DISABLED CHILDREN'S PARTNERSHIP (DCP)

Left Behind – Six Months On

The impact of reduced support for Disabled Children, their Parents and Siblings

Parent Panel January 2022 - Survey 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 a series of surveys (1, 2, 3, 4) undertaken between January and June 2021. The results provided an understanding of disabled children and their families experiences in real time. 898 parents have taken part in the series of surveys to date.

Since the previous panel survey took place in June 2021, the government announced a winter plan for England, Plan B, to be used to prevent the NHS from being overwhelmed. This was in response to high numbers of COVID cases, with daily cases reaching 234,766 per day in January 2022. Face masks became compulsory again in early December but no further restrictions were implemented with household mixing allowed over the festive period.

In view of the above developments, a survey was undertaken with the parent panel in January 2022, to understand their experiences during the previous six months living through the COVID-19 pandemic. It was conducted between 14th January and 14th February 2022, and is based on 232 parent responses received. In view of the size of the sample, further analysis was undertaken to assess if this was a particularly isolated group of respondents. However, this was not the case. In previous surveys, this group's average isolation scores were in line with the wider group of parents responding to the survey.

During previous surveys, parents with disabled children were consistently 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. Disabled children and their siblings were also socially isolated, despite schools reopening and social restrictions easing. Families reported a lack of support from education, health and social care services. Delays to therapies, diagnostics and treatments have had an impact on disabled children's development, their conditions or disability, hindering their ability to take part in activities that non-disabled children may take for granted.

The impact of the pandemic has severely exacerbated challenges that families with disabled children already faced accessing support. Before the pandemic, just 4% of parents of parents said they received the support needed to care safely for their disabled child (5). Our analysis of local authority spending in the five years before the pandemic, demonstrates that more than half of local authorities across England cut their spending on services that disabled children rely on such as direct payments and short breaks (6). This is in addition to delays in EHCP assessment and backlog in services that families are currently experiencing.

Key Findings

This latest survey reveals that disabled children and their families continue to be severely isolated. Despite household mixing allowed during the Christmas period, almost half (49%) of disabled children and their siblings (46%) did not see a friend online or in person over the festive period. The proportion of parents socially isolated has increased over the last six months, with 7 in 10 parents socially isolated.

The proportion of parents with poor mental wellbeing (83%) and anxiety (82%) remains high and again has increased since the last survey. Almost 3 in 5 of parents taking part in this survey have probable depression. Comparison of parental mental and emotional health with the general population during the pandemic, shows 71% of parent’s anxiety levels and 84% stress levels are higher. This demonstrates a disproportionate impact on parents’ with disabled children when compared with other adults in England.

The toll the pandemic continues to take on disabled children and their families is concerning, not least due to the worsening levels of isolation and mental health, but our survey also shows that support is not forthcoming. Families find themselves amidst a backdrop of delays, interrupted services and absent support. 64% of parents are experiencing delays to health services, 54% to therapies and 43% to social care. Plugging the gap due to the lack of support from services continues to have detrimental impact on parents. In addition to poor mental health, 68% of parents report that their physical health has deteriorated during the previous six months due to delays or reduced support. Almost a third of parents (30%) feel that they are at risk of family breakdown and 72% felt that they required respite care during last twelve months.

Disabled children and their families’ lives continue to be disrupted, with delays and backlog to health, social care and education services now common place. Disabled children are unable to regain the momentum lost during the pandemic. 88% of parents reported that their children missed school during the autumn 2021 term, with the average number of school days lost reported to be 22. Almost half (48%) indicated that days lost at school were the result of COVID-19 outbreaks. More than half (53%) of parent’s reported that their social care was disrupted due to staffing shortages and 47% due to staff sickness.

This latest survey provides evidence that families are bearing the brunt of delays to services and reduction in the provision of support. It concludes that the needs of disabled children and their families have not diminished during the previous six months, needs are increasing across the whole family. It is imperative that disabled children’s needs are prioritised as we move to ‘*live with’* COVID-19.

Recommendations

The findings emphasise the need for dedicated, funding recovery activity for disabled children and their families, and enhanced support even as the country moves into the ‘living with covid’ phase. This must include

- 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.
- Short breaks for families to address high levels of family exhaustion
- Therapies catch-up plan to address where children have regressed or plateaued in their speech, communication, physical development, or social skills

Detailed Findings

Introduction

The structure of this report is organised into two parts. It commences with stark findings demonstrating the ongoing detrimental impact of the pandemic on disabled children, their siblings and parent carers. The poor outcomes described in this section are a direct consequence of the reduction in support and delays to services. The disruption to services experienced by disabled children and their families are outlined in the second part of this report.

Survey Respondents

- 74% had one child, 22% had two children and 4% had three or more children
- The most common reported conditions were learning disability (67%), speech, language and communication difficulties (62%), autism spectrum disorder (61%), social, emotional and mental health needs (53%), physical disability (39%).
- 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
- 92% of parents were white and 7% were black, asian or another ethnic minority
- 90% were mothers, 6% were fathers, 3% were grandparents and 1% were non-parent guardians.
- 19% lived in the South East, 13% in the North West, 12% lived in London or the South West, 11% lived in East Midlands, 10% in the West Midlands and 8% lived in Yorkshire and Humber, East of England and the North East.
- 80% of families lived in an urban area and 20% lived in rural areas.
- 63% of disabled children were aged 6-15 years, 26% were aged 16-19, 14% were aged 20+ and 8% were aged 5 years and below.
- 29% of families were shielding, although the shielding scheme was paused in England on 1st April 2021.

Part 1: Disabled children and family outcomes

Throughout the series of panel surveys, parents completed a series of standardised questionnaires to understand changes to their mental wellbeing, anxiety and stress levels. They also completed social isolation questionnaires for themselves and on behalf of their disabled children and their other children. The timing of surveys coincided with restrictions easing in England to understand any changes this may bring to outcomes for the family. This section will present finding for disabled children, followed by siblings and parent carers.

Disabled Children

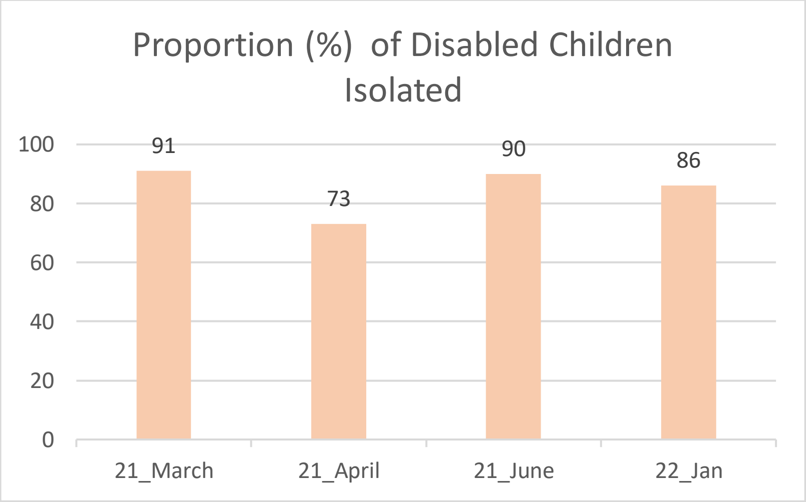
Social Isolation

Our research findings during the pandemic confirmed the detrimental impact of the pandemic on disabled children. Over the survey series, parents completed the Lubben social network questionnaire (7) for their disabled children to assess the levels of social isolation experienced. The Lubben social network questionnaire is used by services during usual times to identify people at risk of social isolation, so that further support can be provided.

Figure 1 below, illustrates the level of social isolation between survey 2 and January 2022 for disabled children. Despite a small decline in the proportion of disabled children isolated, the proportion of those isolated remains very high at 86%.

> *Isolation has proven more damaging for my child than covid……My child can not home school due to severe learning disabilities so is constantly missing out on*

Figure 1 – Proportion of disabled socially isolated during between March 2021 and January 2022



> *The pandemic has caused my sons anxiety to increase to such an extent that he has become agoraphobic. He hasn't left his room for over 18 months. This means he's received no education for almost all this time. The lack of mental health support in adult services means that I can't see this situation changing any time soon*

> *The impact on my child's mental health has been the most worrying aspect during this time. He is now having strong physical reactions to his anxiety and even with support struggles daily with the unpredictability of each day which is affecting his relationships even with family members and will currently only talk and want to be with myself.*

The Lubben Social Network questionnaire comprises of six questions related to contact with family and friends during the previous month. There is a concerning pattern with regards to friendships for disabled children. Parents report that their disabled child is having less contact with friends since the previous survey six months ago. The table below illustrates the increasing levels of isolation experienced. It should be highlighted that the previous month included the Christmas period, however despite this the proportion of disabled children isolated from friendships increased rather than declined.

Table 1 – Disabled children's contact with friends during the previous month.

Statement	Proportion (%) June 2021	Proportion (%) January 2022
Disabled child does not see a friend online or in person in the last month	31%	49%
Disabled child does not have a friend to talk to about private matters	39%	64%
Disabled child does not have a friend that they feel close enough to call on for help	43%	65%

> *No support for emotional and social…..my autistic child has not seen other children and given no support on how to make friends. No interaction with other children during lock downs, learning and it doesn't seem important to anyone and we are kept adrift. Saliva Pcr tests have been made available for travel but not for people who's lives are impacted by lack of availability. This is starting to feel like discrimination.*

Parents were asked to indicate, the impact that disruption and delays to services or support had had on their disabled child in the last six months.

The detrimental impact of reduction in support reported by parents is listed below:

- 70% of disabled children's development has been negatively affected
- 68% of disabled children are more anxious
- 66% of disabled children's emotional or mental health has deteriorated
- 53% of parents said that their disabled child has regressed
- 50% of disabled children's disability or condition has deteriorated
- 46% of disabled children's physical health has deteriorated
- 43% of parents indicated that their disabled child is showing signs of depression
- 31% of disabled children are experiencing more pain.

> *"We have spent years working on our son to socially interact but the pandemic has regressed our son not just the two years it's been going but about 8years. Our experience with no support no respite has taken its toll on my health".*

> *"My daughter is in supported learning at college. It is accessing the community, working towards independent living is having a huge impact".*

> *Regression in all areas, but since my Son is at a special school, all children are behind the national guidelines so no hope of extra support or the likelihood of being able to resit the year. He will leave the placement in July, despite being the youngest in his year group, & no idea of where he will go next or whether our local LA will take lack of education, support & therapies due to Covid into consideration.*

Siblings

Almost half (46%) of disabled children's siblings are socially isolated. Despite a decline in the proportion of those isolated since June 2020, this is still a concerning picture for siblings especially when considering the timing of the survey following the Christmas period. In addition, almost a third of siblings do not have a friend that they can call on for help.

Parents were asked to consider the impact that delays to services or reduction in support has had on their disabled children's siblings. The findings below illustrate the detrimental impact that the disruption to services and support continues to have on the siblings of disabled children.

- 62% more isolated
- 62% more anxious
- 54% confidence has deteriorated
- 53% lonelier
- 48% more problems sleeping
- 41% showing signs of depression
- 40% downhearted, weepy or teary

Parent Carer

As described above parent's completed a series for themselves and on behalf of their disabled children and other children. In addition to the Lubben Social Network Score (7), parents completed the short version of the Edinburgh-Warwick Mental Wellbeing Scale (8) to measure levels of mental wellbeing. The General Anxiety Disorder (GAD) questionnaire (9) was used to measure levels of anxiety and the Perceived Stress Scale (10) was completed to measure stress levels.

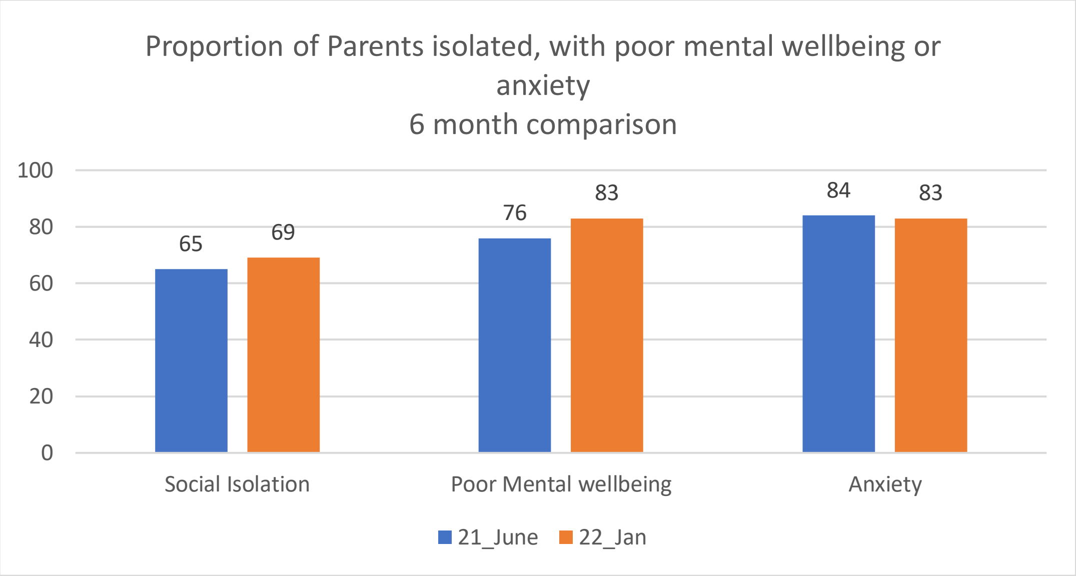
The Edinburgh-Warwick Mental Wellbeing Scale (8) score can demonstrate 4 categories of mental wellbeing: high mental wellbeing, average mental wellbeing, possible depression and probable depression. As illustrated in figure 2, the proportion of parent carers reporting poor mental wellbeing has increased. 83% of parent carers have poor mental wellbeing (26% possible depression and 57% probably depression).

The general anxiety disorder (GAD) questionnaire (9) enables response scores to be categorised into four groups: no anxiety or mild, moderate or severe anxiety. In this survey the proportion of those reporting anxiety has increased to 83% of the panel (32% mild, 26% moderate, 26% severe).

The proportion of parent's reporting that they are isolated has increased to 69% (previously 65% in June 2021). In addition, 84% of parents have higher stress levels when compared with the general population during the COVID pandemic (11).

> *"It's hard not to be anxious when there is a virus that can harm your child everywhere it's been worse this last year as it seems to have moved on for everyone else except those with vulnerable children".*
>
> *"I am angry how we have been shielding as a family since March 2020 and have been entirely abandoned. Restrictions are out the window, cases are rocketing, support is non existent and yet these vulnerable children remain unvaccinated".*

Figure 2: Parent levels of isolation, mental wellbeing and anxiety – six month comparison.



In addition to the standardised questionnaires parents were asked to indicate the impact that reduced support or delays had had on them over the last 6 months. The results are outlined below demonstrating ongoing needs of parent carers:

- 76% emotional or mental health has deteriorated
- 75% feel more isolated
- 74% feel more anxious
- 71% confidence has deteriorated
- 68% physical deteriorated
- 67% feel lonelier
- 64% felt their relationships (familial and friendships) have suffered

Panel survey report '*Left Behind'* (4) outlined the added pressures placed on families through lack of support for their disabled children. In this survey, almost a third (30%) of parents feel that they are at risk of family breakdown.

The negative outcomes described above should be viewed from the perspective of the whole family. The situation for disabled children and their families is not getting better. Each passing day with such poor levels of wellbeing and high levels of social isolation, the greater the risk of long term problems. The following section, provides further insight into why outcomes remain low and outlines the difficulties parents face to gain support for their disabled children.

Part 2: Support for disabled children and their families

Previous reports have highlighted the lack of support across a number of sectors that disabled children rely on for support, within and beyond the home.

Parents were asked a series of statements about the support they received over the last six months. As illustrated below, around half of parents responded did not feel that they had the support that they needed.

- 57% did have the amount of support needed to care their disabled child
- 48% are not able to access support for their physical health
- 46% are not able to access support for their mental or emotional health
- 47% felt that the support they received from family or friends has not improved.

Access to Support – is it getting better or worse?

Services that disabled children rely on for support were disrupted during the pandemic. 75% of parent carers previously reported (1) that they could not access routine health appointments for their disabled child. During the same period 70% were unable to access physiotherapy, occupational therapy, play therapy, speech and language therapy or music therapy. Such services are vital for disabled children in order to manage their conditions, develop, remain free from and ensure they reach their potential later in life.

Support is provided across a number of sectors such as health services, social care and education. Our previous research demonstrated that access to therapies, short breaks, equipment, devices and aids were particularly affected during the pandemic.

In this latest survey, parents report that they are still struggling to access services that they rely on for support. Table 2 below, illustrates the proportion of families reporting that access to services is worse or much worse since June 2020.

Table 2: Proportion of parents reporting that access to services is worse or much worse than June 2020.

Support / services	Proportion (%) January 2021
Health Services	40%
Therapies	40%
Social Care	38%
Education	34%
Short Breaks	33%
Equipment, Aids and Devices	23%

It has been reported that NHS and social care providers are under significant strain and community health services are at full stretch (12). Parents report that they are continuing to experience delays to services. The services that parents report the greatest delays with are health services and therapies, as illustrated in Table 3.

> *There has been no support. Nothing. We have been left behind no services. Nothing*

> *Delays in getting her operations last year caused a great deal of anxiety as she couldn't have the major surgery before two other procedures which were delayed 3 times due to Covid and staffing*

Table 3: Proportion of parents reporting delays to services that they rely on

Support / services	Proportion (%) Experiencing delays January 2021
Health Services	64%
Therapies	54%
Social Care	43%
Short Breaks	42%
Education	40%
Equipment	34%

Parents taking part in the survey panel, will be at different stages of their journey in terms of assessment of need, diagnosis and provision of support and care for their disabled child. Parents experiencing delays as described in Table 3, were asked to indicate the type of delay. For all services listed, delays were most common for disabled children waiting for the provision of support, as outlined in Table 4.

Table 4: Proportion of parents reporting delays, experiencing delays in the provision of support

Support / services	Proportion (%) January 2021
Short Breaks	73%
Therapies	66%
Social Care	64%
Education	61%
Equipment	51%
Health Service	42%

So, for example a parent reporting a delay in the provision of support from short breaks has been referred to short breaks, an assessment of need has taken place but the provision of support has not yet been provided. Survey questions were included to understand the nature of the delays experienced. Using short breaks as an example 91% of families are waiting for more than 3 months, 61% more than 6 months and 43% families are waiting over 12 months.

> *Unable to access Shortbreaks due to there being hardly activities for learning disabled children to access in our local area*
>
> *We had to make a formal complaint about the lack of provision. This complaint has achieved nothing, it has taken 6 months, it has caused huge extra stress and the council deny any failures*
>
> *Respite had to Close for some months during lockdown so they're now trying to work through a back log of 'owed respite' and prioritising families 'most in need'. I*

> *understand this, however, it's simply a further delay to families who also desperately require the service.*

Social Care

Parents are still experiencing disruption to their social care. The most common reasons for disruption to social care that parents reported were due to issues with the social care workforce. 53% of parents reported disruption due to staffing shortages and 47% due to staff sickness. In addition to staffing issues experienced, almost 4 in 10 (38%) of parents stated that they had had difficulties when trying to spend direct payments. In the absence of usual provision parents may wish to spend their direct payments on agreed support, with parents prevented from spending payments with alternative providers. This survey confirms, that this is not an issue that has gone away as the pandemic progressed and services re-opened.

72% of parents responding to this survey indicated that they felt they had needed respite during the last 12 months of the pandemic, however 36% did not have access to respite during that same period. Our previous report *"Left Behind"* highlighted that almost half of parents cited that the lack of respite was the most common problem causing strained relationships with their partner. Lack of respite puts families at further risk of family breakdown.

> *Assessment last summer and Direct payments agreed. However, I'm still waiting for it to begin. Keep chasing but delay from finances. Difficult to get a PA to support*.

> *My son cannot do full day/night respite - we have to have respite 1 hr at a time. We should have 6 x 1hr breaks through out the week, but there are no carers available. We have one, but when he is ill or away, we have no respite.*

> *Respite was stopped for 18 months during the pandemic but has recently started again however there are staffing issues due to the omicron strain of covid*

Therapies

Table 5 below, illustrates the delays parents are experiencing when waiting for therapies.

Table 5: Proportion of families experiencing delays to therapies, by length of delay

Therapy	Proportion of disabled children waiting for more than 3 months	Proportion of disabled children waiting more than 6 months	Proportion of disabled children waiting for more than 12 months
Physiotherapy	97	44	28
OT	95	45	29
Speech, language and communication therapy	89	55	36
Music Therapy	80%	47%	47%
Play Therapy	82%	59%	41%

Hydrotherapy	91%	52%	39%
Talking therapies	83%	50%	33%

As table 5 above demonstrates, the majority of disabled children are waiting longer than the 13 week statutory timescales to access services. For example, 9 in 10 disabled children are waiting for more than 3 months for physiotherapy, occupational therapy, speech, language and communication therapy and hydrotherapy. 8 in 10 disabled children are waiting more than 3 months for talking therapies, play therapy and music therapy.

> *Also the biggest loss of service during lockdown was of the on-site therapy services offered alongside education, all the therapists seemed to be redeployed elsewhere within Acute services and disabled children and young adults were again forgotten about.*

Support that disabled children rely on is usually provided by more than one service and will involve monitoring, review and treatments through the course of their lives. Table 6 provides an overview of health service delays reported by parents and the current length of such delays.

Table 6: Proportion of families experiencing delays to health services, by length of delay

Health Services	Proportion of disabled children waiting for more than 3 months	Proportion of disabled children waiting more than 6 months	Proportion of disabled children waiting for more than 12 months
Routine Appointments	91	47	19
Treatments	95	57	34
Diagnostics	91	45	23
Operations	92	58	39
Medicines Management	70	32	17

Education

The pandemic resulted in school closures in England. Despite re-opening education is still disrupted for disabled children and their families, many who remain clinical extremely vulnerable to COVID-19. 80% of parents taking part in this survey stated that the pandemic has had a negative impact on their child’s educational attainment.

Parents were asked to indicate how many days their disabled child had missed at school during the autumn 2021 term. 88% of disabled children had missed school during this period, with an average of 22 days lost, equivalent to more than 4 school weeks. The reasons for school absence are listed below with almost half of disabled children affected by a COVID-19 outbreak.

Reasons for school absence (more than one may apply):

- 48% COVID outbreak
- 40% illness but not COVID
- 27% due to staff shortage
- 17% needs not met at provision

> *"There're unable to do a pcr test so is constantly asked to isolate"*
>
> *"We have an EHCP delay over changes made in lockdown which now leave my child at risk"*
>
> *"No access to tracheostomy trained travel escort"*
>
> "*We were asked to keep child at home due to lack of staff"*
>
> *"My 18 year old Autistic son missed out on a transition period to work experience provision for young people with EHCPs. As it was lockdown there was very little job experience he could do during the first year and it is only getting going now half way through his second year as places are opening up. We are now being told he may not get a third year to expand his work options and this is devastating as he will lose his EHCP as there is no alternative for him".*

In response to the pandemic, the government has implemented the national tutoring programme (13), with the aim to provide targeted support for children and young disabled people in schools most affected by disruption to their education. 36% of parents indicated that they did not feel the tutoring support targeted their child's needs appropriately and 63% stated that the school did not provide clear information on the process to allocate tutoring support.

> "*I have homeschooled both my SEN boys from March 2020 to May 2021, then again October 2021 to present. No information re tutoring has been provided to me by either school"*
>
> *"My son is at a special school so I'm not how the national tutoring programme would apply. But he was definitely negatively impacted by being out of school during the pandemic (for long periods determined by the school despite him having an EHCP and being utterly unable to engage in any "school" work at home".*
>
> *My son's final year at a specialist FE college was ruined by the pandemic. The tutoring programme seemed to totally ignore students with PMLD and those who learn differently.*

For children that require their needs to be assessed, parents reported delays waiting to see an education psychologist, with almost half waiting for over 12 months as illustrated below in Table 7.

Table 7: Proportion of families waiting to see an Educational Psychologist, by length of delay

Service	Proportion of disabled children waiting for more than 3 months	Proportion of disabled children waiting more than 6 months	Proportion of disabled children waiting for more than 12 months
Educational Psychologist	94%	68%	46%

As with all children, disabled children want to take part in activities and to have the same opportunities as their non-disabled peers. Parents were asked to indicate if their disabled child was able to take part in their usual activities and if this was getting better or worse. Those reporting that access to usual activities was getting worse or much worse are listed below:

- 51% social activities
- 48% leisure activities
- 45% time with friends or family
- 42% other clubs and groups
- 37% educational groups
- 31% sports clubs

> *Disruptive impact - We finally had the EHCP shortly before the pandemic resulting in provision not delivered or lacking and inconsistent. following 2 years of lacking provision, my teenage son attending mainstream education with ASD high and complex OCD and anxiety failed GCSE exams switched off education and is now at high risk of becoming NEET (Not in Employment, education or training).*

> *My child has not been able to do anything outside of the school grounds, the classes have still been isolated from each other*

Clearly from the information above, life is not getting back to normal for disabled children and their families. Despite limited restrictions and the removal of covid regulations, the impact of the pandemic still dominates disabled children's lives.

Conclusion

The series of surveys undertaken with parents of disabled children during the pandemic has provided an understanding of the experiences of families in real time. Despite this latest survey capturing data around the festive period – the proportion of families socially isolated remains high. The proportion of parents reporting poor mental health, and high stress and anxiety levels has increased since the last survey six months ago. Since this panel took place the government has announced the end of legal COVID restrictions as the country now moves to "live with COVID-19". However, families are still unable to access vital services that they rely on for support, experiencing delays across multiple services that they deal with.

Challenges and barriers to support that families with disabled children already faced have been exacerbated by the pandemic. The service backlog has added to the reduction in funding for disabled children's services across the country (6). Disabled children need to be at the heart of policies to ensure they do not remain isolated from friends or upcoming life opportunities. Urgent, targeted action is needed to ensure that disabled children and their families can access the support imperative to reach their full potential, as active members of society.

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