



Disabled
Children's
Partnership

Pears
Foundation



Then There Was Silence:

Report summary for charities and funders

A briefing on the Disabled Children's Partnership (DCP) and Pears Learning Hub final report into the impact of the pandemic on disabled children, young people and their families.

September
2021

Summary

This briefing highlights the key findings from *Then There Was Silence*, the final report from the Pears Learning Hub, a partnership between the DCP and the Pears Foundation, on the impact of the pandemic on disabled children and families. The report draws on evidence from a number of surveys of and interviews with parent carers; Freedom of Information requests of local councils and health trusts; and other research and sources of evidence. This summarises the proposed steps for central and local government, and the NHS.

To view all of the DCP's research into the pandemic, visit:
disabledchildrenpartnership.org.uk



About the Disabled Children's Partnership

The Disabled Children's Partnership is a major coalition of more than 90 organisations campaigning for improved health and social care for disabled children, young people and their families. We believe that disabled children, young people and their families should have access to the services they are entitled to, **when they need them.**

Key findings - the impact of the pandemic on families



Children and families have been isolated, abandoned and ignored.

9 in 10

were socially isolated in June, with three quarters seeing no improvement over the course of 2021 - despite lockdown measures easing.

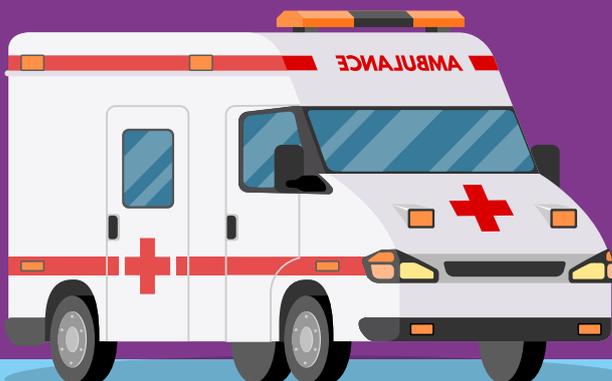
Isolation affected the whole family, with

65%

of parents and

72%

of siblings also isolated in June. These figures are much higher than the general population.



Covid restrictions meant services were stopped or reduced; and many are still slow to return

Paediatric Pain Management clinics were reduced by

84%

The mental health and wellbeing of all the family has deteriorated

There was also a shocking

60%

increase in referrals to paediatric emergency mental health services

Parental anxiety was consistently high with more than

80%

of parent carers of disabled children having some form of anxiety despite the easing of restrictions

Key findings - the impact of the pandemic on families



Children's conditions have worsened and needs become more complex; delays in assessments mean needs haven't been identified

40%

reduction in
paediatric surgery

Almost

50%

reduction in hospital
activity for 0-5 year olds
than before pandemic

67%

67% of trusts completed
fewer physiotherapy
assessments within the
13 weeks target



CLOSED

How the third sector responded to the pandemic

Then There Was Silence also investigated the response of the charity sector to the pandemic.

There was a unanimous perception from charities that disabled children and their families have been largely forgotten by the statutory sector since the start of the pandemic

Parents had almost only praise for the way charities reacted to lockdown.

The role of the DCP was overwhelmingly deemed 'vital' both as a source of information and updates as the pandemic progressed, as well as a lobbying body.

“Sense have been doing everything, I mean they went virtual overnight, supported me and my mental health, supported my children by giving them some entertainment a couple of times a week...and all the proper services ...they all stopped. We were just left in the dark.”

— Parent carer

“So many of the families that we support have multiple agencies involved in working with them. And 60% of them said, 'only Dingley had supported us through this'. I find that really disturbing, because these are people who have physiotherapy, occupational therapy, speech and language therapy, and may be in touch with educational psychologists or so many different people involved. And it just stopped for so many of them.



5 steps for charities

This research has identified five key competencies common to effective responses from charities during the pandemic. Charitable organisations should work to embed these approaches in how they work going forwards to best meet the emerging needs of disabled children and families. This will reflect a shift in working practices and culture for many and build on what has worked over the past year.



1

Charities should increase their capacity to be able to understand changing disabled children's and families' needs



2

Charities should increase their focus on delivering emotional support to families



3

Charities should ensure that they maximise the benefits of online service delivery



4

Charities should adopt a more collaborative, holistic approach to meeting needs



5



Charities should adopt an agile approach to service design and implementation

Five steps for the Disabled Children's Partnership

1

The DCP should maintain a central repository of insight into the changing experiences of disabled children and families

2

The DCP should bring together charities to explore in more depth the practical application of the competencies identified in this report

3

The DCP should continue to work inclusively to harness opportunities for collaboration

4

The DCP should continue draw on the expertise from its range of members to unite charities and families to raise awareness of the issues facing disabled children and their families and to lobby for changes

5

The DCP should encourage funders to take a holistic approach to support for the sector

5 steps for funders

The pandemic, and the resultant reductions in support for children and families, have led to an increased complexity in the support needs of disabled children and their families and high and increasing levels of unmet need. Philanthropic funders with an interest in 'levelling up' should include a focus on disabled children within their programmes. As should those aiming to reach out to groups disadvantaged through the pandemic, or to those experiencing poverty and inequality.



1

Support charitable programmes that take a whole family approach to preventing problems escalating into crisis and breakdown

2

Place an emphasis on programmes that provide emotional support and help families overcome the isolation they have suffered during the pandemic

3

Consider providing unrestricted funds to enable charities to be agile and flexible in responding to needs and working collaboratively with other organisations to secure the best outcomes for children and families

4

Fund services that are developed in co-production with disabled children and their families; and allow flexibility for ongoing feedback from children and families to shape the service as it is delivered

5

Support charities to develop blended approaches to services delivery; and invest in digital capacity, capability and confidence (within charities and within families)





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The Disabled Children's Partnership (DCP) is a growing coalition of more than 90 charities who have joined forces, working closely in partnership with parents, to campaign for improved health and social care for disabled children, young people and their families. We are administered by Royal Mencap Society (registered company in England and Wales no. 00550457; registered charity numbers are 222377 in England and Wales, and SC041079 in Scotland).