



DISABLED CHILDREN'S PARTNERSHIP

THE LONELIEST LOCKDOWN

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

Survey 2

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Introduction

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.

This report reveals the findings from the second survey in this series. This survey focusses on the impact that the COVID-19 pandemic has had on the mental health and wellbeing of disabled children, their parents and siblings. This survey was conducted between 2 and 16 March 2021. The national plan for easing restrictions in England was announced on 22 February 2021 and 43% of respondents completed the survey following the planned return of all pupils to schools on 8th March 2021.

As this was a second survey parents repeated questions regarding their wellbeing, anxiety and stress levels and the findings have been compared with responses in survey 1. 547 families took part in the second survey and we are very grateful to them for their time and for sharing their experiences.

Key Findings

Findings of the DCP second survey reveal disabled children and their families are at risk of developing serious mental health issues as a consequence of the COVID-19 pandemic on their lives.

The impact on disabled children

A high proportion of families are socially isolated to a level where their health may be impacted without intervention. 91% of parents indicated that their child was socially

isolated, with 49% of disabled children not seeing a friend in the last month either online or in person.

Our findings suggest children and young people will require more tailored support following the easing of restriction with more than half of parents reporting a decline in their child's confidence. In particular, parents highlighted a negative impact on life skills such as being out and about (53%), communicating with others (49%) and interacting with strangers (47%). As a result of the pandemic disabled children are continuing to experience poor emotional wellbeing. On average six out of ten parents are observing symptoms associated with anxiety. 72% of parents report that their child is often unhappy, downhearted or tearful. Their siblings are also affected with a high proportion of parents reporting that their other children are having negative issues regarding sleep (67%) and anxiety (59%). Therefore, it is not surprising that 4 in 10 of parent's report that the quality of their life and their disabled child was worse in the last month, with 5 in 10 parents reporting the same for their other children.

The relationship between social isolation and risk to mortality has been widely reported prior to the pandemic². Previous studies of children and adolescents has shown negative consequences of isolation on mental health, behaviour and psychosocial / emotional development with long-term impact into adulthood³. Studies of previous pandemics such as swine flu and SARS have reported that approximately a third of parents said their child needed mental health support due to their experience during the pandemic⁴. There was a significant difference between those experiencing isolation or quarantine when compared to those that did not. Those experiencing isolation were five times more likely to require support from mental health services and experienced higher levels of PTSD.

“Son is screaming daily. Hardly any day care. Supposed to be shielding. Can't get the vaccine easily for him. Tertiary hospitals have been treating non-disabled children so our children have missed so much. As always they are the forgotten or the discarded”.

The impact on the wider family

Compared with the general population, parents completing our survey are experiencing poorer mental wellbeing and higher levels of anxiety, stress and isolation than families before the pandemic and during the early part of the COVID-19 pandemic⁵.

“Sometimes I just cry myself to sleep at night as I’m shielding so as a lone parent the kids pretty much do too”.

“I am physically and mentally exhausted having looked after my son almost single handedly for such a long time”.

Almost 9 out of 10 parents reported some level of anxiety and almost half (46%) had probable depression. To conclude, in usual times 80% of parents would qualify for psychological support within the NHS.

Recommendations

In “The Longest Lockdown” we set out our recommendation for a dedicated, funded COVID-19 recovery plan for disabled children and their families. The findings of this survey further emphasise the need for a holistic approach to meeting the needs of all the family, including supporting mental health and wellbeing; the importance of short breaks; and access to activities to overcome the isolation that many have suffered during lockdown.

Detailed findings

Introduction

547 parents completed the survey, of them:

- 29% of families were shielding.
- The most common reported disabilities had a learning disability (66%), Autism Spectrum Disorder (63%), Speech and Language and Communication Disorders (59%), Social Emotional and Mental Health needs (48%) and Physical Disability (38%).
- 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.
- The majority of parents taking part in the survey were caring for disabled children aged between 6-15 years (81%), 25% aged between 16-19 years, 15% were aged 20 years or over and 9% were aged 5 years and below.
- 91% of parents were white and 9% BAME.
- 91% of participants were mothers, 6% fathers and 3% were grandparents.
- 18% of parents are living in the South East of England, with an average of 10% of respondents from each of the other eight regions of England.
- 79% of families live in urban areas and 21% live in rural areas (broadly representative with the general population).

Impact of pandemic on disabled children and young people

In survey 1, parents highlighted the negative impact the pandemic had had on their disabled child or young person in terms of their overall development. In Survey 2 we asked more details about this to understand what support disabled children and young people may need as restrictions are eased.

54% of parents (of 507 responses) felt that their disabled child had lost confidence over the previous 12 months. This is included life skills such as being out and about (53%), communicating with others (49%), interaction with strangers (47%) and familiar people (38%).

"I have a greater sense of my child being left behind as life returns to job and social opportunities"

In survey 1, families told us that pandemic had a negative impact on the behaviour of their disabled children and their levels of anxiety and mood. In this survey we asked for more detail from families (528 responded). The observations listed below show the proportions of parents who feel their child is demonstrating this behaviour more since the pandemic began.

- 76% do not think things out before acting
- 72% are often unhappy, down hearted or tearful
- 69% many worries, often seems worried

- 65% nervous or clingy in new situations, easily loses confidence
- 65% restless overactive, cannot stay still for long
- 64% easily distracted, concentration wanders
- 60% do not see tasks through to the end
- 56% often complains of stomach aches or sickness

“The lack of activity and boredom has disrupted my child's sleep and due to no physio, hydro or rebound therapy, her hips and legs have become stiffer and causing more discomfort”

“My own Long Covid effects on sleep and limb aches and pains are awful. I can only presume my disabled non- verbal son feels the same and it explains partly his very challenging behaviour. Shielding him at home is a living nightmare - he has hit out in frustration fracturing his hand twice in different places. Subsequent treatment lead to very challenging behaviour itself. He doesn't understand why he cannot go anywhere and I absolutely feel for him. He must think we are being very cruel. I certainly feel like I am”.

“Apprehension stress kicking in as son going back into school. Extra pressure of all services ..health social ed meetings ..starting 16 transition etc move to PIP and all that brings anxiety”.

“Operation cancelled Kids behaviour worse”.

Impact on wider family

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. This section gives an overview of how the whole family has been affected by the pandemic.

Wellbeing

The short version of the Edinburgh-Warwick Mental Wellbeing Scale⁶ was used to measure the levels of wellbeing of parents with disabled children. The results were compared with survey 1.

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 2 was in line with levels reported in survey 1. 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.

“Sometimes I just cry myself to sleep at night as I'm shielding so as a lone parent the kids pretty much do too”.

“I am physically and mentally exhausted having looked after my son almost single-handedly for such a long time”.

“24/7 caring for 2 disabled children for 51 weeks with no respite or support has been exhausting. No school, too dangerous”.

78% of families that were shielding had a low level of wellbeing associated with poor mental health. 31% respondents' score indicates possible depression and 47% had probable depression.

“I already have PTSD and OCD, lockdown did make them both worse than usual but I know the signs and self-helped through the tough times I should imagine there are lots of new sufferers out there who will need help”.

Anxiety

The General Anxiety Disorder⁷ measure enables respondents' scores to be categorised into four groups: no anxiety and mild, moderate or severe anxiety. The average scores for anxiety were marginally higher than in survey 1. In survey 2, 86% of all parents had some level of anxiety with one in 3 (31%, 37% shielding) reporting severe levels of anxiety.

“Worry about the detrimental social effects of lockdowns on child”.

“I've had one child home for a year and one child dying (not Covid), mother in a care home”

Stress

The short form Perceived Stress Scale⁸ 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, with stress levels higher than the general population norms. In this survey 86% of all respondents reported a higher level of stress than expected population norms.

“We are exhausted from having all 3 of our children at home and being in a constant state of high alert due to ongoing fears about our daughter's health”.

“Expectations from outside of our house have ramped up as well because there is the assumption that we have loads of free time now that the kids are back. This just is not the case. Kids appointments have started back up, the calls from school are relentless and there are a LOT of things to catch up on that have been on the back burner for a whole year”.

Social Network Score

The Lubben social network score⁹ 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 results of this measure can be used as a baseline moving forward. The measure is used by services to identify people at risk of social isolation so that intervention can be provided. The table below identifies the average scores and proportion of respondents whose scores are within the threshold of social isolation. A score of 12 or less indicates intervention would be required.

	Average Score	Proportion of respondents scoring 12 or less
Parents	9.5	68%
Disabled Child	5.4	91%
Siblings	10.7	75%

“My daughter is shielding and I’m unable to go to work. I work in a school and whilst we were in lockdown I could work from home but now I’m home with no wages”.

“Care home not proactive in individualised risk assessments for my child. Blanket policies applied meaning that my child was stopped from going to school since December last year even though his school remained open. Care home also stopped me from meeting my child since dec without doing risk assessments. Care home forced my child to isolate in 4 walls without access to fresh air when testing positive with Covid but remaining asymptomatic. He was not allowed out with his own support bubble. My child has Severe Learning difficulties and autism”.

Quality of Life

Parents were asked about the quality of their life, their disabled children's and sibling over the previous month. The proportion of those reporting that their life is worse are listed below:

- 38% parents
- 42% disabled children's life (reported by parents).
- 52% of disabled children's sibling (reported by parents)
- 43% of shielding parents life
- 45% shielding disabled children's life (reported by parents).
- 23% of shielding siblings (reported by parents)

“With two autistic sons to look after and no family to rely on and my mental health problems this pandemic has been a huge impact on me”.

Impact of the pandemic on siblings

In survey 1 parents provided information about how the pandemic affected their whole family. In Survey 2 we asked further information about how the pandemic had affected the siblings of their disabled child.

82% of parents felt the COVID-19 pandemic had affected their child's sibling negatively. The proportion of siblings and the type of difficulty they are experiencing are listed below:

- Sleep 67%
- Anxiety 59%
- Sleep 56%
- Concentration 51%
- Physical health 48%
- Behaviour 42%

“Stress of shielding our son as well as trying to look after our 7 year old who has been struggling with mental health issues”.

References

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