SECRET LIFE OF US:
FIVE STEPS TO ADDRESS THE GROWING CRISIS IN HEALTH AND SOCIAL CARE FOR DISABLED CHILDREN

November 2017
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“We were receiving no support at all and I was relying on my sister and my close family and friends just to get through, day to day. It was a tough time and I felt really degraded as a mother to have to hold my hand up and say I’m really struggling to care for my child. I’m really frightened about what’s going to happen to my family.”

The Disabled Children’s Partnership is a growing coalition of more than 50 charities and organisations which have joined forces with families to launch the Secret Life of Us campaign. Our campaign aims to bring to life the challenges, and the joys, that disabled children and their families face on a daily basis, yet most people are simply unaware of. Many of their stories are hidden, the unnecessary daily challenges ignored by society. We want to shine a light on their secret lives, and raise awareness of the challenges faced by disabled children and their families.

Access to good quality health and social care services provides a lifeline to disabled children and their families. Often quite basic services such as short breaks, equipment and adaptations to the home enable families stay together, work and have a quality of life most families take for granted.

Sadly, families are telling us confidence in health and social care services is at an all-time low. That’s why we are setting out for government our five step plan to address this growing crisis in health and social care for disabled children and their families.

Our five step plan would not only improve outcomes for disabled children and their families – they have the potential to deliver important cost-savings for local and national government.

1 All quotes are from parent carers of disabled children
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<th><strong>Government must:</strong></th>
<th><strong>This would:</strong></th>
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| **Step 1: Make disabled children a priority** | • Facilitate more joined-up and integrated working across Government departments  
• Provide a platform for promoting disabled children as a priority on the Government’s agenda  
• Provide an accountability mechanism to ensure positive change is achieved |

Provide ministerial leadership to ensure a cross-departmental approach to improving outcomes for disabled children and their families.

- Facilitate more joined-up and integrated working across Government departments
- Provide a platform for promoting disabled children as a priority on the Government’s agenda
- Provide an accountability mechanism to ensure positive change is achieved

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<th><strong>Step 2: Review current funding</strong></th>
<th><strong>This would:</strong></th>
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Review funding of short breaks provision for disabled children and families.

- Demonstrate the extent to which each local authority and CCGs are meeting their statutory obligations to provide high quality short break services
- Create evidence on the best ways to sustainably fund short breaks services
- Identify where local authorities and health services are performing well so best practice can be shared and consistently applied

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<th><strong>Step 3: Clarify existing rights</strong></th>
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Clarify current rights and entitlements by co-producing with families guidance for local authorities and clinical commissioning groups (CCGs) on their existing statutory obligations.

- Assist local authorities and CCGs to understand their statutory obligations and wider responsibilities towards disabled children so services are delivered in a consistent and timely way across the country
- Increase the ability for the Government and families to hold responsible local agencies to account
- Provide parents, disabled young people and practitioners with a source of reliable and consistent information so they understand their rights to health and social care and how to challenge decisions

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<th><strong>Step 4: Create a Fund</strong></th>
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Improve health and social care services for disabled children by providing an early intervention and family resilience fund.

- Improve outcomes for disabled children and their families by increasing access to integrated early intervention services such as short breaks.
- Prevent high-cost crisis intervention and family breakdown through increasing the availability of early intervention services
- Support parents and young people to work or study

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<th><strong>Step 5: Change the system</strong></th>
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Commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children and their families.

- Clarify disabled children’s and their carers rights to health and social care services. This would enable local authorities and the NHS to provide consistent support to disabled children and their families
- Provide a clear and concise legal framework that would deliver integrated and timely support
- Help to drive integration between health and social care services, leading to greater efficiencies for local authorities and the NHS
THE CONTEXT:

“Therefore, Jemima has had no support from anyone other than me (her mum), her sister Jessica and our immediate family. It is very rare that I spend a night away from Jemima. Help is not something I knew I could ask for and not something that was ever offered.”

Disabled children and their families should be able to realise the same opportunities and aspirations as non-disabled children and families. To help them do this, they need access to the good quality health and social care services which they are entitled to, when they need them.

Yet, the current state of play does not support this:

1. **There are not enough health and social care services available to support disabled children and their families.** This means they wait too long for support or find that services are no longer available due to cuts in funding.
2. **Many existing health and social care services aren’t good enough and do not meet the needs of disabled children and their families.**
3. **Disabled children and their families find health and social care services difficult to access often due to the complexity of the legal framework.**

Most disabled children receive no regular support from outside their close family and friends and the numbers who receive social care services is reducing. This is despite the number of disabled children in the UK increasing by 33% over the past 10 years to nearly 1 million and their needs becoming ever more complex.

At the same time Government funding for early intervention services such as short breaks has been cut by almost £500 million since 2013. It is projected to drop by a further £183 million by 2020.
Failure to provide health and social care services risks the health of disabled children, impacts on the emotional and physical wellbeing of the whole family and increases the need for more frequent medical interventions or hospital admissions.

However, providing timely early intervention services to disabled children has the potential to significantly reduce current expenditure on crisis interventions and long-term costs. For example:

- Providing support so that disabled children can stay at home with their parents means that £149,240 could be saved for a year’s placement in a children’s residential home.
- 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 year.
- Based on local authority case studies, a potential cost savings of £1,851,550 by using short breaks for just 22 children at risk of going into care.

“Early intervention is key. Delays lead to a reduction in the opportunities to improve my son’s development, thus adding to his challenges and increasing the cost to the public purse.”

That’s why the Secret Life of Us campaign wants the Government to follow our 5 step plan to address this growing crisis.

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1 Disabled Children’s Partnership survey of 2,600 parents, 2017
2 Characteristics of children in need: 2016 to 2017
3 DWP Family Resources Survey (2015/16)
4 Understanding the needs of disabled children with complex needs or life-limiting conditions
5 LGA (2017) Bright futures: Getting the best for children, young people and families
6 Chief Medical Officer annual report 2012: children and young people’s health
7 The economic benefits of better provision of equipment for disabled and terminally ill children, BHTA 2014
8 Impact of the short break programme on the prevention of disabled children entering the ‘looked after’ system, 2011 [PDF]
OUR 5 STEP PLAN WILL HELP ADDRESS THE CHALLENGES FACING DISABLED CHILDREN AND THEIR FAMILIES

“I have constantly had to fight to get my disabled children the support they deserve and I am still fighting. I feel let down; I have been dismissed on numerous occasions and made to feel worthless as a parent carer.”

1. There are not enough health and social care services available to support disabled children and their families. They wait too long for support or find that services are no longer available due to cuts in funding.

- It is estimated that there will be a £2 billion funding gap in children’s services by 2019/20. Yet for every £1 spent on preventative work for children in need, £4 is spent on child protection work.
- Disabled children waited more than half a year after referral to begin receiving support in a third of cases across a range of health and social care services.

“I was receiving short breaks of 3.5 hours a week until Jan ‘16, when I was told, without warning, that it had stopped with immediate effect. Since then my daughter has become a hermit and only leaves the house to go to school, she has NO quality of life.”

2. Many existing health and social care services aren’t good enough and do not meet the needs of disabled children and their families.

- Specialist equipment which protects the health of disabled children and those who care for them is underprovided by the bodies which have a statutory obligation to meet the needs of disabled children.
- Some families with disabled children have to take out loans or fundraise for necessary equipment or treatments.

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10 LGA (2017) Bright futures: Getting the best for children, young people and families
11 Losing in the long run (Action for Children, NCB and Children’s Society)
12 Contact: Waiting times for services (2015)
13 Failing Disabled Children across the UK, BHTA 2016
14 Counting the Costs (Contact, 2012 & 2014)
“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.”

3. Disabled children and their families find health and social care services difficult to access often due to the complexity of the legal framework.

- Existing law related to disabled children and their families stems from over 10 different Acts of Parliament, regulations and guidance which have developed over the past 50 years
- The cost of a range of preventable health and social outcomes faced by children and young people over a 20-year period is estimated to be as high as £4 trillion\textsuperscript{15}

“In my area there is no access to social services. The local authority does not have any clear guidelines on how parents can access these services on their website. There are long waiting lists for most services especially CAMHS and Occupational Therapy. There is a lack of play areas that are suitable for disabled children.”

These challenges illustrate there is an unacceptable contrast between the quality of life and the opportunities available to disabled children and their families, compared to those without disabilities.

**But this does not need to be the case.**

We believe that disabled children, young people and their families should have access to the services they are entitled to, when they need them. This is not asking for disabled children to be singled out or treated differently, this is asking for fairness.

\textsuperscript{15} Backing the Future: why investing in children is good for us all (nef and Action for Children 2009)
The Secret Life of Us campaign is led by:

Action for Children  
Contact  
Council for Disabled Children  
Family Fund  
National Autistic Society  
Royal Mencap Society  
Scope  
Sense  
The Children’s Trust  
Together for Short Lives  
WellChild

Together with our parent group:

Alison Macleod  
Angela Harman  
Hayley Smallman  
Leanne Cooper  
Rick Bolton  
Rosalind Goodier  
Ruby Kearns  
Samantha Bossi  
Stephanie Nimmo

Supported by:

4in10 Child Poverty Campaign  
Ambitious About Autism  
Ataxia  
Bobath Centre  
British Healthcare Trades Association  
Carers Trust  
Carers UK  
Chailey Heritage Foundation  
Challengers  
Child Poverty Action Group  
Children England  
Children’s Hyperinsulinism Charity  
CLIC Sargent  
CPotential  
Credo Care  
Down’s Syndrome Association  
Family and Childcare Trust  
Fragile X Society  
Guide Dogs  
I CAN  
KIDS  
The Muscle Help Foundation

Mytonic Dystrophy Support Group  
NASS Schools  
National Deaf Children’s Society  
Rainbow Trust Children’s Charity  
Reaching Families  
Rett UK  
RNIB  
Royal College of Paediatrics and Child Health  
Seashell Trust  
Sebastian’s Action Trust  
Seeability  
Shine  
SNAP charity  
Special Needs Jungle  
Swings and Smiles  
The British Academy of Childhood Disability (BACD)  
The Communications Trust  
The Together Trust  
Thomley  
Whizz Kidz  
Working Families  
Young Minds

Join Us
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Email: info@disabledchildrenspartnership.org.uk  
Facebook: DCPcampaign  
Twitter: @DCPcampaign

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