SECRET LIFE OF US CAMPAIGN:
The case for a Disabled Children’s Fund
The current funding gap

IN NOVEMBER 2017 THE DISABLED CHILDREN’S PARTNERSHIP COMMISSIONED RESEARCH BY DEVELOPMENT ECONOMICS TO QUANTIFY WHAT THE CURRENT FUNDING GAP IS FOR DISABLED CHILDREN’S SERVICES. FOR EXAMPLE, SERVICES SUCH AS SPECIALIST EQUIPMENT, SPEECH THERAPY AND SHORT BREAKS.

They concluded that an estimated additional £433.9 million needs to be allocated to disabled children’s social care services by local authorities and £1.1 billion by the NHS.

The Disabled Children’s Partnership is therefore calling on central government to pledge £1.5 billion a year to a Disabled Children’s Fund to plug the current funding gap. This equates to just 0.2% of total government spending.

By making this pledge, the government would

• ensure disabled children and their families have the support in place when they need it, which will in turn prevent them from reaching breaking point.
• enable local authorities and the NHS to meet their statutory duties and improve the availability and quality of services
• support parents and young disabled children to work and succeed at school

Why this pledge is needed?

If your child was poorly, wouldn’t you expect to be able to get the right treatment and care from the NHS to help your child get better? If your child needed extra support so they could communicate better or play with their friends, wouldn’t you expect the help to be available?
Of course the answer is yes. That’s why we pay our taxes. It’s every child’s right. However, it may surprise you that for disabled children the right to help and support is often denied.

Most parents of disabled children have to go through long exhausting battles to gain basic support. Some even have to resort to legal challenges through the courts. They are the lucky ones; many receive no support at all.

This is because health and social care services for disabled children are underfunded. This isn’t anything new but it’s getting worse. A consequence of this is that local councils and their health partners are forced to restrict the help available, often only providing support when families are at breaking point. The crisis in disabled children’s services has been bubbling under the surface for some time, but is now becoming intolerable.

In 2017 the Disabled Children’s Partnership launched its Secret Life of Us campaign to:

- reveal the daily challenges facing families with disabled children
- call on government to address the growing crisis in health and social care services through a Disabled Children’s Fund.

**WHAT IS THE IMPACT OF THIS FUNDING GAP?**

**FAILURE TO PROVIDE FUNDING FOR HEALTH AND SOCIAL CARE SERVICES RISKS THE HEALTH OF THE CHILD AND INCREASES THE NEED FOR MORE FREQUENT MEDICAL INTERVENTIONS OR HOSPITAL ADMISSIONS.**

Families of children with complex needs are providing intense high level care day in and day out. When they don’t get support they fall into crisis and crisis intervention costs significantly more:

- It costs £149,240 for a year’s placement in a children’s residential home¹.
- Modelling shows that if money was properly invested in better equipment, the proportion of disabled children requiring additional treatment or surgery would be halved, saving £130 million per annum².

“**SUPPORT FOR DISABLED CHILDREN IS SIMPLY NOT FIT FOR PURPOSE. THE PROFESSIONALS WE ENCOUNTER REALLY TRY THEIR HARDEST TO MAKE LIFE EASIER FOR US. BUT THEY ARE UNDER RESOURCED. AND THEY MAKE NO BONES ABOUT TELLING US THAT. WHICH I FIND HARD BECAUSE, ULTIMATELY, THAT’S NOT MY FAULT**”

A PARENT CARER

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¹ Chief Medical Officer annual report 2012: children and young people’s health
² The economic benefits of better provision of equipment for disabled and terminally ill children, BHTA 2014
Based on local authority case studies, providing 22 children at risk of going into care with short breaks has a potential cost saving of £1,851,550.

The annual cost of family breakdown is £1,820 for every taxpayer (£48 billion total cost)

Closing the funding gap would improve outcomes for disabled children and their families by:

- supporting parents to return or stay in work
- reducing parental mental health problems and the associated need for medication or counselling
- helping to prevent family breakdown by reducing isolation and stress
- giving disabled children more opportunities to enjoy a normal life
- helping siblings adjust, improving attendance at school and education attainment

By supporting families sooner, a disabled children’s fund can also help reduce costs to the state/taxpayers by:

- reducing the child being an in-patient beyond what is necessary
- reducing re-admission to hospital
- preventing high cost residential placement
- avoiding missed hospital or GP appointments.

RESEARCH METHODOLOGY

GROSS EXPENDITURE BY LOCAL AUTHORITIES ON SOCIAL CARE SERVICES WAS OBTAINED BY A FREEDOM OF INFORMATION REQUEST IN NOVEMBER 2017. IT EQUATED TO £738.7 MILLION.

An extensive literature and data review was undertaken to establish health spending. This found that current healthcare spend on disabled children on prescribed drugs; inpatient care; GP contacts, accident and emergency visits and outpatient attendances equated to £1.9 billion in 2016.

Development Economics worked out the funding shortfall for disabled children’s services though a data review of other organisations’ research including the LGA and Children’s Commissioner, a roundtable and interviews with academics as well as a questionnaire of charities who support disabled children and their families.

These findings were the main basis on which the percentage increase/decrease in spend required to sufficiently meet the needs of disabled children was calculated for health and social care services in England.

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3 Julia’s House Children’s Hospice and Bournemouth University, 2017: The effect that having a child with a life limiting illness has on relationships.
WHAT THE EVIDENCE TELLS US:

Research carried out by the Disabled Children’s Partnership shows that:

• Most disabled children receive no regular support from outside their own close family. 4
• 1 in 10 parents believe health and social care services meet the needs of their disabled children.
• 9 in 10 parents say they had to fight to get the services they need. 5

At the same time the number of disabled children who receive social care is reducing 6. This is despite the number of disabled children in the UK increasing by 33% over the past 10 years to nearly 1 million 7 and their needs becoming ever more complex 8.

Furthermore, Government funding for early intervention services has been cut by almost £500 million since 2013. It is projected to drop by a further £183 million by 2020 9.

ABOUT THE DISABLED CHILDREN’S PARTNERSHIP

THE DISABLED CHILDREN’S PARTNERSHIP IS A GROWING COALITION OF MORE THAN 60 CHARITIES TO IMPROVED HEALTH AND SOCIAL CARE FOR DISABLED CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES.

Families have told us they face four big challenges.

• There are not enough services
• Many of those that exist are not good enough
• Families cannot access them easily
• Services do not always work together and communicate well with each other

That’s why we published a five step plan that Government must take to address the growing crisis in health and social care for disabled children.


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4 Disabled Children’s Partnership survey of 2,600 parents, 2017
5 Disabled Children’s Partnership survey of 2,600 parents, 2017
6 Characteristics of children in need: 2016 to 2017
7 DWP Family Resources Survey (2015/16)
8 Chief Medical Officer annual report 2012: children and young people’s health
9 LGA (2017) Bright futures: Getting the best for children, young people and families