*

- *The specialist provision the Government expects to be provided in schools when children return and the process for ensuring reallocation of health and care staff to support this*
- *The support that will be available for those children who continue to be home-schooled, including a Government statement about how the Government will ensure that quality is maintained at a time when other children will be returning to the classroom*
- *The process and timeframes for resuming the SEND review and its additional terms of reference to account for the impact of the pandemic on SEND support and provision. The review should contain an explicit focus on how the Government will monitor the ongoing education of all children, including those with the most complex needs, and ensure that they are offered a school place as soon as possible, once parents and schools have established confident safe practices*

*ii) A clear Government plan for ending the SEND easements under the Coronavirus Act 2020, ensuring there is no further extension of these amended arrangements beyond the 25th of September deadline set out in the Regulations. The plan should also address the following issues:*

- a) How children with SEND can be expected to return to school/settings without the support outlined in their EHC plans which enables them to access learning*
- b) What children and young people with SEND will need to supplement provision in an EHC plan, or on SEN support, during and after lockdown*
- c) How preparations for transition into new educational settings and phases of education will be undertaken, with a focus on accessibility/reasonable adjustments, to restore a sense of belonging and welcome*
- d) How to restore wellbeing during reintegration, to support a positive return to current schools/settings, and avoid the issues that can lead to disruptive behaviour and exclusion*
- e) Entitlements for families to resume the support they require*
- f) The continued support of those who are still being required to shield*

### **Social Care**

*iii) Local authorities to clarify in their Local Offer what support families of disabled children are entitled to in their local area. Specifically, they must set out:*

- *Services and support that are currently available during the pandemic*
- *Any specific support available to those families who are shielding*
- *How services are responding to the pandemic*
- *A clear complaints process to give families clarity on how to raise concerns so these can be managed and understood at the earliest opportunity*

- iv) *A Government plan to support the re-opening or expansion of home, community, low level mental health, CAMHS and short breaks support for disabled children and their families. This should include:*
- *Establishing a ‘whole family support’ model that meets the needs of parents, siblings/young carers and wider family members with a caring responsibility, as well as the disabled child itself, including:*
    - *Young carers’ assessments for all newly identified young carers to ensure appropriate support is put in place*
    - *Packages of support for siblings, especially for sibling carers and those who have to stay at home as a member of the household is shielding*
  - *The sharing of existing safe practice in community provision such as short breaks*
  - *Putting in place measures to re-start assessments for children’s social care, including whole family assessments*
  - *Measures to enable more flexible commissioning arrangements, use of direct payments and deployment of facilitative staff*
- v) *The forthcoming Children’s Social Care Review must include a focus on social care support for disabled children to address the specific issues they experience and to help clarify some of the findings from the initial Children in Need review*

### **Health**

- vi) *Ensure that NHS staff are now redeployed into their substantive posts and the full range of health support in the community is available for children with SEND*
- vii) *The Department for Education to work with DHSC and NHSE on an urgent mental health strategy to prevent young people with learning disabilities and autism being admitted to inpatient units.*
- viii) *A statement from Government clarifying when usual health monitoring and routine surgeries and treatments will resume along with a contingency plan in the event of current procedures (in particular aerosol-generating procedures (AGP) such as endoscopic procedures and steroidal injections used for pain and mobility) being banned in UK hospitals*

### **Finances**

- ix) *All unpaid carers across the UK to be eligible to receive a carer's covid-19 payment in recognition of the extra care they are providing in lockdown, similar to that being paid to carers in receipt of carers allowance in Scotland. Many carers will be facing extra costs during this pandemic, with higher food costs, new cost associated with home schooling and an increase in household bills both factors.*

- x) *An additional sum of financial support to be made available to families of children who are shielding to account for the impact of longer-term lockdown on their income and expenditure.*

### **3. Additional planning and funding:**

Our survey reveals a picture of reduced support and increased pressures on families of disabled children during the crisis. This is bound to result in an increase in the needs of many people across the country. The health and social care was already in crisis, without the resources to support disabled children in a way that prevented them from reaching crisis point. The system will be even more stretched in future. The government needs to start planning at this stage for enhancing funding for disabled children's health and social care so that they are not left even further behind their peers.

In the immediate term, families are crying out for more support, both financial and health and social care. Education support, therapies, respite and equipment have all been reduced or would only be accessed in settings that are currently closed. Families are being expected to fill the void but this is unethical and unsustainable for much longer.

#### **We are calling for:**

- i) *An additional disabled children and families funding package to be made available to local areas (local authorities and CCGs) to:*
- *Provide the £1.5bn required across health and social care to fill the existing funding gap*
  - *Establish a £500m fund for local authorities to apply for to help develop provision to intervene early with at-risk families and prevent their needs from reaching breaking point*
  - *Meet the cost of disabled children's health and social care post pandemic, including sufficient funding for ongoing home school resources for those children remaining at home to shield and their siblings, especially equipment, accessible learning resources, remote technology, positive behaviour support and therapies*
- ii) *A clear requirement of local authority and health commissioners to evidence how their practices in local areas are ensuring that families receive the support they need.*

### ***About the Disabled Children's Partnership***

*The Disabled Children's Partnership is a major coalition of more than 70 organisations campaigning for improved health and social care for disabled children, young people and their families. The Partnership is led by Action for Children, The Children's Trust, Contact, Council For Disabled Children, Family Fund, Mencap, National Autistic Society, Scope, Sense, Together For Short Lives and WellChild.*



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