

Rt Hon Nadhim Zahawi MP, Rt Hon Sajid Javid MP
20 Great Smith Street
Westminster
London
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26 November 2021

Dear Secretaries of State,

Urgent clarification of how Spending Review funding will meet the health and social care needs of disabled children and families

We the undersigned are writing to you as a broad group of charities that work directly with disabled children, young people, parent carers and siblings of disabled children. We seek urgent clarification about how funding streams announced at the Spending Review will tackle unmet need in disabled children's health and care services, such as the ongoing delay to short breaks, and how the money will help disabled children and families recover from the stark mental and physical health impacts of the pandemic.

The pandemic, and its associated restrictions, have had a devastating impact on disabled children and their families. Ongoing Disabled Children's Partnership (DCP) surveys into the impact of the pandemic with parent carers, disabled young people and siblings have revealed that families have consistently been unable to access pre-pandemic levels of therapies, respite care, health services and equipment, amongst other services.¹ Over 80% of families saw both formal and informal support – like short breaks – reduce. As support has been taken away, parents have had to become full-time specialist teachers and carers during the pandemic, often without the necessary support.

DCP freedom of information requests also reveal that local authorities and community health services have struggled to meet their legal targets in providing assessments for health and care services, creating an ongoing backlog – leaving many disabled children unable to access the support they need to manage their conditions.² The same freedom of information requests reveal that 40% of local authorities cut respite care for families with disabled children during the pandemic. These findings therefore confirm that as parent carers needed respite more than ever local authorities have instead cut these essential services.

As a result of these ongoing delays, the mental and physical health of disabled children and families have been heavily impacted. Nearly three quarters of disabled children have seen progress managing their conditions – and their overall development – regress. Symptoms of depression and anxiety in parent carers have been consistently higher than population averages, and disproportionate number of siblings of disabled children are socially isolated. With COVID rates remaining high, many families who were shielding feel forced to continue to isolate – bringing with it the continued impacts of this seclusion.

However, we know that even before COVID provision for disabled children's services was not fit for purpose. *The gap widens* – a recent piece of economic analysis by the disability equality charity Scope and the DCP – revealed that the funding gap in disabled children's

¹ <https://disabledchildrenspartnership.org.uk/leftinlockdown/>

² <https://disabledchildrenspartnership.org.uk/left-behind/>

social care services has continued to increase to £573 million from the latest data available.³ Prior to COVID, a DCP survey of over 3,000 parents found that only 4% had sufficient support to care for their disabled child safely. We need to create a better system of support. This is why we support the ongoing DCP call for a Disabled Children's Innovation Fund.

At the Spending Review, it was encouraging to see signs that the government is recognising the need to invest in support for disabled children and their families. With so many children with SEND struggling to get the right school placement, the additional capital funding for specialist education places is welcome. We are also pleased to see additional funding for local authorities; education recovery; reducing NHS backlogs and for Family Hubs.

However, there will be many calls on these new resources and, without direction from government to service providers, it is far from clear how they will address the gaps in provision for vital health and care services for disabled children, such as respite care; or provide the specific support disabled children and families need to recover from the disproportionate impact of the pandemic they have experienced.

We are, therefore, calling on your departments to use your spending review settlements to fund specific health and care support for disabled children and their families, in particular to provide more short breaks and respite care and to create a Disabled Children's Innovation Fund, as recommended by the DCP, to identify and provide effective early care to children and young people who are at risk of poor outcomes to prevent problems occurring or getting worse.⁴

We are also calling on the government to provide a public statement clarifying how the NHS recovery, local authority grant, education recovery, and Family Hubs funding will be used to tackle the backlog in disabled children's health services, help every family get the social care they deserve, reduce pressure on families, and allow disabled children to recover lost progress in managing their conditions.

Disabled children and their families cannot be left in lockdown. The government must seize the chance to build them a better future in a post-COVID world. We hope to hear from you soon.

CC: Will Quince MP, Minister for Children and Families, Gillian Keegan MP, Minister for Care, and Chloe Smith MP, Minister for Disabled People

Yours sincerely,



Alison Garnham
Chief Executive, Child
Poverty Action Group



Amanda Batten
CEO, Contact and Chair
of the Disabled Children's
Partnership



Andy Fletcher
Chief Executive, Together
for Short Lives

³ <https://disabledchildrenspartnership.org.uk/the-gap-widens/>

⁴ <https://disabledchildrenspartnership.org.uk/we-need-a-disabled-childrens-innovation-fund-heres-why/>



Angela Voyajolu, CEO,
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Liz Ryburn
Support Team Manager,
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SCOPE
= Equality for
disabled people

James Taylor
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Jane Gates
Chief Executive,
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Joe Levenson
Executive Director of
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Jolanta Lasota,
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Julie Calveley,
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Kate Steele
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Charities working for children and families

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CEO, Children England



Keith Sinclair
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Include Me TOO



Patsy Hallmey, Founder,
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