DISABLED CHILDREN'S PARTNERSHIP

THE LONGEST LOCKDOWN

The experiences of disabled children and their families during lockdown 3

Survey 1

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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. 635 families responded to the first survey in January 2021, and this paper reports on what they told us. We are very grateful to them for their time and for sharing their experiences.

Key findings

The findings reveal disabled children are not receiving support for their disability or medical condition via health services or their school placement. Parents report a detrimental impact of their child's disability during a time of reduced level of informal and formal support at home during the pandemic.

75% of families reported delays to routine health appointments for their disabled child. Over half (51%) of families stated that these delays had a negative impact on their child's condition. As a result of these delays, families reported additional problems with: anxiety and behavior (70%), sleep (66%) and loneliness (65%). More than 3 in 10 families (34%) felt their disabled child had depression.

The situation is compounded for those children accessing support for their disability via their nursery, school, college or placement. 70% or more children could not access therapies such as Occupational Therapy, Physical or Physiotherapy, Play Therapy, Speech and Language Therapy or Music Therapy. 72% of families reported that their EHCP or SEN plan had been negatively affected during the pandemic, with 67% stating that they were getting some or none of the support detailed.

Recommendations

This survey forms part of the growing evidence of the devastating impact of the pandemic on disabled children and their families. As well as the immediate impact on families, children's longer-term education, health and wellbeing are at risk. Most are still unable to access health appointments and therapies as schools remain closed for the majority, despite reassurances that lessons have been learnt from lockdown 1 and health professionals would not be redeployed.

The DCP is calling for an ambitious and funded Covid recovery and catch-up plan for disabled children covering not just education, but also health and wellbeing; and for swifter access to Covid vaccines for them, their parent carers and siblings.

The DCP is calling an ambitious and funded Covid recovery and catch-up plan for disabled children covering not just education, but also health and wellbeing. A narrow focus on attainment is unlikely to be successful in enabling the majority of disabled children to catch-up. Not least because where an absence of therapies and services has caused children to fall behind in terms of speech, communication, social and motor skills, or for them to be in pain, they will not be ready to learn.

The DCP's Covid recovery plan includes:

- A therapies catch-up plan to address where children have regressed or plateaued in their speech, communication, physical development, or social skills
- Short breaks/respite 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.

To secure this we are calling on:

- The Department for Education to ensure that catch-up initiatives include plans to scale up therapeutic interventions, short breaks and transition support for disabled children and young people
- NHS England to develop a catch-up plan for disabled children prioritising equipment, health services and therapeutic interventions

- The Cabinet Office to ensure that leadership to address the needs of disabled children does not fall between government departments, and to evaluate outcomes for disabled children through the recovery period compared to their peers
- The Department of Work and Pensions to identify how financial support can be better targeted at families with disabled children to help with the increased care costs caused by Covid lockdown. Eg Carers allowance hasn't been increased like Universal credit and remains one of the lowest benefits
- Clinical Commissioning Groups and primary care networks to work with Parent Carer Forums to ensure local implementation of national guidelines for vaccines for carers and hopefully, later, for clinically extremely vulnerable children and those with long term conditions
- Funders to support charities and local groups to meet the additional needs of disabled children and their families through the recovery period.

Detailed Findings

Introduction

635 parents completed the survey, of them -

- 28% of families were shielding
- 56% of parents had a disability or condition
- 28% of respondents were single parents
- 29% of respondents were key workers
- 93% of the panel were aged between 30 and 59 years of age
- 20% of respondents were from the South East with an average of 10% of respondents from each of the other eight regions of England
- Children had an average of 4 conditions or disabilities
- The most common reported disabilities were Autism Spectrum Disorder (69.1%), learning (66.1%), speech, language and communication difficulties (59.4%).

  Responses were received from parents of children with Social, Emotional and Mental Health Needs, Physical Disability, Complex Health Needs, Rare Conditions, ADHD, Multisensory Impairment, Life Limiting or threatening condition, Visual Impairment, Hearing Impairment and undiagnosed conditions.

This is broadly in line with what we know about the wider population of families with disabled children.

The Pears Learning Hub research is focused around three themes:

- Schooling and education
- Health, with a focus on children with complex needs and/or who are shielding
- Family support.

The survey asked parents questions across these themes. Their responses are detailed in the report. We have included quotes from the free text sections of the survey in italics.

Schooling and education

“No support: I’m working full time whilst supporting three children at home”

“Our daughter has hearing loss, vision problems, blue light sensitivities hence five Zoom lessons a day is overwhelming”

“Home-schooled at the moment with no additional support or anything different to non-disabled kids”

The survey asked whether children were getting the support set out in section F of their Education, Health and Care Plan (which specifies special educational provision that must be made).

515 parents whose children had EHCPs responded to this question. Of them

- 16% said yes
- 46% said they were getting some of it
- 21% said they were getting none of it
- 17% were unsure

55 families were waiting for an assessment for an Education, Health and Care Plan. Of those:

- 27% waiting for more than 6 months
- 5% waiting 3-6 months
- 20% % waiting up to 3 months
- 47% were unsure

The legal deadline for assessments is 20 weeks.

The survey asked about the impact of the pandemic on children’s SEN support plans and educational attainment:

- 72% said that their EHCP or SEN support plan had been negatively affected by Covid (574 parents responded to this question)

- 77% of parents felt their disabled child's educational attainment had been affected by the COVID-19 pandemic. (599 parents responded)

- 35% of parents said that their disabled child's examinations or transition had been affected by the COVID-19 pandemic (593 parents responded).

"Our children are unseen victims of the pandemic in so many ways – relates to transition assessment of non-disabled kids"

"A lot of my son's targets are about independence; a lot of this has not been able to happen, eg trips to local shop and café to practice money and social skills"

Exercise and activity

The survey asked parents about physical exercise:

- 73% of parents said they didn't think their disabled child was getting enough physical exercise (608 parents responded)

- 64% of reported that a reduction in activity levels had affected their child's health negatively (590 parents responded).

Support at school for children's disability or medical condition

"School is short staffed. All NHS Physiotherapy and Speech and Language Therapy has been pulled"

"My son had an intensive physiotherapy programme 3 days a week and hydrotherapy once per week. He has had NONE of this taking place"

"Neither of the schools will allow visitors so SALT, CAMHS and OT haven't been able to visit"

"No OT, HI, sensory support etc as professionals not allowed in school. Daughter has to attend a school out of area so local departments won't see her"

Parents were asked if their disabled child received any support in education settings for their disability or medical condition. Their responses compared the level of support they received pre-pandemic to that they received in lockdown 1 and lockdown 3.

1. Medical Support (266 parents)

30% of those receiving medical support before the pandemic continued to receive this during the first lockdown. 36% reported receiving medical support in lockdown 3 **Therefore, 64% of families are still not experiencing pre-pandemic levels of support.**

2. Physical or Physiotherapy (259 parents)

15% of those receiving physiotherapy before the pandemic continued to receive this during the first lockdown. 30% have received physiotherapy during lockdown 3. **Therefore, 70% of families are still not experiencing pre-pandemic levels of support**.

3. Speech and Language (329 parents)

16% of children receiving speech and language therapy at school continued to access this service during the first lockdown. 30% have received speech and language therapy during lockdown 3. **Therefore, 70% of families are still not experiencing pre-pandemic levels of support.**

4. Music Therapy (160 parents)

17.5% of children receiving speech and language therapy at school before the pandemic continued to receive this service during the first lockdown. 31% reported access this service during lockdown 3. **Therefore, 69% of families are still not experiencing pre-pandemic levels of support.**

5. Play Therapy (126 parents)

16% of children receiving play therapy at school before the pandemic continued to receive this support during lockdown 1. 29% continued to receive this service during lockdown 3. **Therefore, 71% of families are still not experiencing pre-pandemic levels of support.**

6. Hydrotherapy (150 parents)

5% of children receiving hydrotherapy at school before the pandemic continued to receive this support during lockdown 1. 11% of those were able to access this service in lockdown 3. **Therefore 89% of families are still not experiencing pre-pandemic levels of support.**

7. Occupational Therapy (298 parents)

19% of disabled children receiving Occupational Therapy at school before the pandemic continued to receive this support during lockdown 1. 27% access this service during lockdown 3. **Therefore, 73% of families have are still not experiences pre-pandemic levels of support.**

8. Talk Therapies (97 parents)

29% of children receiving support through talking therapies continued to receive this support during lockdown 1. 36% have had access to this service during lockdown 3. **Therefore, 64% of families are still not experiencing pre-pandemic levels of support.**

9. Personal Care (243 parents)

33% of disabled children receiving personal care continued to receive this support during lockdown 1. 47% have had access to this service during lockdown 3. **Therefore, 53% families are still not experiencing pre-pandemic levels of support.**

10. Technological Devices (145 parents)

38% of disabled children had access to technological during the first lockdown with 54% having access during the third lockdown. **Therefore, 46% of families are still not experiencing pre-pandemic level of support.**

11. Communication Devices (160 parents)

32% of disabled children who had access to communication devices through education before the pandemic could access those devices during lockdown 1. 49% of disabled children have access during the third lockdown leaving **51% of disabled children without access to communication devices.**

12. Medicines (227 parents)

67% of disabled children who accessed medicines through education provision had access to this during lockdown 1. 73% have access during lockdown three. **Therefore, 27% do not have access at pre-pandemic levels.**

13. Medical Devices (63 parents)

43% of disabled children who accessed medical devices through their education provision pre-pandemic continued to access then during lockdown 1. 52% continue to access devices during lockdown 3. **Therefore 47% of disabled children do not have access to pre-pandemic levels.**

Health, including shielding and children with complex needs

We asked parents for their view on information about shielding. Of the 275 parents who responded -

- 35% of families shielding considered government messaging was either poor or very poor. 37% of families shielding considered the information given by health professionals to be poor or very poor.

Parents were asked about whether they had experienced delays in accessing health services. 583 parents responded.

- 75% of families reported delays to routine appointments.
- 11% experienced delays for operations.
- 31% experienced delays to treatments.
- 28% experienced delays with provision of equipment or support aids
- 21% experienced delays with appointments with regards to maintenance of that equipment or support aids.

"Cancelled operation twice. Complete stop on physio support"

"Incontinence services has been cancelled twice"

We asked about the impact of these delays on children's disability or health condition.

- 51% of families reported that the delay with appointments had had an impact of their disabled child's disability or health condition.
- 52% of families reported that the delays in appointments with health professionals had a negative impact on their disabled child's disability or health condition.

"Developed agonizing complication/comorbid condition to his main disability, no specialists have been available to see him, left in agony for five week before the

episode subsided, then finally received a scan 4 months later when the condition was no longer in flare"

"Medicine became unavailable and had to be changed mid lockdown. It didn't agree with him and he reacted badly, still affecting him now and other meds/conditions also affected"

"My child has regressed irretrievably, I despair he will ever be able to catch up"

"Along with his autism diagnosis we've had delays to him receiving treatment for allergies (he has a reaction in June and we still haven't been able to get him tested) and eczema"

Families reported additional negative impact of delays in services on their disabled child in the following areas: sleep (66%), behaviour (70%), anxiety (70%), loneliness 65% and depression 34%.

"My son has become mentally unwell and has been struggling to engage in anything"

"CAMHS have just left us to get on with it"

Support for Family

"It's been absolute hell"

The survey asked parents about the level of support their families received.

- 82% of families who received formal support from services, charities or the voluntary sector before the pandemic reported that that service had decreased during the pandemic.

- 86% of families who received informal support from family, friends or neighbours before the pandemic reported that the support had decreased during the pandemic.

With regard to different types of provision:

- 40% of families who accessed short breaks care at home before the pandemic accessed the same service during autumn 2020, with this declining to 26% of families during lockdown 3.

- During autumn 2020, 30% of families who accessed day care away from home before the pandemic could still access the service during autumn 2020, with this declining to 20% during lockdown 3.

- 37% of families who accessed overnight short-term breaks before the pandemic could access the service during autumn 2020, with this declining to 30% during lockdown 3.

- 19% of families who accessed residential breaks before the pandemic accessed the service during autumn 2020, declining to 15% during lockdown 3.

- 9% of families who accessed family link schemes (where disabled children are supported to take part I leisure activities) before the pandemic could access the service during the autumn 2020. 11% were able to access the service during lockdown 3.

- 44% of families who received Domiciliary Support at home before the pandemic could access the service during autumn 2020 and lockdown 3.

- 52% of families who received support from a personal assistant continued to do so in the Autumn 2020 with 51% continuing to receive support during lockdown 3.

- 41% of families reported that their child had a social worker appointed before the pandemic. Of those 40% reported that the support received from the social worker since the pandemic had been less.

- 10% of families reported that they were currently awaiting a social work assessment. 54% of those were waiting for more than 6 months. 12% of families were awaiting for adaptations to their home.

Finally, the survey used standardized tools to assess parents' wellbeing, stress and anxiety. [1]

- In this survey, Parents reported an average wellbeing score of 18.59 at this time. The average score for the general adult population in England is usually reported as 23.6. Therefore, the respondents of this survey had a lower wellbeing than the rest of the population.

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[1] Wellbeing measure – Short Warwick Edinburgh Well-Being Scale (SWEMWBS)
Perceived Stress Scale (PSS-4) short item
General Anxiety Disorder (GAD-7) - @NHS Health Scotland, University of Warwick and University of Edinburgh, 2008
References
https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/about/wemwbsvsswemwbs
Perceived Stress Scale short item - The PSS Scale Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. Journal of Health and Social Behavior, 24, 386-396.
GAD-7 Spitzer RL, Kroenke K, Williams JB, et al; A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006 May 22;166(10):1092-7. GAD-7

- Parents reported an average Perceived Stress Score of 8.1 which is higher than the average score of 6.1 of general population. Therefore, respondents of the survey have higher stress levels than the general population.

- Anxiety Score of 10.4 compared with an average score of 2.95 of the general population. Therefore, the average score of our survey indicated that the families were experiencing a higher level of anxiety that equates with moderate levels of anxiety.