

Written evidence submitted by Disabled Children's Partnership

EDUCATION COMMITTEE: THE IMPACT OF COVID-19 ON EDUCATION AND CHILDREN'S SERVICES

EVIDENCE FROM THE DISABLED CHILDREN'S PARTNERSHIP

1. The Disabled Children's Partnership is a coalition of more than 70 charities campaigning for improved health and social care for disabled children and their families. We believe that disabled children, young people and their families should have access to the services they are entitled to, when they need them.

<https://disabledchildrenpartnership.org.uk/about-us/>

2. We are grateful to the Committee for inviting us to give oral evidence to the inquiry. This written evidence reiterates and expands the points our chair, Amanda Batten, made at the 1 July hearing.

Survey of parent carers

3. Between 1 and 17 May, we ran a survey of parent carers of disabled children on the impact of Covid-19 on their families. The survey covered the following areas:

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

4. We had a large response to the survey, with more than 4,000 parent carers completing it. The nature of the survey means that this was, of course, a self-selecting survey. However, the size of the response; the breakdown of respondents (eg by child's disability); and similarities of the findings to other research over the period can give us a high degree of confidence that it is representative of the experiences of disabled children and their families.

Survey findings

5. Our survey report is available at

<https://disabledchildrenpartnership.org.uk/left-in-lockdown/>

Overall, it paints a picture of –

- increased caring load, both for parent carers and for disabled children's siblings.

- exhausted, stressed and anxious parents who feel abandoned by society. In many cases, the support families previously received has now stopped.
- declining mental and physical health for all members of the family
- parents being 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 Covid-19.
- the little support that had previously been provided for families often having stopped altogether
- negative impacts on children's friendships; learning and communications; mental and physical health: emotions and behaviour have all been negatively impacted.
- increasing financial pressures on families.

6. This picture was reflected in the personal quotes included in responses; here are just a small selection of those:

"The impact is huge: absolutely no break from caring. It's really, really intense and quite overwhelming and you're just left to it"

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

"We now have no respite and no break from 24/7 care needs. We are all completely exhausted both physically and mentally."

"I'm overpowered with guilt that I'm not supporting my other children as well as I should"

"It's now time for government to stop treating parents of disabled kids as a forgotten underclass"

"My biggest fears are about how this will continue longer term"

"We have left completely alone. Not even a phone call."

7. Specific quantitative findings included –

- 72% of parents said they are providing a lot more care compared with the amount before lockdown
- 68% said non-disabled siblings were also providing a lot more care
- 76% of those who were previously receiving support caring (such as short breaks/respite care) had seen it stop
- half of parents whose children had been received therapies or other extra support had seen this stop

- parents not having sought necessary medical health for their disabled children (44%), themselves or their partner (54%) or their non-disabled children (17%)
- 70-80% of parents reported worsening emotional and mental health for both their children and themselves; although a minority report improvements
- 45% said their disabled children's physical health had declined; and 54% the same about their own
- 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.
- 64% of parents were worried about how much home school they were doing with their disabled child; and 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
- two-thirds of children going through an assessment process had seen it delayed; whilst 43% of annual reviews had lapsed or been put on hold.
- Families faced financial pressures, through either, or both, a reduction in income (39%) or increased costs (61%). 21% will go into debt as a result

A system already in crisis

8. It is important to view this evidence in the context of a system of support for disabled children and their families that is already in crisis, as highlighted in your Committee's report on Special Educational Needs and Disabilities published last year. The findings on the amount of care parents are providing; and on the lack of support, need to be seen in the context of research prior to lockdown which showed, for example, that

- 24% of parent carers of disabled children were provided more than 100 hours of care per week (Contact 2017¹)
- only 4% said they had sufficient support to care safely for their child (DCP, 2019²)
- There is £1.5bn funding gap in health and social care for disabled children (DCP 2018³)

What needs to happen now

9. Our survey took place during the height of the lockdown. However, the issues it raises remain. Parents are particularly concerned that they will be left behind and even more forgotten as lockdown eases and the majority of children return to school

¹ https://contact.org.uk/media/1169000/caring_more_than_most_full_report.pdf

² <https://disabledchildrenspartnership.org.uk/families-of-disabled-children-call-on-government-to-giveitback/>

³ <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2018/07/Case-for-a-Disabled-Childrens-Fund.pdf>

in September. They are concerned about the implications for their children and their families of the changes to advice on shielding. They urgently need support such as short breaks and therapies reinstated. They will need reassurance and support for their children to return to school in September; and for those children for are not able to return to school at that time will need tailored provision to ensure they do not fall further behind.

10. We therefore are calling on the government to have a clear plan in place to support disabled children and their families over the coming months, resulting in

- Disabled children and young people receiving a regular amount of funded support with care, emotional and physical well-being needs at home or in the community.
- The right support funded and in place for return of children to school – and for home schooling for those who cannot return – with the right support funded and in place
- Priority given to those children who cannot attend school due to complex health conditions or needing to shield with their families.

11. We also re-iterate our existing calls for government to

- Prioritise disabled children and their families, including by appointing a Minister for Disabled Children with responsibilities across government
- Review the existing guidance and legal framework for health and social care for disabled children; and ensure that the needs of disabled children and their families form part of the Department for Education's Care Review.
- Provide additional money to fill the funding gap for health and social care services, and introduce a dedicated Disabled Children's Innovation Fund

Disabled Children's Partnership

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