



Disabled
Children's
Partnership

Failed and Forgotten

Research by the Learning Hub at the
Disabled Children's Partnership

Who we are

The Disabled Children's Partnership is a coalition of over 100 organisations that campaign for improved health and social care for disabled children, young people and their families. The Learning Hub, established in 2020, is a collaboration with Pears Foundation to build the evidence base for disabled children in response to the disproportionate impact that the COVID-19 pandemic had on their lives and futures.

What we found

Sadly, despite the country emerging from the Covid pandemic, disabled children and their families continue to face massive challenges in accessing the support they need.



What we did

In October and November 2022, we surveyed 2,200 parent carers of disabled children to ask them about the current experiences of families with disabled children. Those parent carers between them look after 2,904 disabled children and 1,914 siblings. We also made Freedom of Information requests to Integrated Care Boards in the NHS and local authority children's social care departments; and we examined publicly available NHS and local authority data.

We are on multiple waiting lists that are over 18 months wait which will mean my daughter will be in reception and her developmental delays will become worse. - Parent Carer

This is having a severe detrimental impact on the physical and mental health, wellbeing and life chances of all members of the family – the children themselves; their siblings; and their parents – with children suffering avoidable pain.

Disabled children and their families rely on multiple services and

1 in 5

are experiencing delays with more than 10 health services.

Children and families are more isolated even than during the pandemic, with many not seeing anyone outside their family.

These problems existed pre-Covid, worsened during Covid and persist now.

Our analysis shows that **50% of local authorities planned to cut budgets for disabled children during this financial year¹. (Not including the High Needs Funding Budget).**

Only

1 in 5

parents said that their family received the support needed to enable their child to fulfil their potential.

Children face long and multiple waits for assessments and to receive support across education, health and social care.

My son was funny, kind, smart, funny. He is now a shell and no one cares.

- Parent Carer

The cost of living and energy crises have hit families with disabled children. They disproportionately suffer from poverty; many parents have had to give up their careers to care for their children; and they often face higher costs, including higher energy costs because of specialist equipment.

Our detailed findings

Lack of support from services

Only **1 in 7** said that their disabled child has the correct level of support from social care, **1 in 5** from health services and **1 in 3** from their education setting.

Over the years, support has declined to an alarming rate. Our eldest child is entitled to 4 hours a week care but hasn't accessed it since the pandemic due to no available support/care staff either from an agency or via personal contacts... each service seems to be running on empty. It's a shocking state of affairs.

Looking towards adulthood and routes towards independence, just **12%** of parents reported that their disabled child gets the correct level of support from their training, employment or voluntary placement.

3 in 4 parent carers told us that they have had to give up employment, or their whole careers, due to the lack of support available.

Almost half of parents are unable to work and are experiencing poverty.

3 in 4 parents say that financial constraints due to the cost of living crisis will have a significant impact on their disabled child.

NHS data shows that the proportion of disabled children waiting for treatment is equivalent to adults, and disabled children waiting for equipment, such as wheelchairs, are likely to wait longer than adults.

The most common delays are for reviews within health services and assessments from social care.

Impact of delays on disabled children

Of those who are experiencing delays with therapy services, both physical and talking therapies, almost **3 in 5** are waiting more than 12 months for appointments.

We are awaiting Speech and Language Therapy for 3 years for a non-verbal child!

1 in every 2 disabled children experiencing delays seeking support for self-harming, self-injurious and high-risk behaviour are also waiting for more than a year to be seen.

70% of disabled children and young people needing a personal assistant are facing delays due to the lack of availability of the workforce.

Half of disabled children are facing delays in assessment for support for household tasks, household equipment and adaptations, and **39%** of parents report delays to short breaks.

Half of parent carers said that their disabled child's therapy, mental health or communication needs were not met within their education settings.

Of those pupils waiting to see an educational psychologist, half are waiting for over a year meaning that, during extensive periods of a disabled child's life, they are attending school without their needs identified or met. Lack of support concerns parents.

Half of parent carers are concerned that their disabled child or young person is vulnerable to being exploited or coerced into behaviours or relationships that may put them at risk emotionally and physically due to the lack of support available.

Over 3 years waiting for CAMHS to diagnosis for ADHD, mental health and social interaction not addressed. No trauma support offered. Currently not attending school. Arrested over 10 times still not addressed. Now potential gang grooming due to being vulnerable.

7 in 10 parents told us that their disabled children's health has deteriorated and they are more anxious due to the lack of support available.

7 in 10 reported that their disabled children's behaviour is more challenging due to stress, anxiety and pain, and more than half state that their child's development has regressed.



Impact of delays on disabled children's families

The impact of the lack of support for parents is high levels of mental health problems (87%) and physical health problems (82%)

More than half of siblings are taking on more caring responsibilities. Anxiety and isolation levels reported among siblings are high (69% and 67% respectively), with more than half experiencing deteriorating levels of confidence.

'No family. No friends. We don't go out, no social media, no groups, no nothing. We attend hospital and school only'.



The Government must act now

The Minister for Disabled People, working with the network of Ministerial Disability Champions, must ensure that the needs of disabled children and their families are prioritised across all parts of the public sector.

The Department for Education, working with the Department for Health and Social Care, must ensure that its reforms to special educational needs and disability do not make it harder for parents to get the support their children need. They must invest in support, develop a workforce strategy and strengthen accountability.

In taking forward reforms to Children's Social Care, the Department for Education must include a specific focus on disabled children and their families in the proposed 'Family Help' arrangements, build on the lessons from the Short Breaks Innovation Fund and increase the focus on disability within children's social work training.

The recent announcement of a review by the Law Commission into the legal framework for disabled children's social care presents an opportunity to improve the complex nature of the current law that families rely on. It is vital that it is taken forward in full partnership with parents and young people.

Read the full report here:

<https://disabledchildrenspartnership.org.uk/failedandforgotten-read-our-new-report>

The Department for Health and Social Care and NHS (England) must ensure all Integrated Care Systems develop and prioritise clear plans for eliminating the extensive and growing backlogs in assessments and therapies/treatments for disabled children.

The government must support families with disabled children during the cost of living crisis including:

- An energy assistance payment for families of seriously ill and disabled children to cover the cost of running lifesaving medical and disability equipment.
- Bring forward the further £150 Disability Cost of Living payment and benefit uplift announced in the Autumn statement.
- Reverse eligibility changes to the Warm Home Discount that excluded disabled people.
- Social tariffs for households on disability benefits.



For more information on the DCP's research and campaigns, please

disabledchildrenspartnership.org.uk

or email us on:

disabledchildrens.partnership@mencap.org.uk

Statistics from this briefing are from the DCP reports of surveys of parent carers and our FOI requests from local authorities and NHS trusts - all of which are available to download on our website.



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The Disabled Children's Partnership (DCP) is a growing coalition of more than 100 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).

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