



#CountDisabledChildrenIn Campaign Overview

Key stats and recommendations
for local councillors, journalists
and others

Spring 2022

Campaign overview

What is the #CountDisabledChildrenIn campaign?

- In Spring 2022, local councils in England will be deciding their budgets for disabled children's health and social care services.
- Parent carer forums, local charities, campaigners, and others already advocate for the rights of disabled children and their families in local areas. #CountDisabledChildrenIn aims to add to these voices by equipping individual campaigners and local groups with additional national research and tools to do their own campaigning locally, and ultimately help amplify the voices of families with disabled children as council's plan their budgets.

Why is the campaign needed?

- Many national and local groups, such as parent carer forums, the National Network of Parent Carer Forums, charities, campaign groups like the DCP, and others have been pushing for better funding for disabled children's health and care services for many years – and despite this work there is, sadly, clear evidence that too many families are still not getting the services they are entitled to.
- Research from the DCP shows that families have been consistently **denied the therapies, short breaks, and other support** they are entitled to – both before the pandemic and even worse during it. There remains **a large funding gap** in services, **too many children are seeing their progress regress**, and too many parent carers face **huge levels of mental health problems** and exhaustion.

This is an injustice, and has to change.

What are we calling for?

At Rishi Sunak's 2021 Autumn Budget, no dedicated health and care support for disabled children and families was announced. However, a total of £4.8 billion in extra government funding for local councils was released.

As councils plan their budgets, we are asking them to use some of this money to invest in disabled children's health and care, correct years of underfunding, and give every family the support they are entitled to. Full recommendations are set out on page 4 of this briefing.

This campaign is a continuation of the DCP's #GiveItBack health and social care funding campaign. To find out more about our campaigns, go to:

disabledchildrenspartnership.org.uk/our-campaigns/



Why should local councils invest more in disabled children?

It's the right thing to do.

- Disabled children have a **right to progress and achieve** great opportunities like their peers. However, without proper health and care services, many young people will be in unnecessary pain, and will not be able to properly manage their conditions.
- **Parent carers have a right to breathe**, and to not be constantly exhausted and isolated. Without proper care services, many parent carers and siblings will get little break from caring, especially when disabled young people have complex needs.

It makes financial sense.

- By investing in the health of disabled children and families early, **councils will be able to save public money** by avoiding family breakdowns, preventing the need for more expensive medical procedures, and as more parent carers and disabled young people enter employment and pay tax.

Campaign Stats



The impact of the pandemic on disabled children and families.

The DCP's pandemic research has consistently shown that families with disabled children have felt forgotten and isolated, as essential support services – which were already stretched – were further reduced, leaving many disabled children unable to access vital services they need to manage their conditions.

- **Over 70% of disabled children** could not access pre-pandemic levels of therapies and health services.
- **40% of local authorities** reduced respite care for families as services were diverted – despite the prevalence of relationship breakdown and social isolation in parents.
- **7 in 10 NHS Trusts** were unable to meet their targets for providing services for physiotherapy appointments and **over half of local authorities** did not meet their targets for providing vital Education, Health and Care plan assessments.
- **Nearly three quarters (71%)** of disabled children's progress managing their conditions – and their overall development – regressed.
- **More than 80% of parent carers** of disabled children had some form of anxiety despite the easing of restrictions.

For more information on our pandemic research, go to disabledchildrenspartnership.org.uk/leftinlockdown/



Public support for disabled children and families.

In December 2021, the DCP commissioned Opinium to poll the public about their views on disabled children's services.

The results clearly show the public think disabled children and families deserve better support and that they currently are not getting it.

From a poll of 2,000 adults in the UK:

- **Only 18%** thought that disabled children and families got the right support from councils and the NHS.

Pre-pandemic funding gaps in disabled children's services.

COVID-19 has had a devastating impact on disabled children and their families. But the system that is supposed to support them was already in crisis before the pandemic hit.

- Economic analysis by Development Economics shows that before the pandemic there was a **£2.1 billion funding gap in disabled children's health and care**. This includes a £534 million gap in social care, and a £1.55 billion gap in NHS spending.
- Addressing the gap would **support disabled children and families to get services and support** that are not currently being delivered consistently across local areas, such as respite care, therapies, rehabilitation support, provision of medicines and in-home support.
- Investment in disabled children's health and care would create the potential for **net positive gains for public finances** in the medium and longer term, as more parent carers enter employment and medical procedures are prevented.

Pre-pandemic surveys of thousands of pandemic parent carers reveal:

- **Only 4% of parent carers** felt they got the right support to safely care for their disabled children.
- A third of parent carers said their disabled child has been in **unnecessary extra pain** because the right equipment, doctor or health service hasn't been available.

For more information on our funding gap research and surveys, go to [Bit.ly/DCPGiveItBack](https://bit.ly/DCPGiveItBack)

- **73%** said that the delays disabled children and families have experienced to health and care services in the pandemic were unacceptable.

- **64%** thought local councils and health services had a responsibility to provide respite and breaks from caring to families (yet our above statistics show these services are not meeting these legal responsibilities).



5 steps for local government and the NHS

In light of the significant detrimental impacts disabled children and their families have experienced throughout the pandemic, and the large amount of unmet need that existed before COVID-19, local government and health services must take dedicated action to help families recover and address years of inequality.

1

Prioritise the meeting the needs of disabled children and their families within covid recovery plans and programmes

2

Tackle the backlog in EHCP, therapies and other assessments and ensure that children's needs are re-assessed in light of missed support during the pandemic

3

Ensure the right support is in place for all children and families, including education, health (including mental health), therapies and equipment

4

Take a whole family approach to assessments and support, including siblings. This should include the provision of respite/short breaks and opportunities for families to take part in activities to overcome the isolation felt by so many families

5

Invest in health and care services through the new local authority grants from central government.

If you have any questions about the campaign or this briefing, contact the team at:

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