DISABLED CHILDREN'S PARTNERSHIP

NO END IN SIGHT

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

Survey 3

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Introduction

The Pears Foundation Learning Hub is a partnership between Pears Foundation and the Disabled Children's Partnership (DCP) – a coalition of more than 80 organisations – to research the impact of the pandemic on disabled children and their families in England - and evaluate responses to it.

As part of this work, the DCP has established a Parent Survey Panel to carry out a series of surveys during 2021 to track the experiences of disabled children and their families. The panel of 1,200 families has been set up to be broadly demographically representative of the population of families with disabled children across England in terms of geography, disability and ethnicity. The findings from the first survey were reported in *The Longest Lockdown*[1] and the second survey *The Loneliest Lockdown*[2].

This report reveals the findings from the third survey in this series. This survey was conducted between 1st and 15th April 2021. In England, step two of the roadmap for easing lockdown restrictions commenced on 12th April enabling non-essential shops and leisure facilities to reopen. Prior to this, step one included the return to school on the 8th March and social contact was reintroduced between two households or six people outdoors from the 31st March.

The Longest Lockdown report highlighted challenges for disabled children receiving support for their disability or condition at their school or education and accessing health services. *The Loneliest Lockdown* report illustrated the high levels of isolation experienced by disabled children and the wider family during the third national lockdown at the start of 2021. 9 out of 10 parents reported some level of anxiety and almost half had symptoms of depression.

Survey 3 – which forms the basis of this report - explored the experiences of families returning to school and assessed the impact that the easing of restrictions had on their levels of wellbeing, stress, anxiety and social isolation compared with previous surveys. Many thanks to the 420 families from the panel taking part in this third survey, we are very grateful to them for their time and for sharing their experiences.

Key Findings

Findings of the DCP third survey reveal that despite the easing of lockdown restrictions, a high proportion of disabled children and their families are still experiencing severe levels of social isolation. Although there has been some improvement for families in terms of accessing support via school or the health service, the difference between current and pre-pandemic levels of support is vast. More than half of families are unable to access therapies vital for their disability. Sixty percent are experiencing delays and challenges with accessing the health service appointments they need. These figures in isolation are concerning, but to an even greater extent alarming when considered in context. A large proportion of families with disabled children have multiple diagnosis culminating in multiple appointments with a variety of services.

Lack of support and its impact on parents' mental wellbeing has been well documented in our two previous survey reports. This survey confirms that anxiety, stress and mental wellbeing levels experienced by our panel are significantly worse than the general population. Consecutive surveys demonstrate that this is an ongoing problem for families rather than a short-term response to the events of the pandemic. The lack of access to multiple services across education and health has been detrimental to the mental health of parents as carers, with their disabled children and wider family persistently isolated. Disabled children and their families are at risk of developing additional long-term health problems, ultimately culminating in adverse outcomes for their future goals and aspirations.

Education

Overall families responding to the survey indicated that the return to school on the 8 March 2021 had gone as expected. However, this survey demonstrates challenges for some families, in particular those shielding and those in transitional age groups, particularly those over 16 years of age. A third of families responding to our survey are shielding. More than three in four of these have been shielding since the pandemic began, with one in five unable to access learning online at home.

One in four families rate the mental health or emotional support offered through school as poor. Almost half of families reported that they were still unable to access pre-pandemic levels of support for their disabled child at school or educational setting. Half of disabled children are not receiving the occupational therapy, physiotherapy or speech and language therapy they require due to their condition or disability.

> *"I fought for my daughter to return to college as autism issues were outweighing COVID and tracheostomy issues. Huge battle. But we went back in December. Only to be told on the same day that our waking care respite package has been cut. I told them to have my daughter and all her belongings as I was exhausted and ill. I was told no-one could or would take her away as her needs were too complex".*

Health

Survey 1 revealed that 75% of families were experiencing delays to routine appointments and treatments. Six out of ten families are still experiencing delays to appointments required to review, monitor and treat long-term conditions. The cumulative effect of these delays is highlighted when considering the number of health services that families need to access for their disabled child. More than half of families surveyed access four or more health services, with one in five accessing seven or more services. Therefore, delays to reviews and treatments increase the burden on families to chase and manage appointments, with health care support for those with dual diagnosis increasingly fragmented.

Family Support and access to information and advice

Due to the pandemic, 87% of parents reported that they had sought information or advice for their disabled child. The main source of information was local or national organisations and helplines. Half of parents required information about education and a third required information regarding family support or health.

A key response to the pandemic has been an increase in the use of digital technology although there is clearly a risk of digital exclusion for some. A third of parents reported that the most common challenge was the poor inaccessible design of technology for people with disabilities and poor or unreliable internet connection when accessing digital content.

Social Isolation, Mental Wellbeing, Stress and Anxiety

The Loneliest Lockdown report revealed the high proportion of families socially isolated to the level where their health may be impacted without intervention. The questions in survey 2 were repeated for all family members. Despite a decline in the proportion of parents and disabled children experiencing social isolation more than half of parents and three in four disabled children are still socially isolated. The proportion of siblings experiencing social isolation remained the same (three in four) and the level of siblings isolated on average was worse than reported in survey 2. Therefore, the easing of restrictions has not alleviated the level of isolation revealed in the previous report.

> *"In summary, it seemed to be that under legislation, we could ask for 'reasonable adjustments' to be considered for our daughter but they would not have to be granted eg no zoom, off-line lessons self-explanatory, closed captions on zoom, 1:1 catch up. The senco said that she was trying not to 'break' the teachers and give them too much to do. Seems it was deemed acceptable to break my child though".*

Recommendations

In *The Longest Lockdown* we set out our recommendation for a dedicated, funded Covid recovery plan for disabled children and their families. The findings of this survey, further emphasise the need for a holistic response that properly makes up for the disproportionate impact that disabled children, young people and their families have felt during the pandemic, with a focus on health and wellbeing. This should include:

- A 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

420 parents completed the survey, of them:

- 30% of families were shielding.
- The most common reported conditions were learning disability (53%), autism spectrum disorder (47%), speech and language and communication disorders (37%), social emotional and mental health needs (37%) and physical disability (32%).
- Responses were also received from parents of children with complex health needs, rare conditions, ADHD, multisensory impairment, life limiting or life threatening conditions, visual impairment, hearing impairment and those with undiagnosed conditions.
- Parents taking part in the survey were caring for disabled children up to 25 years of age.
- 91% of parents were white and 9% black, Asian or minority ethnic.
- 91% of participants were mothers, 6% fathers and 2% were grandparents.
- 17% of parents are living in the South East of England, 14% from the North West with an average of 10% of respondents from each of the other seven regions of England.
- 79% of families live in urban areas and 21% live in rural areas (broadly representative with the general population).

Education

In England all children returned to school on 8th March 2021. Seventy-eight percent of parents in this survey planned for their disabled child to return to school, with 90% of those able to return as expected. Overall, families reported that the return to school had gone well.

> *"just really relieved that school were able to facilitate face-to-face lessons again, as online learning is so difficult for my child to access and participate in. She needs a lot of assistance from us as parents in home-schooling and that has been exhausting.*

> *School environment and contact with others is so important for kids and they've missed out on this enormously over the last year".*

However, 14% of parents said that the return had been worse than expected.

> *"My son cannot return to school yet due to the emotional impact COVID has had on him".*

> *"It has affected her mental health, She has lost all confidence she had gained. Struggles to communicate as isolated so long".*

Thirty percent of families responding to survey 3, are shielding, with 78% of those shielding since the start of the pandemic. The majority were able to access learning at home but one in five shielding families were not able to access online learning at home.

> *"We were given laptop to access online learning but we didn't have Internet so was sent a dongle but that worked off mobile connection and we have very patchy signal so my children [are] rarely able to access any learning".*

One in five parents reported that the school did not provide any preparation for their disabled child to return to school.

> *"I am still shocked by the lack of preparation given, the information/experience the school has with my child in understanding his needs and given that we are well into lockdown so this is not a new situation".*

> *"She has really struggled again returning to school with school based anxiety. Her school have given little to no emotional support and very late support in returning to school (not discussed until the Friday before)".*

Families that were able to return to school were asked to rate four aspects of school life: learning support; mental health or emotional support; infection control and transport.

- 63% rated the learning support offered by school as good or excellent.
- 75% rated infection control at school good or excellent.
- 74% of parents rated school or college transport excellent.

- 49% of parents rated mental health or emotional support provided by school as good or excellent.

26% of parents rated mental health or emotional support as poor.

> *"My son was excluded from some of the social activities school had planned for the first 2 days. He was the only one excluded."*
>
> *"They said they were changing my daughter's 1-2-1 with immediate effect. No warning, no training. My daughter is blind, also with complex medical and physical needs. I spent first three weeks before Easter trying to help with training and persuading them to keep the 1-2-1s in place until Easter to give us time to transition"*

In survey 1, 35% of families reported that the pandemic had affected their child's examination, assessment or transition. This latest survey revealed that 49% of parents reported that their disabled children's transition had been negatively affected by the pandemic. Therefore, there is evidence that the longer-term impact of the pandemic is only now becoming clearer as time progresses.

Of those reporting challenges to their disabled child's planned transition, more than 69% were related to stages for older disabled children, aged 16 and above as illustrated in Table 1.

Table 1 – Parents reporting challenges in transitional stages.

Transitional Stage	Proportion reporting challenges (%)
Starting nursery or preschool	5
Starting primary school	5
Primary Age – changing school	4
Primary to secondary school	16
Secondary to Post-16	18
16-18 to further education	22
Transition to employment	4
Transition to adult services	25

> *"Our 3 years old has been identified as needing hoisting for nappy changes etc and there is no one doing the moving and handling training for nursery provision because of COVID. She should have started January 2021 then it got pushed back to after April and still hasn't started"*

> *"Missed all volunteering and work placement opportunities and is now reluctant to try. Also independent travel has gone three steps back..."*

> *"There are not enough placements for young people. There is a lack of funding and job opportunities. They shouldn't have closed Remploy".*

> *"Not remotely complete with only 2 months to go. Uncontactable and a new children's social worker allocated who has no knowledge of my daughter or her family".*

> *"Transition to adult health services is proving very difficult. Not currently able to have education due to health problems".*

In survey 1, 67% of families reported that their disabled children were not able to access all of the support listed in their EHC (Education, Health and Care) plan. In this survey, 48% of parents reported that they are still unable to access support at their child's school or educational placement that they had received before the pandemic.

Of those the proportion of families **still unable** to access support for their child's disability are summarised by service below:

• occupational therapy	56%
• speech and language therapy	54%
• physical therapy or physiotherapy	51%
• hydrotherapy	39%
• medical support	36%
• communication devices	31%
• technological devices	27%
• talking therapies	24%
• medical devices	21%

personal care	20%
music therapy	19%
play therapy	17%

> *"There has been no OT support at all since January 2021 even when my child has OT provision on his EHCP. Raised formal complaints to LA but still no response and ongoing".*

> *"I am really concerned that my son has only done around 12 weeks in school in the last year (March to March) and seems to be regressing in some of his learning abilities and behaviours. I'd like more communication about how his school and other services might help to alleviate this, whether through summer schools or other mechanisms"*

Health Appointments

Disabled children access a number of services to support their condition or disability for a variety of reasons: to monitor or manage children's condition or disability; to address unexpected poor health; review treatments or medication for children with progressive conditions; to identify additional support via equipment, mobility or community aids and further referrals as additional needs become apparent. Therefore, delays in accessing services creates a number of issues in the management and support of disabled children's conditions.

Six in ten families responding to this survey are still experiencing some form of delay with health appointments. Of those, the proportion of families **experiencing delays** with appointments are summarised below:

routine appointments	89%
treatments	41%
equipment / support aids provision	38%
equipment /support aids maintenance	30%
operations	28%

"Meds and feeds are based on weight and he's not been weighed for over a year".

"Mental health & social skills have been negatively affected due to pandemic and probably worse than pre-COVID.

Impact on Wider Family

Family Support

In response to the pandemic services across health, education and the community have moved online. In view of many services continuing with some level of online activity in the future, this survey asked parents about the challenges they experience using technology at home.

poor or inaccessible design for people with disabilities	32%
internet connection at home or poor or unreliable	31%
not enough tablets or computers to use to go online	20%
lack equipment or other necessary devices	18%

Information & advice

Parents were asked about their information needs they had due to the pandemic. Forty-nine percent of families sought help from local charities or organisations, 45% from national helplines and charities with 28% contacting local SENDIAS (SEND Information, Advice and Support) services. The reason parents required advice is listed below:

Education	50%
Family Support	36%
Health	33%
Rights and Entitlements	29%
Social Care	27%
Finances and/or Benefits	20%

- Signposting 18%

"Contact, the Disabled Childrens partnership, SENDIAS and the local Parent Carers Partnership have all been invaluable in letting me know my rights so I can have all the relevant evidence to push for the correct policies for my son to be in place".

Social Isolation, Mental Wellbeing, Stress and Anxiety

Parents were asked to indicate how they were feeling in terms of their mental wellbeing, stress and anxiety. They were also asked to indicate their social interaction and quality of life for themselves, their disabled children and their siblings.

Wellbeing

The short version of the Edinburgh-Warwick Mental Wellbeing Scale[3] was used to measure the levels of wellbeing of parents with disabled children. The results were compared with the previous surveys.

The Edinburgh-Warwick Mental Wellbeing Scale enables respondents' scores to be categorised into three categories: a high level of wellbeing, average wellbeing and low level of wellbeing. The scores for low level of wellbeing can be used to indicate possible depression and probable depression.

The average well-being score of all participants in survey 3 was in line with levels reported in previous surveys. In survey 2, 80% of all respondents had a low level of wellbeing associated with poor mental health. Of those 33% of all respondents' score indicates possible depression and 46% probable depression. In survey 3, 65% of parents scores reflect possible or probable depression. The average panel score for mental wellbeing was significantly lower than the general population.

Anxiety

The General Anxiety Disorder[4] measure enables respondents scores to be categorised into four groups: no anxiety and mild, moderate or severe anxiety. In survey 2, 86% of all parents had some level of anxiety with 31% reporting severe levels of anxiety. In survey 3, 80% of parents had some level of anxiety with 22% experiencing severe levels of severe anxiety. Parents are reporting anxiety at a significantly higher level than the general population are reported during the pandemic.

Stress

The short form Perceived Stress Scale[5] was used to measure the level of stress parents were reporting. The average stress levels of all respondents remained the same as reported in survey 1 and 2, with stress levels significantly remaining higher than the general population norms. There was some reduction in the proportion of those with higher stress levels than the general population when compared with the previous survey however, with 65% of respondent are still experiencing a higher level of stress than expected population norms. These stress levels are significantly higher than what the general population are experiencing during the pandemic.

> *"I found it very difficult having no time to myself, being constantly surrounded by family full time and all the demands on me physically and emotionally was hugely stressful. I never got a moment by myself and I need that ... my daughter needs constant attention"*

Social Network Score

The Lubben social network score[6] was introduced in survey 2 to assess the levels of social isolation experienced by families as lockdown restrictions are eased. Parents provided information about their social networks and that of their disabled children and other children. The measure is used by services to identify people at risk of social isolation so that intervention can be provided. A score of 12 or less indicates intervention would be required.

The questions were repeated in survey 3 to assess changes, however there was no change in the average social isolation score for parents or disabled children between survey 2 and survey 3. The siblings of disabled children did deteriorate when compared with survey 2 demonstrating the isolation for siblings getting worse not better. As Table 2 below illustrates, the proportion of families who are socially isolated has improved since survey 2 however, one in two parents and three in four disabled children and siblings are socially isolated.

Two in five disabled children and one in four of their siblings did not see a friend online or in person in the last month.

Table 2 – Social Interaction of parents, disabled children and siblings

	Survey2	Survey 3	Survey 2	Survey 3
	Average Score 12 & less = socially isolated	Average Score 12 & less = socially isolated	Proportion of respondents scoring 12 or less	Proportion of respondents scoring 12 or less
Parents	9.5	9.2	68%	57%
Disabled Child	5.4	5.5	91%	73%
Siblings	10.7	7.7	75%	76%

> *Organisations contacted are still not providing the services we need due to social distancing guidelines. My son has now been waiting for overnight respite for over 12 months. His brother is unable to access young Carers services for the same reason.*

References

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