



**DISABLED CHILDREN'S PARTNERSHIP (DCP)**

# **Left Behind**

**The Impact of the Pandemic on Disabled Children, their Parents and Siblings**

**Freedom of Information and Parent Panel Survey 5 Results**

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## Introduction

The Disabled Children's Partnership in collaboration with Pears Foundation established the Pears Learning Hub to research the impact of the COVID-19 pandemic on disabled children and their families. As part of this work, a survey panel of parents was established and freedom of information requests were submitted to local authorities and NHS trusts in England. Five parent surveys (1,2,3) were conducted between January and June 2021, providing an understanding of disabled children and their families experiences in real time, with this the report outlining the results of the final survey. 884 parents have taken part in the series of surveys, with 67% taking part in more than one survey.

Previous reports have revealed that parents with disabled children are experiencing significantly lower levels of mental wellbeing, and higher levels of social isolation, anxiety and stress when compared with the general population during the pandemic. This is an ongoing problem rather than a one-off response to lockdown restrictions. Results from our previous surveys showed that disabled children and their siblings are socially isolated despite schools reopening and social restrictions easing. Chronic stress, anxiety and poor mental health will have long term consequences for disabled children and their families without tailored support.

Disabled children receive support in their educational setting through either Special Educational Need Support or an Education Health and Care Plan (EHCP) (4). Families report a lack of support from education, health and social care services at a time when informal support from friends and family is reduced. Delays to therapies, diagnostics and treatments have had an impact on disabled children's development and their conditions or disability.

Freedom of information requests were submitted to local authorities in England in February 2021 and NHS trusts in March 2021, to understand how the provision of services that disabled children rely on for support and provide assessment of their needs have been affected by the pandemic. The data from the freedom of information requests referred to in this report was collated by quarter for the year 2019/20 (quarters 1 to 4) and 2020/21 (quarters 1-3). The average level of activity pertaining to EHCPs, short breaks, physiotherapy, speech and language, occupational therapy, children's and adolescent mental health (CAMHS) and Autistic Spectrum Disorder (ASD) services was collated for the same period.

There were challenges to obtaining responses from local authorities and NHS Trusts. The guidelines (7) state that a response should be received within 20 days of the FOI submission. However, due to the pandemic, the timeline was waived with staff at local authorities and health trusts attention diverted to the pandemic response. Therefore, this report includes responses received up until 31<sup>st</sup> May 2021. The Disabled Children's Partnership campaigns for disabled children aged 0-25 years of age and their families. Information was requested for disabled children and young people upto age 18 and 19-25 years. However, minimal information was provided for the latter age group, therefore the FOI findings in this report refers only to disabled children up to 18 years of age.

In our *Longest Lockdown Report* (1), 72% of parents said their disabled child's EHCP or SEN support plan had been negatively affected by the pandemic. 67% of parents who had a child with an EHCP reported that their child was not receiving all of the support set out in their plan. This provides a picture of disabled children who are already known to the SEND

system. The FOI data collected by the DCP, provides an understanding of how the pandemic has affected disabled children and their families applying for support.

The final parent panel survey, analysed in the report, examined disabled children and their families experiences following the lifting of restrictions in England on 17<sup>th</sup> May 2021. It was conducted between 1<sup>st</sup> and 21<sup>st</sup> June 2021. It aims to assess if families are receiving support from education, health and social care and the impact of the pandemic on the wider family, including relationship and financial pressures. This report is based on 290 parent responses received from the final parent survey. The FOI data presented, adds context to these findings. It draws on data regarding EHC applications and new referrals to children's health services, the latter of which contribute to evidence required for EHCPs and additional support identified throughout a disabled child's development.

## Key Findings

The latest parent panel survey in this series, confirmed that, despite the lifting of restrictions, parents and disabled children remain socially isolated. In addition, there is evidence of systematic pressures creating a barrier for disabled children when applying for support during their time in education. Data obtained from the freedom of information requests, provide a snapshot of provision of service in the first nine months of the pandemic. The responses received confirm services that disabled children rely on for diagnosis, support and treatment are continuing to operate at lower levels with contact with fewer families than before the pandemic.

Parents are experiencing ongoing high levels of stress, anxiety and social isolation against a backdrop of services providing a lower level of support than when the pandemic started. In addition, those parents report increasingly strained relationships with their partner in the second year of the pandemic. Importantly, the most common problems occurring were associated with the lack of respite for their disabled child and the administrative tasks connected to requesting and maintaining support from the system. Consequentially, family breakdown is a risk due to the lack of support from services with 49% of parents indicating the lack of respite is currently the most common problem causing strained relationships with their partner.

71% parents reported that their child's progress had regressed due to delays to service caused by the pandemic. Almost three quarters (73%) state that this is the case for their disabled child's communication and more than half (58%) for their mental health. FOI data requests revealed that operational and administrative disruption, as a consequence of the pandemic, resulted in 10% reduction of the EHCP referrals local authorities received in the first 9 months of 2020/21. In combination with disruption to health services, disabled children requiring assessment by therapy services or support from mental health services have been confronted with similar obstacles. The local NHS trusts responding to the FOIs are operating at lower levels since the pandemic when compared with the same period the previous year. For example, 83% of Trusts providing information to the FOI request received fewer referrals to physiotherapy services in 2020/21, than the same period the previous year.

The figures above are for children who are new to the service. They may or may not have a diagnosis and the appointment may be to assess their level of need for further treatment or support. Similarly, Occupational Therapy appointments may open the pathway for a child to

receive particular equipment or sensory programmes that can help advise how to manage intolerances to particular foods, sounds, lights. Therefore, barriers for disabled children accessing such services may increase anxiety and reduce confidence, with risk of long terms problems increased. Delays to such appointments also challenge the EHCP process, as evidence from appointments is collated to support the application of a disabled child's needs.

9 in 10 parents responding to our final survey report their disabled children - and 7 in 10 siblings of disabled children - are socially isolated at a level that before the pandemic, would have identified them to services for further intervention. Interventions for disabled children and siblings may include one to one buddy systems or group activities with their peers. The threshold used in order to demonstrate social isolation is the equivalent of a having contact with two or less family or friends per month. A third of parents (31%) report that their disabled child and 18% of siblings did not have contact with any friends in the last month (online or in person). 16% of families responding stated that they were continuing to shield despite the scheme pausing on 1<sup>st</sup> April 2021, due to the vulnerability of their disabled child or another family member. The impact of the pandemic on the wider family is illustrated by the proportion of parents (42%) providing care for someone other than their disabled child. This is in addition to providing more than 20 hours per week of care (79% daytime, 53% night-time) for their disabled child.

The economic impact of the COVID pandemic in England has been widely reported, with the size of the drop in GDP (Gross Domestic Product) the steepest decline since records began in 1948 (6). 37% of parents responding to this survey in 2021 report a reduction in family income due to the pandemic. A third of those report that this is a consequence of the lack of support received during the pandemic for their disabled child (practical or financial).

As the final report of our panel survey takes place against the backdrop of restrictions easing in England, it could be hoped that disabled children and their families would be experiencing some relief from the pressures of the pandemic. However, this report once again demonstrates the ongoing disproportionate impact the pandemic has and continues to have across multiple services disabled children and their families rely on for support – despite society reopening and government interventions.

## Recommendations

The Disabled Children's Partnership recommends a dedicated, funded COVID-19 recovery policies for disabled children and their families. These policies should include

- therapies catch-up plan to address where children have regressed or plateaued in their speech, communication, physical development, or social skills.
- Short breaks for families to address high levels of family exhaustion.
- Flexibility to extend or allow repeat funding for young people in further education, especially where courses to facilitate independence and employability have been impacted.
- Additional support for children and young people at key transition points.
- Additional support for the mental health and wellbeing of children and families.
- Access to activities to overcome the social isolation that many have suffered during lockdown.

# Detailed Findings

## Introduction

### Freedom of Information Requests (FOI)

FOI requests were sent to 152 local authorities in England. 92 local authorities responded. 82 provided valid information about EHCP applications and 49 provided information about short breaks.

In addition, FOI requests were sent to 223 NHS Trusts, covering acute, mental health, specialist or community services. 109 NHS Trusts responded to information: 43 referred to children and adolescent mental health services (CAMHS); 32 to Autism Spectrum Disorder Service (ASD); 30 referred to physiotherapy; 26 referred to occupational therapy and 25 referred to speech and language therapy.

### Survey Respondents

- 72% had one child, 22% had two children and 6% had three or more children
- The most common reported conditions were learning disability (66%), autism spectrum disorder (62%), speech, language and communication difficulties (61%), social, emotional and mental health needs (48%), physical disability (38%).
- Responses were also received from parents of young people with complex health needs, multisensory impairment, ADHD, rare conditions, visual impairment, life-limiting or life-threatening condition, hearing impairment and undiagnosed conditions
- 91% of parents were white and 9% were black, asian or another ethnic minority
- 92% were mothers, 5% were fathers, 2% were grandparents and 1% were non-parent guardians.
- 16% lived in the South East, 15% in the North West, 12% lived in London, 11% lived in East Midlands, West Midlands or Yorkshire and Humber, with representation from other regions ranging from 7.1% in the East of England and 10.7% in West Midlands and Yorkshire and Humber.
- 82% of families lived in an urban area and 17% lived in rural areas.
- 62% of disabled children were aged 6-15 years, 25% were aged 16-19, 16% were aged 20+ and 8.4% were aged 5 years and below.
- 28% of families were shielding, although the shielding scheme was paused in England on 1<sup>st</sup> April 2021.

## Applications for Education Health and Care Plans

In January 2021, 72% of parents of disabled children reported that their child's EHCP had been negatively impacted by the pandemic, with 67% not receiving all of the support confirmed specified in the plan (1). 32% of parents taking part in the survey panel who had applied for an EHCP plan, waited for more than three months for an assessment. To further understand the impact that the pandemic had had on those applying for support through an EHCP, Freedom of information requests were submitted to 152 local authorities in England in February 2021.

82 local authorities provided information per quarter, regarding EHCP applications between April 2019 to December 2020. The findings reveal that 63% of local authorities that responded, received fewer EHCP referrals in the first 3 quarters of the pandemic than the previous year. This could be due to the closure of schools and diversion of local authority staff to the pandemic response.

The SEND Code of practice (5), requires that local authorities should make an initial decision about whether an EHCP assessment will take place. In the first quarter of the pandemic (April-June 2021), 70% of local authorities completed a lower number of EHCP decisions within the six-week timeframe. In the last quarter of 2020, prior to the third national lockdown in January 2021, 57% of local authorities were still completing fewer EHCP decisions within six weeks.

For the same period, the picture is similar for those EHCP applications that already had an assessment underway. 54% of local authorities were undertaking a lower number of EHCP assessments than the same quarter the year before. A comparative proportion (55%) of local authorities completed a lower number of EHCP assessments within a 20-week timescale for the same period the year before.

Therefore, the findings regarding EHCP applications demonstrates that prior to the recent set of restrictions in England in January 2021, local authorities were receiving and processing lower number of EHCPs when compared to the previous year. A comparison of the number of EHC applications for the 82 local authorities that responded was calculated and compared between April-December 2020 and April -December 2019. The impact on the numbers of disabled children is listed below taken from the EHC applications received:

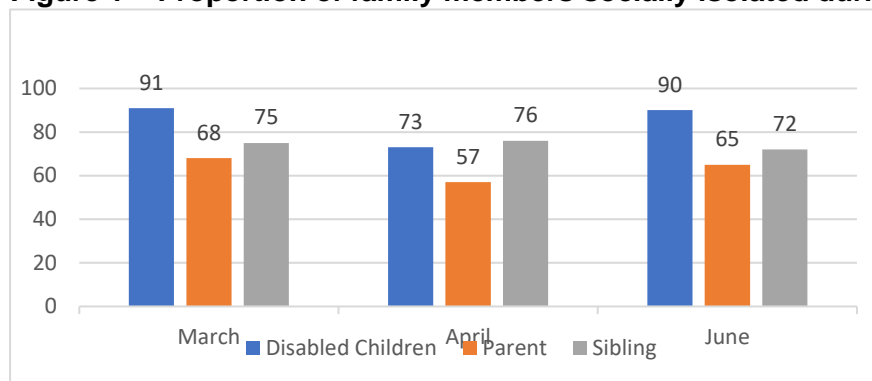
- 10% reduction in EHCP applications (equivalent to 3243 families)
- 7% reduction in decisions at 6 weeks to undertake assessment (equivalent to 1463 families).

Published education figures (report that on average, 60.4% of the EHCPs were completed within 20 weeks of referral. In the last quarter of 2020, 45% of local authority completion rates were lower than the national average. The findings from the FOI requests reveal that the pandemic has impacted on the ability of local authorities to process EHC applications and therefore creates an obstacle for disabled children accessing support.

## Impact on disabled child

Previous reports from our panel survey have demonstrated the detrimental effect of the pandemic on disabled children. The Lubben social network score (8) was used to assess the levels of social isolation they experience (parents and siblings results are reported later in this report). The measure is used by services to identify people at risk of social isolation, so that support can be provided. Figure 1 below, illustrates the level of social isolation between survey 2 and survey 5 for all family members.

**Figure 1 – Proportion of family members socially isolated during 2021**



Despite the recent easing of restrictions and the majority of children returning to school, 90% of parents stated that their disabled child was socially isolated. 31% did not have contact with a friend online or in person during the last month. The impact of isolation on health is understood, with parents expressing concern about the future implications of social isolation on mental health, with future difficulties unknown.

*Damage to mental health is very difficult to gauge as the effects usually only manifest themselves further down the line.*

Due to isolation and lack of support during the pandemic, 71% of parents felt that their child's progress had regressed. Of those, 73% reported their child was experiencing issues with social communication, 58% mental health, 42% cognitive understanding, 31% physical symptoms and 21% medical symptoms.

*My son's communication with other people regressed during lockdown, as a result of only having Mum and Dad to sign to. He became demotivated about doing this, as he needs the stimulation of other people outside the family to get him going and trying to tell them what he has been doing.*

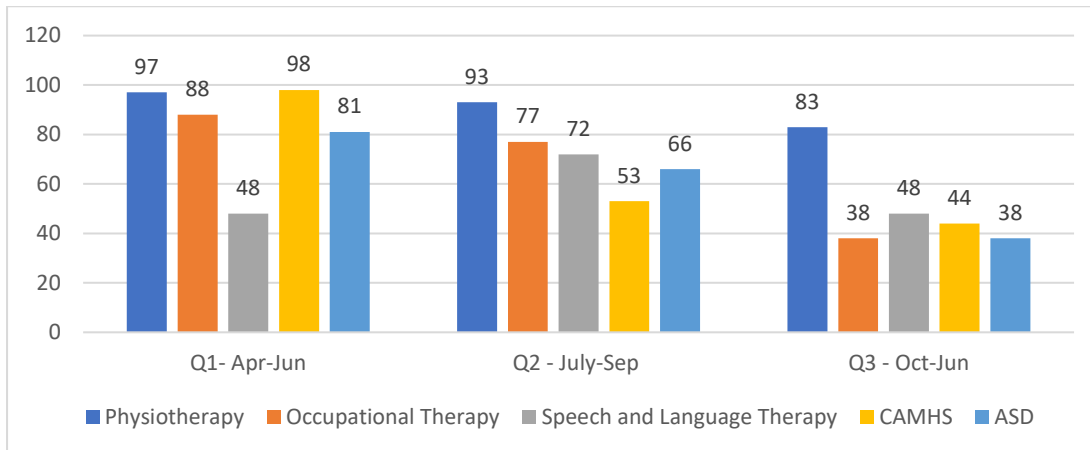
*Lack of [mental health] support has ended up [with disabled child] as an inpatient in a mental hospital*

## Health Service Appointments (FOI results).

The freedom of information requests submitted to NHS trusts were used to assess if the pandemic had had any impact on new referrals to services for children's services. The period between the first 9 months of the pandemic (April – December 2020) and the previous year (April 2019 – March 2020). In addition to support, the services provide assessments that contribute to diagnosis and reports required for EHC applications and plans. Children's services included physiotherapy, occupational therapy, speech and language, child and adolescent mental health services and autism spectrum disorder pathway were contacted. The findings (figure 2) below indicate the impact the pandemic has had on children's services and reveal another barrier / bottleneck in families seeking support.



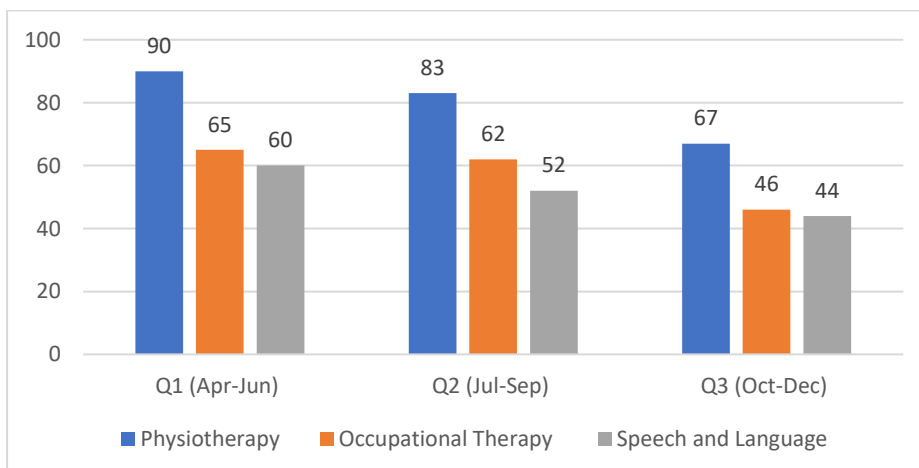
**Figure 2 – NHS Trusts receiving fewer referrals for therapy services during the pandemic for the same quarter the previous year.**



The findings illustrate the health service response to the pandemic diverted attention away from professionals for non-urgent referrals to therapy and support services for mental health and autism spectrum disorder. Disabled children rely on such services for assessment, diagnosis and support. As demonstrated above, prior to the last quarter before January 2021 lockdown, almost three quarters of trusts that responded, were receiving fewer referrals to occupational therapy, almost half were receiving fewer referrals to physiotherapy and speech and language therapy and around 4 in 10 trusts were receiving fewer referrals to CAMHS and ASD services than before the pandemic.

The time to first appointment from referral for physiotherapy, occupational, speech and language services is 13 weeks. The proportion of trusts providing a first appointment within 13 weeks at a lower rate in the first three quarters of 2020 (compared with 2019), is illustrated in figure 3, by quarter by service.

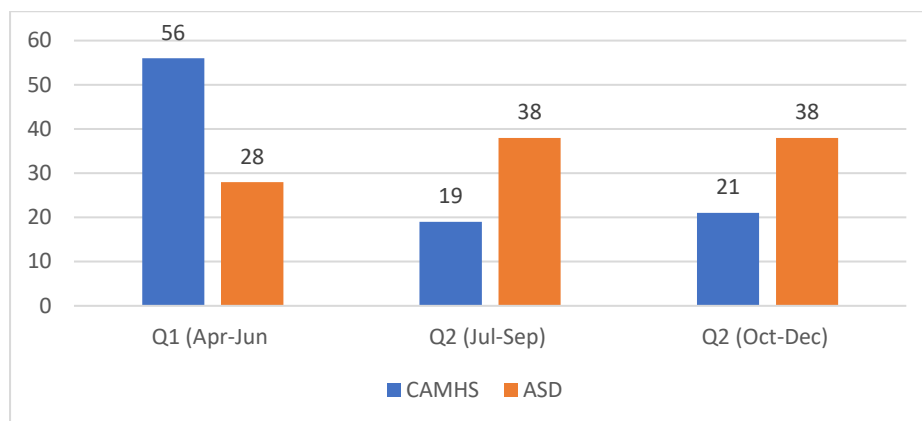
**Figure 3 – Proportion of Trusts completing fewer assessments within 13 week timescale from referral.**



As illustrated, a similar pattern emerges of families waiting longer than expected for first appointments. The case is consistent when first appointments are analysed for children’s mental health services and autism services, illustrated in figure 4.



**Figure 4 – Proportion of trusts providing lower number of first appointments within 6 weeks than the previous year,**



To demonstrate the impact of the lower level of referrals and appointments on families, the number of referrals April to December 2020 were compared with the year before. How this equates to families missing out on services is listed below, taken from the FOI responses received:

- Physiotherapy service saw 8525 fewer children
- Occupational Therapy services saw 2425 fewer children
- Speech and Language therapy services saw 1490 fewer children.
- Autism services saw 1111 fewer children.

The data revealed that in contrast despite the proportion of CAMHS services not working at pre-pandemic levels, over all the Trusts responding to our request saw an additional 3631 children for mental health support.

### Parents experiences of delays to health appointments services

Parents taking part in the panel survey have continued to report delays to health services throughout the panel survey. Therefore, despite the FOI request timescale (up to end of 2020) establishing disruption in the first nine months of the pandemic, the findings from the parent panel survey confirm barriers are ongoing due to the backlog in the system. Disabled children rely on support from such services for diagnosis, assessment, treatment, equipment provision or intervention advice, all of which can ensure barriers to education are removed with additional appropriate support provided were needed in the education setting.

The backlog of services, and delays in therapies has been reported in our previous surveys (1, 3). Despite some improvement, delays to services are still a common experience for families. The proportion of parents reporting delays are listed below:

- 65% delays to routine appointments,
- 36 delays to treatments,
- 28% delays to equipment or support aid provision,
- 13% delays to equipment / support aids maintenance,
- 10% delays to operations.

Parents report that the delays to health care have an impact on their disabled children.

- Almost half (46%) of parents report that their children’s conditions are affected
- A third (33%) of parents reported their child’s development is affected

- Just under a third (29%) report that their child's condition has regressed.

*His physical health (in particular) his scoliosis has been significantly adversely affected due to lack of support and access to equipment and appointments during the pandemic. We are now at the mercy of an extra long waiting list for surgery due to the pandemic and his condition is rapidly worsening.*

*Consultant had to continually cancel follow up appointments in order to see more new cases regardless of a previous operation not fixing original problem therefore disease has now eaten more of my child's body, which has to be controlled by more surgery but this is hugely delayed now also and still don't have a date for surgery.*

*Child has not been able to access standing frame or walking frame so has lost ability to weight bear and needs leg splints*

*Left in pain as can't access appropriate services.*

As the responses above demonstrate, the impact of delays to disabled children's services have impacted their mental health and physical health requiring further intervention either where it was earlier than anticipated or not previously expected or required. Parents report that they require additional support in addition to what would usually be provided due to the level of regression or delay on their child's condition, disability of development.

*My child has missed 6 hours OT support from January to May and now he got OT support but no extra sessions to compensate.*

## Parental Wellbeing, Anxiety, Stress and Social Isolation

Previous DCP survey reports have revealed significantly poorer mental health outcomes and higher levels of anxiety, stress and social isolation for parents with disabled children, compared to the rest of the population during the pandemic. Despite restrictions lifting there was no evidence of improvement for parents of disabled children (see figure 1 for social isolation).

### **Wellbeing**

The short version of the Edinburgh-Warwick Mental Wellbeing Scale (9) was used to measure the levels of wellbeing of parents with disabled children. The scores can demonstrate 4 categories of mental wellbeing: high mental wellbeing, average mental wellbeing, possible depression and probable depression. In this survey 76% of parents responses indicate possible or probable depression.

### **Anxiety**

The general anxiety disorder (GAD) questionnaire (10) enables response scores to be categorised into four groups: no anxiety or mild, moderate or severe anxiety. In this final survey the proportion of parents are continuing to report anxiety at significantly higher levels than the general population. Parents experiencing anxiety remained high (84%, 80% in survey 3). In particular, those experiencing severe levels of anxiety increased by 9% between survey 3 and the final survey.

## **Stress**

The short form Perceived Stress Scale (11) was used to measure the level of stress parents were reporting. The average stress levels of respondents remained higher than that of the general population.

## **Social Isolation**

As with disabled children, the Lubben social network score (8) was used to assess the levels of social isolation experienced by parents. The measure is used by services to identify people at risk of social isolation, so that support can be provided. Compared with previous surveys there was no change to parents' social isolation scores. 65% of parents are socially isolated at comparative levels of survey 2 in March 2021, as illustrated previously in figure 1.

In addition to the level of social interaction that parents had, this final survey explored the nature of their support network. 27% of parents indicated as having no family members in their support network and 33% had no friends in their support network, 15% had neither. This reveals that 73% are vulnerable to social isolation due to lack of numbers within their social network (2 or less). More than half of respondents would like their friends or family to check in more often than they do (56% friends, 54% family).

## **Wider Family**

### **Shielding**

A third of families taking part in our survey panel were shielding due to government guidance. Despite shielding being paused in England on 1<sup>st</sup> April 2021 (12), 16% of families responding to this latest survey will continue to shield due to either concerns about their disabled child or another member of their family. Parents no longer shielding reported that the use of lateral flow test and vaccinated adults around their children provided reassurance and increased their confidence to stop shielding. However, of those no longer shielding many were still keeping interactions to a minimum. Parents still fear the threat of COVID on children who are clinically extremely vulnerable if they are exposed to the virus. A year on from the start of the pandemic parents reported there was more now known in terms of how the virus would be expected to affect their child.

*Feeling more confident after our immunology consultant advised me that he thought my son would be ok if he did catch the virus*

*Although fully vaccinated I am concerned with the Delta variant and how it might affect my daughter if she gets COVID.*

*Only going to garden centres or quieter places still feel unsafe amongst larger groups of people - anxiety is much higher than before about going out and being in company*

*We are being cautious. They are back in education in a specialised setting and has met with some family but is not yet going elsewhere*

### **Sibling Social Isolation**

The lack of contact with others has an impact on the siblings of disabled children in the household. 72% of parents stated that the sibling of their disabled child is socially isolated, with 18% not having contact with a friend online or in person the last month. See figure 1 for comparison with previous surveys.

## Support

### **Support from Services**

As discussed above, parents report the consequences to delays in health care on their disabled children. In this survey parents were asked to compare the level and quality of therapies, health, social care and education before the pandemic and at the time of the survey (June 2021). 74% of families stated therapy services were little or much less with regards to the level and quality before the pandemic, 70% reported the same for health services, 56% social care and 50% education. This indicates the increasing burden on families due to the lower level and lower quality of services supporting their disabled child.

*Therapy provision in school still seems to be reduced despite having missed so much over the last year. Social Care assessments have a backlog.*

*We have been totally discharged from (CAMHS) as they are overwhelmed by new cases and thanks to Covid she wasn't making progress as she refused to engage via zoom. We now have no support at all. School fail to do anything at all to help. Including engaging with other professionals.*

*They have returned to school but has restricted access to activities due to lack of qualified staff which the LA have failed to employ due to specialist carers burnout over Covid*

*Has lost therapeutic support, although some loss was due to Covid restrictions, much was due to Local Authority ceasing to fund support. They say little progress so therefore support not working so wouldn't be funded. Don't accept (or don't want to see) that Covid has had an affect on overall situation. Their reasoning being that Covid has affected everyone so therefore they don't accept that this has affected his progress.*

### **Parent relationship with partner**

The additional strain the pandemic has placed on household members has been widely reported internationally during the pandemic. In this final DCP survey, parents of disabled children have reported that relationship problems with their partner increased since the pandemic began. However, the results reveal that the most common problems putting strains on relationships before and during the pandemic are associated with the system designed to support their disabled child. As Table 1, demonstrates, the parents responsibility to manage administration tasks to do with their child's appointments, education and/or social care and lack of respite was the most common cause for relationships problems.

There was a 22% increase in the proportion of parents reporting that the lack of respite put a strain on their relationship during the first year of the pandemic. Now in the second year

since the pandemic began, half of parents responding to our survey report that the lack of respite for their child is still causing problems with their relationship. Table 2, illustrates that the most common causes of relationship problems for parents from March 2021 has been those associated with caring duties for their disabled child and decisions pertaining to their care. There was a 10% increase in parents reporting that money worries were causing problems in their relationship and an 8% increase due to currently working long hours.

**Table 1. Proportion of parents reporting the reason for strained relationship with their partner pre-pandemic, year 1 of pandemic and second year of pandemic.**

	<b>Pre-Pandemic</b>	<b>Year 1 of Pandemic (23/03/20-22/03/21)</b>	<b>Current (24/3/21 onwards)</b>
<b>Managing admin for disabled child</b>	<b>38%</b>	<b>43%</b>	<b>45%</b>
<b>Lack of respite</b>	<b>38%</b>	<b>57%</b>	<b>49%</b>

**Table 2 - Proportion of parents reporting the reason for strained relationship with their partner pre-pandemic, and current second year of pandemic.**

	<b>Pre-Pandemic</b>	<b>Current (24/3/21 onwards)</b>
<b>Practical aspect of caring for disabled child</b>	32%	40%
<b>Sharing tasks</b>	32%	37%
<b>Decisions about caring for disabled child</b>	27%	36%
<b>Money worries</b>	26%	36%
<b>Caring responsibilities for someone other than disabled child</b>	29%	35%
<b>Household chores</b>	31%	35%
<b>Lack of work-life balance</b>	26%	31%
<b>Understanding each other</b>	26%	30%
<b>Family rows</b>	21%	27%
<b>Working long hours</b>	18%	26%

## **Hours caring for disabled child**

The *Left in Lockdown* report revealed that parents with disabled children felt abandoned during the first stages of the pandemic. In this final survey, 79% of parents indicated that they spend 20+hours caring for their disabled child during the daytime and 53% are caring more than 20+ hours during the night per week.

## **Hours caring for other people**

42% of parents indicated that they were an unpaid carer for someone other than their disabled child. 24% of those care for somebody during the night (0-5 hours per week) and 14% provide care for someone other than their disabled child for 20 or more hours per week during the day. Prior to the pandemic, 17% of all carers provided unpaid support to more than one person (13), much lower than the proportion of parents of disabled children responding to our survey.

## **Short Breaks**

The freedom of information submissions to local authorities provided a snapshot of how the provision of short breaks had been affected by the pandemic. As with EHCP applications and health service contacts, information was analysed comparing activity during the first 9 months of the pandemic and the previous year. Information received revealed that of those local authorities that responded:

- 40% provided fewer short breaks overall
- 50% provided fewer short breaks at home.
- 78% provided fewer short breaks away from home.
- 73% provided fewer overnight stays.
- 60% provided fewer residential overnight stays.

## **Education**

The majority of parents (69%) responding to our final survey report that their disabled children had returned to school. However, 11% had not returned due to the lack of provision, with it either not suitable or not enough staff. As discussed earlier in this report, delays to service has meant disabled children may experience more poor health or worsening physical deterioration making the return to school difficult.

*No information given to me regarding returning to nursery*

*Overwhelmed with anxiety and unable to attend regularly. In Year 11 and as of end of May has been told he has finished school for good, as there are no exams. No places offered for vulnerable children at all - absolutely shocking*

4% of parents reported that they had been encouraged to move their child to a different school without following exclusion processes. Although a minority, it demonstrates examples whereby COVID restrictions may mean that the support provided is not appropriate for the disabled child.

*Mental health got worse so attendance slipped, then was sectioned*

*College discontinued him, LA ignoring request for review (and complaint re: same)*

## Household Income

The decline in economic activity due to the COVID pandemic and the impact on household finances (14) has been widely reported. Families of disabled children indicated the impact that the pandemic has had on their family income. 39% of parents reported that their family income had dropped due to the pandemic. However, 28% of families reported that the reduction in their family income was due to the loss of support received for their disabled child, meaning that they had to stop working to provide care.

There were 2.5 million food parcels provided by the Trussell Trust network of food banks during the first year of the pandemic, 33% increase in the previous year (15). 17% of parents responding to our survey reported that they had relied on food banks during the first year of the pandemic.

## Conclusion-

The support that disabled children and their families rely on from multiple services across education, health and social care diminished as a consequence of the pandemic, leaving families with disabled children disproportionately affected. The information retrieved from the freedom of information requests reveal a snapshot of Local Authorities and NHS Trusts unable to perform at pre-pandemic levels. The consequence is extensive period of waiting times for families (who may not be already known the system) referred for support, assessment, treatments and /or intervention creating an ongoing backlog of unmet need.

The parent panel results reveal that 71% of disabled children have gone backwards in terms of their condition or development due to the pandemic. The majority of families already accessing services report that the quality and level of services they currently receive is less than before the pandemic. Parents are experiencing chronic levels of isolation, stress, anxiety and poor mental health despite the easing of restrictions. Increased relationship problems due to the lack of respite increased significantly during the pandemic and remains the most common cause of relationship problems between parents. Financial, relationship, and health challenges of parents have fused with a lack of respite and increasing needs of disabled children. Without urgent focussed action, disabled children and their families are at an even more increased risk of family breakdown and crisis.

## References

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