



Disabled Children's Innovation Fund proposal July 2021

The problem: There are 1.1 million disabled children in the UK. Families are struggling with the impact of cuts to services and not getting the help they need for their children, with some only getting it when they reach crisis point. Families are facing financial difficulties and their emotional resilience is tested on a daily basis. Covid has made this worse for many. The economic disadvantages are huge:

- The annual cost of family breakdown has been estimated as £48 billion, or £1,820 per taxpayer.
- The economic impact of parents with disabled children having to leave work is placed at £685 million per annum.
- Intervening late with children and young people experiencing a range of emotional, social, and health difficulties costs government services £17 billion per year.
- Providing just 22 children at risk of entering the care system with short breaks can generate savings of up to £1,851,550.



What's needed:

- System-level change as well as service-level transformation
- Early intervention and emotional support for disabled children and their families
- A whole-family approach
- Joined-up working between health and social care services, education and others; to include shared budgets
- A stronger evidence base on which to develop sustainable, cost-saving, replicable service models



Government should invest £41 million in a Disabled Children's Innovation Fund

This could have two areas for investment:

1. Identification and evaluation of existing good or promising practice
2. Piloting new, innovative services with evaluation built in from the start

This would build on previous innovation funds and projects delivered by the What Works centres. It would allow Government to support the development of a stronger evidence base to guide future investment, cost savings and most importantly meet the needs of disabled children and their families.

Summary

In 2017, the DCP launched the Secret Life of Us campaign, aimed at recognising and transforming the realities of everyday life for families with disabled children (1). Since then, we have developed our 'three pillars' outlining what the Government should do to make sure health and social care services work better for disabled children and their families (2). As part of this, we are calling on Government to create a Disabled Children's Innovation Fund.

We're asking Government to commit £41 million in the Comprehensive Spending Review to set up a Disabled Children's Innovation Fund. This would evaluate existing good or promising practice and also invest in and evaluate new, innovative services and ways of working.

Covid has had a devastating impact on disabled children and their families. The Comprehensive Spending Review is an opportunity for Government to demonstrate its commitment to disabled children alongside the forthcoming National Disability Strategy, SEND Review and Independent Review of Children's Social Care.

The Disabled Children's Partnership

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.

Rationale for a Disabled Children's Innovation Fund

Economic analysis commissioned by DCP in 2017 found that there was a £1.5 billion funding gap across health and social care support for disabled children and their families (3). We are about to review this figure but we already know that Covid has had devastating impact on the lives of disabled children and their families. Government must give back the funding for core services that has been lost over the last decade.

Alongside filling the funding gap, there needs to be transformational change to the way that disabled children's health and social care services are delivered. There needs to be a greater emphasis on identifying needs earlier and rather than at crisis point. This should involve recognising and meeting the needs of the family as a whole, rather than the child in isolation.

That's why we're calling on the Government to establish a Disabled Children's Innovation Fund. An innovation fund model would provide financial backing to organisations delivering ground-breaking support and approaches in early intervention.

This would be based on the Early Intervention Foundation's definition of identifying and providing effective early support to children and young people who are at risk of poor outcomes to prevent problems occurring or getting worse (4). This should also consider key transition or escalation points in a child's life. The Fund would promote whole-family care, with a long-term view to 'scaling up' successful programmes into sustainable provision.

Our ask for an Innovation Fund is timely as Government is currently reviewing the SEND system and the National Disability Strategy will be published soon. Alongside this, the Independent Review of Children's Social Care case for change sets out an urgent need for reform.

Defining the problem

Prior to the pandemic

There are 1.1 million disabled children in the UK (5). Families with disabled children were already facing a dual crisis before the start of the pandemic. Firstly, they were seeing core services squeezed more than ever (6). Secondly, families struggled with the impact of cuts and stripped back support are not getting the help they need to do the best for their children, and are often only being offered support once they reach crisis point.

In terms of spend on early intervention, evidence shows a 48 per cent decrease in spending on early intervention services between 2010-11 and 2019-20 and states that local authorities are having to prioritise spending on late interventions ahead of preventative measures (7).

A survey of directors of children's services found that 89 per cent were finding it increasingly challenging to fulfil their statutory duties under Section 17. And where children are in touch with services, interventions are focused on child protection concerns, rather than on identifying and responding to a broad range of needs (8).

Too many families struggle on a tight budget which is having a negative impact on relationships and on their children's health and wellbeing. Parents with young disabled children have told us that fatigue caused by providing extra care, combined with financial strain and a lack of personal time, has led to significant pressures on their emotional resilience (9).

Research shows that:

- 80 per cent of parents and carers with disabled children have suffered ill health as a result of going without various services (10).
- 48 per cent of parents and carers have argued with their partners or children due to the stresses of managing debt (11).

- 41 per cent of parents with disabled children aged zero to five told us that they were not offered any emotional support during their child's diagnosis journey (12).

Furthermore, we know that disabled children can face multiple barriers which lead to poorer outcomes. For example, Government's review of children in need found that children who have needed a social worker have poorer educational outcomes at every stage of education than those who have not (13).

Allowing children and families to spiral into crisis also has enormous economic disadvantages:

- The annual cost of family breakdown has been estimated as £48 billion, or £1,820 per taxpayer (14).
- The economic impact of parents with disabled children having to leave work is placed at £685 million per annum (15).
- Intervening late with children and young people experiencing a range of emotional, social, and health difficulties costs government services £17 billion per year (16).
- Providing just 22 children at risk of entering the care system with short breaks can generate savings of up to £1,851,550 (17).

Economic analysis commissioned by Together for Short Lives (18) estimated the potential benefits of short breaks and found that for each parent carer who experiences a reduction in stress as a result of a short break:

- Expenditure on GP visits would reduce by £41 per year.
- Expenditure on mental health would reduce by £920 per year.
- Number of days taken off work would reduce by 2-3 days per year.

It also suggests that 'the total potential benefits to taxpayers from providing short breaks to all parents of children in palliative care could be in the region of c£5 million per year, based on the assumption that there are around 25,000 children in palliative care in the UK, with parents most commonly acting as their primary carer.'

The impact of Covid on families with disabled children

The Covid pandemic has exacerbated many existing issues for disabled children and their families and created additional new ones. The DCP (19) has surveyed over 4,000 parent carers over the last year survey on the impact of Covid and submitted Findings include:

- Nearly three quarters (71 per cent) of disabled children have seen progress managing their conditions – and their overall development – regress due to the pandemic.
- Over 70 per cent of disabled children are still unable to access pre-pandemic levels of therapies and health services.

- Social isolation in families with disabled children has only got worse even as the lockdown has eased and schools have reopened, with 9 in 10 disabled children and 6 in 10 parents socially isolated. Our previous surveys also showcased high levels of social isolation, showing how consistent this problem has been during the pandemic.

Freedom of Information requests to local authorities and health service providers found that:

- 7 in 10 NHS Trusts are failing to meet their targets for providing services for physiotherapy appointments and over half of local authorities have failed to meet their targets for providing vital Education, Health and Care plan assessments – leaving many disabled children unable to access vital services they need to manage their conditions.
- 40 per cent of local authorities have cut respite care for families – despite the prevalence of relationship breakdown and social isolation in parents.

In 2020, the LGA (20) warned that:

‘Referrals to children’s social care have fallen during the pandemic and lockdown and a surge in the number of children needing support is anticipated as we move out of the initial response phase. The real challenge for children’s services, in both financial and delivery terms, is therefore yet to come.’

We have also seen the damaging impact of Covid on the charity sector. Estimates have suggested that the crisis cost at least £4bn to the sector over 12 weeks, and that this figure will rise to £12bn across the year (21). However, we know from our DCP members that many organisations are showing great innovation and leadership by adapting services in response to the pandemic, e.g. by moving face-to-face support online.

How would a Disabled Children’s Innovation Fund work?

The innovation fund model

A Disabled Children’s Innovation Fund would encourage and support early intervention and whole-family care within disabled children’s health and social services. The Fund would build on previous Government innovation funds and evaluation projects delivered by the What Works centres. It would allow Government to support the development of a stronger evidence base to guide future investment, cost savings and most importantly meet the needs of disabled children and their families. Bringing together evaluation of existing practice and new ideas allows a wealth of evidence to be generated.

We suggest a minimum investment of £41 million which could involve two streams of work. These could potentially look like:

Stream 1: Evaluation of existing good or promising practice

£1 million spread across up to 10 projects over two years. This could include a rapid evidence review of existing evidence.

This is based investment of around 100k on each evaluation.

Stream 2: Investment in developing and evaluation new service models

£40 million spread across up to 15 projects/programmes over three years. This could be a mix of one service in one area or multiple services in one area to compare impact and economies of scale.

Funding should be open to competitive tender from all providers who can meet the aims and principles of the Fund.

Follow-up funding would then be required to disseminate the findings of the evaluations and support roll-out of services that are shown to improve the lives of disabled children and their families.

Aims

The aims of the Fund would be:

- To deliver inclusive, joined-up early intervention and emotional support services for disabled children and their families. Thereby reducing the pressures on crisis interventions, including Section 47 enquiries and numbers of children in care.
- To provide evidence of effective ways of supporting disabled children and their families at the earliest point of identified need. Especially around key transition or escalation points such as between the early years and school or in adolescence.
- To allow better identification of, and planning for, local need to ensure that a range of support is available for disabled children and their families.

To identify and promote innovative, sustainable models that ensure families with disabled children:

- Know about support available at an early stage that helps the whole family
- Can access that support enabling them to better navigate systems and deal with the myriad barriers to getting the right support for their child
- Are better able to manage their own emotional wellbeing and to create and maintain positive relationships

Principles

The Fund must support projects that:

- Contribute to system-level change as well as service-level transformation
- Prioritise the early identification of needs
- Benefit the whole family rather than child in isolation
- Facilitate joined-up working between health and social care services, including around assessment and planning of support, as well as education and other services (such as housing) where appropriate. This could include shared budgets
- Offer sustainable and replicable models of service
- Have evaluation embedded from the start
- Relieve financial pressure on health and social care systems
- Embed co-production between service providers and families

Ideally, funded projects will also:

- Generate cashable savings by reducing the numbers of specific interventions undertaken by government services (NHS appointments, social care interventions) – though it is accepted that many valuable services cannot be judged on these terms
- Work through partnerships between third sector and Local Authority/NHS providers to increase the chance of success and reduce risks of service duplication.

Further consideration should go to whether the Fund targets families which are not in receipt of services.

These principles are deliberately top line to enable local areas to apply them within their individual contexts and infrastructure.

Economic and social benefits

Supporting this fund would show the Government's commitment to investing in the future of disabled children and their families. But it would not require unrealistic investment. Like many innovation funds, it would support an initially restricted group of services across a range of locations. However, if successful projects were replicated at scale, this would lead to long-term economic gains and significant social impacts. The Fund should also invest in projects delivering quantifiable financial returns.

The Fund could support projects that help to reduce parental conflict/family dysfunction, for example. As research shows, this would alleviate pressure on children's mental health and adult health and social care services (22). With sufficient infrastructure in place for "upscaling" successful projects, the Fund would generate

long-term economic savings. The Fund should also invest in services with more direct, calculable money-saving benefits: for example, services that provide an alternative to specific social care and NHS interventions (23).

The Fund would also generate strong social return on investment, provided that the model included robust planning for upscaling successful projects. Research on early intervention shows that ‘preventing issues ... from arising in the first place, or working to reduce their impact on people’s lives, has the potential to lead to significant social and economic benefits, and – over the long term – to help build communities that are better-off, more resilient, and more supportive places for children and young people to grow up in’ (24). Outcomes that have positive knock-on social effects like these are worth investing in.

Evaluation and measuring impact

DCP engaged with the What Works Centre for Children’s Social Care and the Early Intervention Foundation prior to the pandemic to test our thinking around the Fund. Our conversations reinforced the need for evaluation to be embedded into the Fund from the start to finish. Government should work with the What Works centres to ensure this happens and builds on existing good practice. The impact measurement systems used by the Early Intervention Foundation to rate and rank early intervention services in their EIF Guidebook provide a helpful framework (25).

Positive long-term benefits, leading to impact and contributing to national measures, might include:

- Increase in numbers of parents/carers able to return to or stay in work.
- Increase in number of families staying together, reducing pressure on areas such as residential care, social housing and Universal Credit.
- Reduction in number of mental-health related NHS referrals amongst family members.
- Reduction in prevalence of challenging behaviour that risks admission to inpatient units.
- Disabled children recognised as Children in Need at earlier stage.
- Reductions in waiting times for accessing health and social care services.
- Greater proportion of EHC Plans to be offered to children aged 0-5 (26).
- Reductions in numbers of children at risk and looked after children.

Funded projects should be tested against the principles listed above, as well as for sustainability and replicability at scale. Consideration should be given to nationally set frameworks for evaluating the quantifiable savings made by individual projects.

Delivery

Funding would benefit individual families across England through local projects. There would be an expectation that projects could be upscaled and sustainable in the long term.

The Fund would be open to organisations from across third, public and private sectors able to fulfil the stated aims, principles and outcomes, and should prioritise collaboration with governmental providers

The Fund provides an opportunity to build on the creation of the Cabinet Office Disability Unit and could be administered by DfE, or jointly by DfE and DHSC.

Best practice and lessons to learn

Projects similar to those which the Fund would support have been helped by similar Government initiatives. But for every such project there are many more doing valuable work in the disability-specific health and social care space without governmental backing.

DfE's children's social care innovation fund, for example, has recently provided up to £1.6million to the Building My Future (BMF) programme in Ealing. This investment has been used to develop and test innovative approaches to short break provision for young people aged 11-25 with autism or learning difficulties who are also experiencing mental health or behavioural issues (27).

BMF extends a local best-practice model for short breaks services into mainstream as well as specialist schooling. It also involves developing a Risk of Escalation Tool to identify young people who would benefit from the programme, and establishing a multi-professional team to combat the issues they experience during the programme.

The BMF programme, which has been co-produced with families and children, is an example of the kind of valuable work that could be supported on a larger scale if an innovation fund with a disability-specific remit were established. As it is, too many children and families like those benefiting from BMF are being failed by the health and social care system.

With the Government's support we can help these children and families. But doing so requires creative thinking and financial investment. That's why we're calling on government to support this ground-breaking proposal, and to give more disabled children and their families access to the services they deserve.

Who has DCP engaged with?

The idea was developed by DCP during 2019 based on evidence around increased need, reduced resources, cost-saving and early intervention. DCP produced a proposal paper in February 2020 and has had positive discussions with:

- Department for Education SEND review team, SEND policy team, Health and Social Care Team, Social Care Directors and Chief Social worker
- Cabinet Office Disability Unit
- HM Treasury Local Government and Reform Team and the Education Spending Team
- No.10 Special Adviser Jean-Andre Prager
- Department for Health and Social Care - David Nuttall, Deputy Director, Dementia and Disabilities (shared, meeting postponed)
- What Works Centre for Children's Social Care
- Early Intervention Foundation
- Society of Local Authority Chief Executives (SOLACE)
- Local Government Association
- Children's Commissioner for England's office

We have also included the idea in:

- Oral evidence to the Public Accounts Committee
- Budget submissions

Next steps?

During the pandemic, the DCP has focused on gathering evidence on the impact of Covid on disabled children and their families. We know that things have got even worse and we are reigniting conversations about a Disabled Children's Innovation Fund. We would now like to see the Government commit to delivering it in the Comprehensive Spending Review this Autumn.

DCP would be very willing to support the development and delivery of a Fund, potentially by:

- Engaging with any other stakeholders identified by Government departments to help develop the fund proposal.
- Creating and running an advisory group bringing together parents of disabled children and experts from the sector.
- Supporting communications activities, e.g. sharing information with the sector, providing supportive quotes for media.

End notes

- 1 The Disabled Children's Partnership Secret Life of Us campaign information available via: <https://disabledchildrenspartnership.org.uk/secret-life-of-us/>
- 2 Disabled Children's Partnership (2019) Three pillars blog available via: <https://disabledchildrenspartnership.org.uk/three-pillars-to-deliver-better-support-and-care-for-disabled-children-and-their-families/>
- 3 Further information on the economic analysis is available on request.
- 4 More information on the Early Intervention Foundation's definition of early intervention can be accessed via: <https://www.eif.org.uk/why-it-matters/what-is-early-intervention>
- 5 Statistic taken from Newlife website: https://newlifecharity.co.uk/docs/latest_news/EVkuZykylyLYNRLrxu.shtml. Accessed 20th August 2019.
- 6 On the evidence for this, see Disabled Children's Partnership (2018), [Secret life of us campaign: the case for a disabled children's fund](#).
- 7 Williams and Franklin (2021) Children and young people's services: Spending 2010-11 to 2019-20. Available via: <https://www.ncb.org.uk/sites/default/files/uploads/files/Children%27s%20services%20spending%202010-11%20to%202019-20.pdf>
- 8 National Children's Bureau (2017) All Party Parliamentary Group for Children - No Good Options Report of the Inquiry into Children's Social Care in England. Available via: <https://www.ncb.org.uk/sites/default/files/uploads/No%20Good%20Options%20Report%20final.pdf>
- 9 Scope (forthcoming). Our lives, our journeys: early years disabled children.
- 10 Contact (2018). Counting the costs.
- 11 Ibid.
- 12 Scope (2018). [Now is the time](#). Available via: <https://www.scope.org.uk/scope/media/files/campaigns/now-is-the-time-campaign-report.pdf>
- 13 DfE (2019) Review of children in need policy paper. Available via: <https://www.gov.uk/government/publications/review-of-children-in-need/review-of-children-in-need#key-findings-from-our-data-and-analysis>
- 14 Relationships Foundation (2016). [Counting the cost of family failure: 2016 update](#).
- 15 Working Families (2018). [Parents of disabled children and paid work](#).
- 16 Early Intervention Foundation (2018). [Realising the potential of early intervention](#); Early Intervention Foundation (2016). [The cost of late intervention: EIF analysis 2016](#).
- 17 Together for Disabled Children (2011). [Impact of the short break programme on the prevention of disabled children entering the looked after system](#).
- 18 Pro Bono Economics (2020) The economic benefits of short breaks for families of children with life-limiting and life-threatening conditions. Available via: <https://www.probonoeconomics.com/Handlers/Download.ashx?IDMF=d7ed90b3-63c6-4ef8-bb0a-3b8d8e6407ee>
- 19 DCP (2021) Left behind. Available as part of series of 'Left In Lockdown' research reports via: <https://disabledchildrenspartnership.org.uk/leftinlockdown/>
- 20 Local Government Association (2020) Estimates Day, Department for Education: Closing the disadvantage gap and support for left behind children House of Commons 7 July 2020. Available via: <https://www.local.gov.uk/sites/default/files/documents/LGA%20Briefing%20-%20Estimates%20Day%20-%20Department%20for%20Education%20-%20disadvantaged%20and%20left%20behind%20children.pdf>
- 21 NCVO (2020) Article available via: <https://www.civilsociety.co.uk/news/charity-sector-will-inevitably-shrink-in-the-immediate-future-warns-ncvo.html>
- 22 Early Intervention Foundation (2018). [Why reducing parental conflict matters for local government](#).

23 An example of such a project in the wider social care space is [Pause.org.uk](https://www.pause.org.uk/). Pause works with women who have experienced, or are at risk of, repeated pregnancies that result in children needing to be removed from their care.

24 Early Intervention Foundation (2018). [Realising the potential of early intervention](#).

25 <https://guidebook.eif.org.uk/>

26 Although 2019 statistics show a 34% increase in the number of children in England aged 0-5 with EHC Plans, the overall proportion of EHC Plans in the 0-5 bracket remains proportionally very low.

Department for Education (2019). [Statements of SEN and EHC plans, England 2019](#).

27 See <https://innovationcsc.co.uk/projects/building-my-future-programme/>