



The social and economic value of short breaks

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This research has been commissioned by Action for Children and Every Disabled Child Matters, however the views expressed in this report do not necessarily reflect the views of these organisations.

Executive summary

Action for Children and the Every Disabled Child Matters Campaign commissioned this report which aims to explore the social and economic value created by effective local delivery of short breaks – the largest component of the Aiming High for Disabled Children (AHDC) programme – aimed at those with the most complex needs. Of the social and economic value created, particular focus is given to the value generated for the state. The report furthermore aims to identify the conditions – for example, the level of national and regional funding or the approach taken to delivery – necessary to maintain the value to the state (identified by the research) created by effective local delivery of short breaks.

AHDC: Better support for families, was launched in May 2007. It is a transformation programme for disabled children's services that is jointly delivered by the Department for Children, Schools and Families (DCSF) and the Department of Health (DH).

The programme is transformative in the sense that there is an explicit requirement to drive positive changes in the strategic and service management of local services. It looks to improve the competencies of service managers and commissioners, and to develop integrated capacities for services and partnerships. Short breaks is a key element of AHDC.

To ascertain the social and economic value created by effective local delivery of short breaks, telephone interviews were conducted with AHDC lead staff from five Pathfinder authorities. This enabled the creation of a 'theory of change' – a description of how the activities that make up the short breaks programme result in social and economic value.

Table E.1 presents an abridged impact map (summary table describing the theory of change), focusing on the key beneficiaries (stakeholders) and the social and economic outcomes created for those beneficiaries.

The long-term outcomes for the state (DCSF and local/national government and public service providers) are derived from the outcomes enjoyed by both the disabled children and their parents. The theory of change highlights that short breaks provide families with a mechanism by which to cope with the pressures of caring for a disabled child. This has an indirect impact on the family environment in terms of less stress for the parents and more time for other siblings, which can be translated into a higher sense of well-being for the family as a whole. This has implications to the state through:

- Financial savings resulting from a reduced chance of disabled children being placed in care.
- A reduction in health costs and increased tax take from reduced stress of the parents, families and carers.
- A cost saving from greater attention being able to be paid by parents to disabled children's siblings, thereby reducing possible problems centred on the siblings' schooling.

Table E.1: Impact map for Pathfinders' short breaks stakeholder groups.

Stakeholders	Long-term outcomes
Disabled children/young people	1. Lead more ordinary lives
Children with high support needs e.g., Groups A & B*	2. Journey towards independence in adulthood
	3. Improved emotional and physical health (health and well being)
Parents, families and carers of disabled child/young person	4. Working towards having a more ordinary life
	5. Experience reduced stress and reduced worry
	6. Have time for themselves and for other children
DCSF, local/national government and public service providers**	7. Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home
	8. Decreased cost to health service from reduction in parents', families' and carers' stress
	9. Decreased cost to schools of educating siblings with behavioural and emotional difficulties

* Definitions for groups A and B are included on page 8

** This grouping of stakeholders is referred to throughout the report as 'the state'.

In arriving at a financial estimate of the impact created for the state through the provision of the short breaks programme, it is vital to recognise the role of other activities/programmes in achieving the stated outcomes (Table E.1). It is also important to consider the durability of the impact.

Table E.2 presents the estimated annual cost savings arising from the current level of short breaks provision in England for the state.

Based on the lack of evidence of enduring benefits beyond the lifetime of the programme's activities, it is recommended that current service levels be maintained in order to maintain savings to the state.

- There are other compelling reasons for maintaining a higher level of service provision. This report has only quantified the economic benefits arising from effective provision of short breaks services, i.e., outcomes benefiting the state. Quantifying the social benefits would be a worthwhile exercise, however, as the investment by AHDC in transforming short breaks provision may well show a good return.
- Our analysis of Pathfinder data returns shows that access to services is still limited, with currently only an estimated 21% of disabled children (that could benefit from short breaks) receiving short breaks services.

Table E.2: Estimated financial savings for the state from the current level of short breaks provision*

Outcome	Value
7. Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home	£28,351,693
8. Decreased cost to health service from reduction in parents', families' and carers' stress	£3,698,123
<i>Cost savings stemming from reduction in GP visits</i>	<i>£2,446,069</i>
<i>Cost savings stemming from reduction in sickness absence</i>	<i>£1,252,054</i>
9. Decreased cost to schools of educating siblings with behavioural and emotional difficulties.	£4,487,757
Total	£36,537,573

* No account is taken of the attribution of other parts of the AHDC programme in calculating the savings for outcomes 8 and 9. The savings attributable solely to Short breaks may therefore represent a percentage of the above figures.

Should effective delivery of short breaks (plus associated activities, as listed in section 4) be made available to all disabled children in England for whom short breaks are appropriate, the potential savings to the state could be in the region of £174 million per annum (Table E.3).

Table E.3: Estimated financial savings for the state from full coverage of short breaks provision*

Outcome	Value
7. Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home	£135,008,061
8. Decreased cost to health service from reduction in parents', families' and carers' stress	£17,610,108
<i>Cost savings stemming from reduction in GP visits</i>	<i>£11,647,947</i>
<i>Cost savings stemming from reduction in sickness absence</i>	<i>£5,962,161</i>
9. Decreased cost to schools of educating siblings with behavioural and emotional difficulties.	£21,370,271
Total	£173,988,440

* No account is taken of the attribution of other parts of the AHDC programme in calculating the savings for outcomes 8 and 9. The savings attributable solely to short breaks may therefore represent a percentage of the above figures.

1. Introduction

Action for Children and the Every Disabled Child Matters Campaign commissioned **nef consulting** to examine the social and economic value created by the short breaks component of the AHDC programme, for disabled children with complex needs. The report places particular focus on the value created for one of the key beneficiary groups – the state – and further examines the conditions necessary to maintain any identified benefits.

This report begins by providing a short overview of the AHDC programme and the policy context in which it is embedded. This is followed by an overview of the short breaks component and emerging best practice among the 21 local authorities selected to serve as Pathfinders. These local authorities are at the forefront of delivering substantial improvements in local short breaks services delivery.

Following the programme and policy section, the ‘theory of change’ – the route by which the activities that constitute short breaks result in social and economic outcomes – is presented. The section summarises the theory of change in the form of an impact map.

Following the identification of social and economic outcomes for a range of beneficiaries (stakeholders), the impact for one particular beneficiary – the state – is examined. The section further examines the necessary external conditions to achieve the identified impact.

The report concludes with a discussion of the findings.

2. Policy and programme overview

Introduction

AHDC: Better support for families, was launched in May 2007. It is a transformation programme for disabled children's services that is jointly delivered by the DCSF and the DH.

The programme is transformative in the sense that there is an explicit requirement to drive positive changes in the strategic and service management of local services. It looks to improve the competencies of service managers and commissioners, and to develop integrated capacities for services and partnerships.

AHDC delivered substantial new funding for measures to improve services for disabled children and their families/carers. The government assists professionals, managers and children's services commissioners to deliver the programme. The programme has a number of features including:

- short breaks
- childcare
- parent participation
- transition support
- palliative care
- core offer and national indicator

The initial funding for AHDC came from the 2007 Comprehensive Spending Review (CSR). It delivered a total funding package of £340 million from the DCSF during 2008–2011. This is supported by an additional funding package of £340 million from the DH, which was allocated to Primary Care Trusts' budgets as part of the NHS settlement to improve services for disabled children and palliative care services.

The funding from the DCSF is allocated in the following ways:

- Short breaks – £370 million
- Childcare – £35 million
- Transition Support Programme – £19 million
- Parent Forums – £5 million.

AHDC constitutes the single biggest investment into the development and delivery of such services in the UK. This is achieved through ring-fencing funding for services and providing a platform for developing partnership structures and funding options for lacking services.

The intention was that the funding would act as a 'pump priming' mechanism to address shortfalls in local capacity and capabilities, and to provide an impetus to change cultures and to drive commissioning of services.

Furthermore, the process aimed to draw in parents as important advocates for the needs of their families, and to create partnerships that placed parents as real participants with powers to change culture and inform change.

The new short breaks approach replaced traditional 'respite care' services with a clear goal that the breaks would be a valued experience for the children and young people themselves.

Policy context

The AHDC programme helps to deliver existing government policy relating to disabled children. The government wants disabled children to be a priority, both nationally and locally: a commitment confirmed in the NHS operating framework, the Child Health Strategy: *Healthy lives, brighter futures* and in the Children's Plan. The broader policy context for the programme is presented below.

The Children's Plan

The DCSF Children's Plan establishes the government's overarching strategy for children's services. A key priority running through the Children's Plan is to make services accessible for disabled children and young people. It allocates £225 million in investment to improving play opportunities, with a focus on inclusive services for children and young people.

Aiming High for Young People

Aiming High for Young People sets out a 10-year framework for the government's aspirations for what young people's services, including those for disabled young people, should achieve.

Disability Discrimination Act

The Disability Discrimination Act 1995 (DDA) – as amended by the Special Educational Needs and Disability Act 2001 – protects disabled children and young people from discrimination in schools and children's services. Local authorities (LAs) and schools have to deliver improvements in access for disabled pupils. In 2005, the Disability Equality Duty was also introduced into the DDA, which asks them to prepare and publish a disability equality scheme.

Improving the life chances of disabled children

This sets out the aspiration that by 2025, disabled people in Britain should have opportunities to improve their lives and be included as equal members of society. The Office for Disability Issues coordinates cross-government work to deliver this vision. It suggests improving support for families with young disabled children to ensure that they benefit from childcare and early education; that their extra needs are met; and that services are centred on disabled children and their families.

Early Support

Early Support is the government's vision to co-ordinate services for families with young disabled children. All LAs should deliver on the Early Support principles; in turn the Aiming High programme is meant to build on its local delivery.

Choice for parents, the best start for children: A 10-year strategy for childcare

This sets out the government's long-term vision for every child to get the best start in life, and to give parents more options to balance work and family life. It addresses families with disabled children.

Removing Barriers to Achievement: The government's strategy for special educational needs (SEN)

This focuses on enabling children with SEN to realise their potential. It is a coordinated programme of actions and review to support early years' settings, schools, and LAs to improving provision for children with SEN.

Safeguarding disabled children: Practice guidance

This is aimed at local safeguarding children board (LSCB) partners and professionals working with children and young people and their families.

Short breaks and Pathfinders

AHDC identified short breaks as the highest priority service for families with disabled children, and of the £430 million allocated to new investment in disabled children's services during 2008–2011, £370 million is devoted to short breaks.

In December 2007, 21 LAs were selected via a competitive process to serve as 'Pathfinders' to spearhead the effort to improve short breaks service delivery. These pathfinders became operational in April 2008. The Pathfinder LAs were judged to have the capacity to:

- deliver immediate improvements to services;
- develop best practice in commissioning and provision; and
- share this learning and best practice with other LAs.

These LAs received an additional year of funding for short breaks.

Pathfinder authorities are supported in their efforts to share best practice by Together for Disabled Children (TDC), a partnership between Serco and the charity Contact a Family. TDC also provides support to all other LAs as their short breaks funding comes on stream in April 2009.

LAs have been issued detailed guidance on effective short breaks service implementation, *Aiming High for Disabled Children: Short breaks Implementation Guidance*, which sets out the standards they are expected to achieve by 2011. It sets out a Full Service Offer for short breaks services, which specifies that revamped services are to focus on certain types of disabled children. This is because 'evidence shows that current short break provision is particularly inadequate for the children and young people with ASD and/or behaviour that challenges, children who have complex health needs, technology dependent children requiring specialist care, and children who have severe physical impairments who require moving and handling.'¹

¹ DCSF/DH (2008) *Aiming High for Disabled Children: Short breaks Implementation Guidance*. p 10. Available at: <http://www.togetherfdc.org/SupportDocuments/AHDC%20-%20Short%20Breaks%20Implementation%20Guidance.pdf>

AHDC's stated focus was on improving short break services for children and young people with complex needs. This is because LAs have traditionally lacked the skills and resources to support them. This study aims to ascertain the social and economic impact of delivering more effective short breaks services to children with complex and/or high levels of needs. We follow the definition provided in the Full Service Offer:²

- a) *children and young people with ASD.* These are likely to have other impairments, such as severe learning disabilities** or have behaviour, which is challenging. Not all children on the Autistic Spectrum will require specialist additional short break services*
- b) *children and young people with complex health needs which includes those with disability and life limiting conditions who have reached the palliative care stage of their life cycle as well as other children and young people with complex health needs as well as other impairments – physical, cognitive or sensory impairments.****
- c) *children and young people aged 11+ with moving and handling needs that will require equipment and adaptations. These children are likely to have physical impairments, and many of them will also have cognitive impairments and / or sensory impairments;*
- d) *children and young people where challenging behaviour is associated with other impairments (e.g. severe learning disability). Children in this group will display behaviour which challenges services or behaviour which causes injury to themselves or others;*
- e) *young people 14+. The young people who fall into this group are young people who are severely disabled and require services that are appropriate to their age.*

* An autism spectrum disorder (ASD) is a lifelong developmental disability characterised by difficulties in three areas: social communication, social interaction and social imagination, sometimes known as the triad of impairments. Children with ASD and accompanying severe learning disabilities have often missed out on short breaks.

** People who have severe learning disabilities are those who need significant help with daily living.

*** These children require support, often including clinical and / or invasive procedures in order to maintain their optimum health on either a regular basis or in an emergency. Some of these children may be dependent on technology e.g. ventilation; tube feeding, dialysis.

It should, however, be noted that definitions of complex needs vary widely in practice, and data collection efforts continue to be seriously hampered by the different definitions in use.³ Our research corroborates this: our interviews with Pathfinder authorities resulted in divergent definitions of complex needs.

² Ibid, p16.

³ Mooney A, Owen C and Statham J (2008) *Disabled Children: Numbers, Characteristics and Local Service Provision* (London: Thomas Coram Research Unit, Institute of Education, University of London).

Best practice amongst Pathfinders

At present there is little information available on the overall progress made by Pathfinder authorities. At present, the only public information available is a 2009 paper⁴ on AHDC by the DCSF and the case study material available on the TDC website, which is undated and largely prospective in nature.⁵

We explored notions of best practice in the interviews conducted with Pathfinder authorities. Definitions of best practice included:

- Understanding what complex needs mean – understanding of the child, parent, family circumstances as well as support networks available to them.
- An assessment of the child's needs is conducted with both parents and child to design a range of services that meet changing needs – a 'continuum of care' that is holistic and long-lasting.
- Early intervention leading to early prevention of negative outcomes e.g., increased stress, placement of child away from their home, etc.
- Capacity-building local mainstream providers to make services more inclusive and accessible to disabled children e.g., youth clubs, brownies, scouts, sports clubs, drama clubs, etc.
- Parent support groups, forums and networks.

It is to be hoped that the evaluation of the Pathfinder programme commissioned by the DCSF from Lancaster University will shed more light on the progress made by the Pathfinder authorities to date. This report was not available at the time of writing.

It is difficult to avoid the conclusion that as long as different service providers continue to use different definitions of complex needs, effective targeting of short breaks services to previously excluded children will be endangered.

⁴ DCSF/DH (2009) *Aiming High for Disabled Children: Best practice to common practice* Available at: <http://www.togetherfdc.org/SupportDocuments/AHDC%20-%20Short%20Breaks%20Implementation%20Guidance.pdf>

⁵ That is, it outlines planned changes rather than evaluating progress against AHDC targets. Efforts to obtain more recent monitoring and/or evaluation material from TDC were unsuccessful.

3. Theory of change

Introduction and methodology

In order to ascertain the social and economic value created by effective local delivery of short breaks (with a particular focus on those with the most complex needs) an understanding of how change is created is required. To capture this information, we invited 5 of the 21 Pathfinders, who have been selected to pilot short breaks services, to describe their story using a storyboard exercise⁶ via telephone interviews. The aim of these interviews was to map out the theory behind how short breaks creates change.

Telling the story involves identifying the needs that short breaks is aiming to address, both in terms of the wider context for service delivery and more specifically for the disabled children and their families. These needs are addressed by the particular activities and actions undertaken as part of short breaks services, which in turn result in some observable and some concrete outputs. Ultimately, the most important part of the short breaks story is represented by the outcomes and what they mean for the beneficiaries.

The scope of this study is to concentrate on the social and economic value (change) created primarily to one stakeholder, the state. To accurately perform this analysis we have mapped out the other stakeholder groups who would potentially be affected by, or have the power to, affect the programme.

Impact map

Table 3.1 illustrates the impact map for short breaks. It summarises the theory of change for the eight stakeholder groups identified through the interviews. These groups included:

- The disabled children themselves.
- The parents/families/carers of disabled children.
- The staff who delivered short breaks services.
- Local mainstream youth service providers (the local community).
- The state (DCSF as well as local/national government and public service providers).

The description of the theory of change for short breaks asserts that in some way each group benefits either directly or indirectly from the programme of care being delivered. These benefits are represented by the 11 possible identified outcomes, of which 3 relate to the state.

⁶ <http://www.proveit.org.uk/storyboard.html>

Table 3.1: Impact map for Pathfinder’s short breaks stakeholder groups.

Stakeholders	Inputs	Outputs/activities	Initial outcomes	Long-term outcomes
<p>Disabled children/young people</p> <p>Children with high support needs e.g., groups (A & B)*</p>	<p>Time:</p> <p>Contribution to design of short breaks service to meet needs (of child)</p>	<p>Customised short breaks service that comprise elements of the following:</p> <ul style="list-style-type: none"> ▪ Overnight breaks ▪ Family-based / Individual day care / Sessional provision ▪ Group-based services - Specialist provision ▪ Group-based services - Non-specialist provision 	<ul style="list-style-type: none"> • Improved health through physical activities • Improved well-being through social contact and by enjoying activities they have chosen to do • Improved ability to form and maintain relationships • Increased interaction with peers through participation in mainstream leisure activities • Learning and developing a range of skills and abilities through variety of activities • Strengthened family relationships through an increased sense of well-being (from short breaks and having breaks from family) 	<ol style="list-style-type: none"> 1. Lead more ordinary lives 2. Journey towards independence in adulthood 3. Improved emotional and physical health (health and well-being)

Stakeholders	Inputs	Outputs/activities	Initial outcomes	Long-term outcomes
Parents, families and carers of disabled child/young person	<p>Time:</p> <p>Contribution to design of short breaks service to meet needs (of parent and child).</p> <p>Additional activities include : parent fun days, knowledge sharing meetings (new contacts)</p>	<p>Customised short breaks service that comprise elements of the following:</p> <ul style="list-style-type: none"> ▪ Overnight breaks ▪ -based / Individual day care / Sessional provision ▪ Group-based services – Specialist provision ▪ Group-based services- Non- specialist provision • Carers’ breaks • Additional parental support and advice (new contacts) 	<ul style="list-style-type: none"> • Child is less dependent on the parent • Creation of a less chaotic and more sustainable family environment • Less anxiety about the child's welfare when using short breaks services • Coping better • More free time to do own things (training, rest , time with other children) 	<ul style="list-style-type: none"> 4. Working towards having a more ordinary life 5. Experience reduced stress and reduced worry 6. Have time for themselves and other children
All staff	Time	Delivery of short breaks services	<ul style="list-style-type: none"> • Job satisfaction 	<ul style="list-style-type: none"> 7. Improved motivation, sense of achievement and well-being.
Local mainstream youth service providers	<p>Time:</p> <p>Learning new skills and knowledge about how to cater for disabled children and be a more inclusive service</p>	Mainstream services are inclusive and available to disabled children	<ul style="list-style-type: none"> • More inclusive and effective services (capacity built) 	<ul style="list-style-type: none"> 8. Increasingly meeting the needs of the local population

Stakeholders	Inputs	Outputs/activities	Initial outcomes	Long-term outcomes
DCSF, local/national government and public service providers	Investment via AHDC and the Child Health Strategy programmes	<p>Provide guidance and funding for the delivery of short breaks services that comprise elements of the following:</p> <ol style="list-style-type: none"> 1. Overnight breaks 2. Family-based / Individual day care / Sessional provision 3. Group-based services – Specialist provision 4. Group-based services- Non-specialist provision 	<ul style="list-style-type: none"> • Disabled children are less likely to be placed in long-term residential care • Disabled children have higher levels of health and well-being • Parents have higher health and well-being • Parents/carers take less time off sick due to stress • Family members and siblings have higher levels of well-being • Local youth services are more effective at meeting the needs of local community 	<ol style="list-style-type: none"> 9. Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home 10. Decreased cost to health service from reduction in parents', families' and carers' stress 11. Decreased cost to schools of educating siblings with behavioural and emotional difficulties.

* Definitions for groups A and B are included on page 8.

To estimate the impact on the state, we have identified the outcomes that occur for those stakeholders closest to the intervention; i.e., the disabled children themselves and their parents/families/carers. There are possible benefits to the state derived from the benefits to other stakeholders e.g., staff and local youth service providers. These, however, are likely to be insignificant by comparison and are not considered in the analysis of the impact for the state (Section 4).

In any story of impact it is important to acknowledge the complex way that outcomes are created and in particular the role of different factors in achieving each one. This is because often an outcome, a long way removed from an intervention for one group of stakeholders, will depend heavily on one being achieved nearer for another group of stakeholders.

The importance of mapping out the theory of change for all benefits to all stakeholders is that it is then possible, by identifying the direct outcomes, to make a stronger case for the indirect outcomes happening, even when some of them are too difficult (or too far into the future) to collect information on.

The needs that short breaks is addressing

The first step in the storyboard exercise is to identify the needs that short breaks aims to address. These are needs expressed at the level of the stakeholders. The interviews identified the following needs:

- Disabled children need to get the support that is right for them, that will help them develop and that is flexible to their changing needs at different stages in their life. This involves:
 - gaining new experiences that are fun and positive;
 - activities that they want to do;
 - 'ordinary' activities that mix with their peers, both abled and disabled;
 - activities that are locally accessible; and
 - reliable, stable activities that they can look forward to.
- Parents need support, knowledge and information to help them cope with the pressures of caring for a disabled child. These services need to reflect the changing circumstances of the family at different stages of the child's life.
- Society needs to accept that caring for a disabled child is everybody's responsibility by making mainstream services more inclusive and accessible.

How it works (activities and outputs)

The next step involved identifying the specific activities that characterise short breaks in terms of where and how its services are delivered.

Where short breaks services are delivered

- Short breaks services should be commissioned and delivered through the LAs and Primary Care Trusts (PCTs) and should be included in the Children and Young People's Plans.

How Short breaks services are delivered

- Short breaks services comprise a range of services that meet the disabled child's and the family's needs. They broadly fall into the following categories:
 - Overnight breaks
 - Family-based/individual day care/sessional provision
 - Group-based services – specialist provision
 - Group-based services – non-specialist provision
- Every child and family is different, so the level of short breaks services they receive reflects this diversity.

Outcomes for beneficiaries

The final step in describing the theory of change involved looking at the outcomes for disabled children, parents/families/carers and the state (the three principle stakeholders).

Disabled children

For disabled children, there is a range of initial outcomes which was summarised in the storyboard exercise by the Pathfinders as follows:

- Improved health through physical activities.
- Improved well-being through social contact and by enjoying activities they have chosen to do.
- Improved ability to form and maintain relationships.
- Increased interaction with peers through participation in mainstream leisure activities.
- Learning and developing a range of skills and abilities through variety of activities.
- Strengthened family relationships through an increased sense of well-being.

Knowing that these things are being achieved is not evidence that short breaks is creating meaningful change, but these achievements are important because if, in an evaluation, it is observed that they are happening, this provides a strong indication that the harder-to-measure and longer-term outcomes in the next column of the impact map are likely to occur.

Meanwhile, the final column of Table 3.1 presents the three key outcomes for this beneficiary group, which represent the important changes that the short breaks services create:

1. *Lead more ordinary lives.*
2. *Journey towards independence in adulthood.*
3. *Improved emotional and physical health (health and well-being).*

These outcomes potentially have significant implications for the state and will be discussed in greater detail in Section 4.

Parents/families/carers

For parents/families/carers, there is a range of initial outcomes which was summarised in the storyboard exercise by the Pathfinders as follows:

- The child is less dependent on the parent.
- Creation of a less chaotic and more sustainable family environment.
- Less anxiety about the child's welfare when using short breaks services.
- Being able to cope better.
- More free time to do own things (time with other children, training, rest).

This stakeholder group forms one of the most important beneficiaries of short breaks services; the outcomes for them are listed below:

4. *Working towards having a more ordinary life.*
5. *Experience reduced stress and reduced worry.*
6. *Have time for themselves and other children.*

Working towards having a more ordinary life (Outcome 4) contributes to the continued commitment and engagement of the parents with these services, and by extension is vital to the overall success of local short breaks services. When parents are involved in the design of the services that will meet their child's need, they feel reassured that the correct services are being delivered (Outcome 5). Likewise, having time for themselves and other children (Outcome 6) is itself an important change that contributes to a sustainable family life.

The state

For the state, there is a range of initial outcomes which was summarised in the storyboard exercise by the Pathfinders as follows:

- Disabled children are less likely to be placed in long-term residential care.
- Disabled children have higher levels of health and well-being.
- Parents have higher health and well-being.
- Parents/carers take less time off sick due to stress.
- Family members and siblings have higher levels of well-being.
- Local youth services are more effective at meeting the needs of local community.

The longer-term outcomes that are related to these initial outcomes are listed below:

7. *Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home.*
8. *Decreased cost to health service from reduction in parents', families' and carers' stress.*
9. *Decreased cost to schools of educating siblings with behavioural and emotional difficulties.*

Outcomes 9, 10 and 11 have the potential to occur through effective delivery of short breaks services, as identified by interviews with the Pathfinders. The story of change highlights that short breaks provides families with a mechanism by which to lead ordinary lives. This has an indirect impact on the family environment in terms of less stress for the parents and more time for other siblings, which can be translated into a higher sense of well-being for the family as a whole. This has implications to the state and will form the basis of our socio-economic value estimations.

Case studies

The impact map illustrated by Table 3.1 is a representation of the short breaks programme, based on the telephone interviews conducted by the research team. As such, it can therefore only provide a certain level of case-specific detail. To place the discussion of outcomes and impacts in a human context, two case studies are presented based on the interviews with the Pathfinder authorities.

Case Study 1

Laura* is a pre-school child who has cerebral palsy and cognitive impairment. As this is a disability from birth she will experience delays in every aspect of her development. The Pathfinder authority performed a needs assessment in co-operation with her parents, and a short breaks programme was created to meet Laura's needs and those of her parents.

Because of the complexity of Laura's needs, an Early Support Key Worker was introduced. This person provided a key contact for the family to help co-ordinate and manage the various health professionals that would be involved in Laura's development and ensure that the family received short breaks services. A home visiting service that included an overnight sitting break was arranged to give Laura's parents time for each other and for her siblings. The parents were also invited to join a mixed group of parents and professionals to share knowledge and information.

A number of changes occurred for Laura and her family as a result of short breaks services. The family had one point of contact in the Key Worker and expressed its relief at having someone who understood its situation. The home visits and the mixed group provided the family with a sense of control, and it felt supported. This reduced feelings of isolation and eased the struggle to access services and information. The family was able to cope better from an early stage and there was a positive impact on Laura's siblings in terms of maintaining a stable family life.

* not the child's real name

Case Study 2

Sam* is a 15-year-old child who has a form of Autistic Spectrum Disorder and a genetic weight condition. There had recently been bereavement in the family and one of his parents had/has mental health issues. Sam has one sister who does not have a disability and who was experiencing a difficult relationship with one of her parents as well as coping with the bereavement. The Pathfinder authority performed an assessment of the family situation with the family, using a parent and child outcomes-focused approach.

Due to the complex nature of the situation, a diverse programme of short breaks services was implemented. This included attendance at a local youth theatre (a taxi service was used to transport Sam), a new bike so that Sam could ride short distances, attendance at a local gym working with a personal trainer 2–3 evenings per week, attendance at the local church, and singing lessons. Short breaks also supported the parent by providing membership at the local gym.

As a result of these short breaks services, a number of changes occurred for Sam, his parents and the family. Sam developed his talent and skills in drama, made friends in the local community and achieved a safe transition to college to study drama and music. His health improved and he became less susceptible to the risks associated with his genetic weight condition. The relationship between the parents and children improved because the parents were allowed time for themselves, were able to plan activities better and manage the relationship with their daughter. The parents' mental health improved and a sustainable family environment was created.

* not the child's real name

4. Impact

The theory of change highlights that short breaks provides families with a mechanism by which to cope with the pressures of caring for a disabled child. This has an indirect impact on the family environment in terms of less stress for the parents and more time for other siblings; this translates into a higher sense of well-being for the family as a whole.

How impact is calculated

When we use the term 'impact' in discussing the impact of the short breaks programme, it is distinct from the outcomes identified in the theory of change, in that the impact is the product of the outcomes.

Where the findings show that a particular outcome is happening (or likely to be happening) for beneficiaries, a range of factors contribute to that outcome, some of which will be related to short breaks, while other will be related to aspects of the disabled child's experience outside of short breaks such as other extra-curricular or participatory activities. The interviews with Pathfinder authorities indicate that disabled children and their families benefit from a large number of programmes. These include:

- Parent support groups.
- Parent information days.
- Groups comprising parents and professionals that meet regularly to network and share knowledge.
- Parent2Parent, a research group set up by one LA to get parent feedback on the basic short breaks offer, the quality of short breaks services and the method of feedback.
- Parents sitting on interview panels for service providers.
- Provider's Day, where parents meet service providers.
- Children's Disability Forum, which meets three times a year to discuss how to make disabled children 'everybody's responsibility'. The Forum is attended by police, PCTs, schools, voluntary organisations, other LA departments.
- Modular training programme for staff and service delivery providers on how to work together to meet the needs of the disabled child needs and make it everybody's business to do so.
- Training for mainstream providers of leisure, community and youth services in order to make their services more accessible to disabled children.
- Road shows at specialist schools.
- Specialist youth club nights that include disabled and non-disabled children.

- Youth club supported by parents – a forum for exchange of information and support.
- Personalised support for parents, e.g., gym memberships.

It is the efficient combination of these programme elements that results in the greater chance of the identified outcomes occurring. In recognising that short breaks is one element of a wider programme, we acknowledge that some of the credit for the value produced must be attributed to other elements of the programme (as well as to external factors that impact the child). This consideration of attribution allows for not over claiming.

Similarly, although some aspects of change may appear quite dramatic, in terms of the progress some of the disabled children/young people and their families may make as a result of receiving short breaks services, there is always the possibility that these changes would have occurred for some of them anyway, i.e., in the absence of short breaks.

The home environment, support networks and family circumstances will all contribute to the sense of health and well-being of those involved. This area of ‘what would have happened anyway’ is known as *deadweight*. In assessing our findings, this must also be acknowledged.

Our calculation involves three steps:

1. Estimating the number of disabled children that are likely to benefit from Short breaks and those with complex needs as a subset thereof.
2. Estimating outcome incidences for these two groups.
3. Sourcing a financial proxy or direct cost for each outcome and determining impact by accounting for attribution, deadweight, and benefit period.

The calculations are based on the outcomes identified in an impact map (Section 3) derived from interviews with only 5 of 21 Pathfinder authorities. The calculation of cost savings to the state is therefore limited to this small sample group of Pathfinder authorities.

Furthermore, there are limitations as a result of the lack of reliable estimates of the population of disabled children generally, and disabled children with complex needs specifically.⁷ This is due to problems with overlapping and sometimes contrasting definitions for disability.

As a result of these limitations, plus a complete absence of cost estimates for savings to the state for children with complex needs, ***our calculations are based on the cost savings for any disabled child. Inevitably, costs for children with complex needs will be higher than those with less complex needs (though it should be remembered an average cost contains both case types). The incidence of outcomes occurring, however, will be lower for complex needs.***⁸

⁷ This is discussed in more detail in Appendix 1.

⁸ Appendix 2 – Children with complex needs account for approximately 29% of disabled children.

We therefore use cost estimates, plus outcomes incidence frequency, for all disabled children (claiming Disability Living Allowance – DLA) in the following calculations as a proxy for cost savings arising from outcomes linked to children with complex needs.

The number of disabled children

A number of researchers, including the Office of National Statistics (ONS), have attempted to arrive at an estimate of the number of disabled children in the UK. The most widely circulated figure is 700,000⁹ or 7% of the child population; it is used by most LAs to make estimates of their local population of disabled children.

This definition, however, has come in for some criticism on methodological grounds.¹⁰

Mooney *et al.* discuss at length why estimates of disabled child populations vary so much, and conclude that ‘the difficulties authorities described centred predominately on issues to do with definitions and the way in which data are collected and managed’, in particular, that different organisations and government agencies apply different ‘definitions, criteria and thresholds’.¹¹ They found that fully 89% of LAs had problems providing data for their survey for such reasons.¹²

In 2008, Mooney *et al.* conducted a survey of 115 LAs to ascertain the prevalence of disability amongst children at a local level.¹³ They conclude, based on comparing their survey results with a range of published figures, that:

...it would be possible to put a lower and upper bound on the number of disabled children in each local authority based on the number of children with a SEN statement and the number of children in receipt of DLA. Since it was widely agreed by local authorities that children in either of these categories would be counted as having a disability, a lower bound could be taken as the larger of these two and an upper bound as the sum of the two. The most likely figure would be somewhere between the upper and lower bounds; its exact position depending on the degree of overlap between the two sources... This results in a lower bound of 288,000 and an upper bound of 513,000 disabled children in England, or on average between 3.0 and 5.4 percent of children under 18 years.¹⁴

⁹ Prime Ministers Strategy Unit (2005) *Improving the life chances of disabled children*. (London: HMSO).

¹⁰ Mooney A, Owen C and Statham J (2008) *Disabled Children: Numbers, characteristics and local service provision* (London: Thomas Coram Research Unit, Institute of Education) p 13.

¹¹ *Ibid*, pp 65/66.

¹² *Ibid*, p 65.

¹³ *Ibid*, p 17.

¹⁴ *Ibid*, pp 7/8.

As Mooney *et al.* have to date made the most comprehensive estimate of the numbers of disabled children, we base our calculation on their data.¹⁵ **We assume a disabled child population of 459,000 or roughly 4.1% of the total England child population¹⁶.**

The number of disabled children that could benefit from short breaks

The above figure of 459,000 includes both children that have SEN as well as those who claim DLA. Having an SEN does not necessarily indicate a need for short breaks services, whereas DLA claimants (those based on a care need) provide a better indicator that breaks from caring are required. In February 2009, a total of 309,750 children under 18 were entitled to DLA in England. **It is this figure of 309,750 that we use as representing the target group for short breaks – 2.8% of the total child population. This figure also represents 67% of our estimated England disabled child population of 459,000.**

Outcome incidences

All Pathfinder authorities are required to return a Local Area Implementation Plan (LAIMP) to TDC for monitoring purposes. The five Pathfinder authorities that participated in this study provided the research team with their most recent returns.

These returns also require LAs to show the proportion of short breaks services provided to children with complex needs.¹⁷

Estimates of outcome incidence have been derived by averaging the data from these LAIMP returns. In 2008/2009, the actual child population of these LAs was 90,379. Using our estimated prevalence rate of DLA disabled children – **2.8%**, the average child population in these LAs is approximately 2,530 children. The LAIMP returns show that in 2008/2009, short breaks services were provided to an average of 549 children. This suggests that **21% of disabled children in the catchment areas of these LAs (for which short breaks could be a benefit) received short breaks services.**

This estimate is lower than the incidence rates estimated by other researchers, which range from 25% to 33%,¹⁸ however, as it is based on actual and recent data provided by Pathfinder authorities, it is in all likelihood more reliable than estimates contained within older studies.

¹⁵ Mooney *et al.* (2008, p 37) found a fairly weak correlation between SEN and receipt of DLA ($r=.24$), so it is reasonable to assume that 76% of SEN children do not receive DLA. Thus we take the lower bound of the range (288,000) and add 76% of the overlap range ($513,000-288,000 = 225,000 \times .76 = 171,000$), resulting in an estimated disabled child population of 459,000 (i.e., $288,000 + 171,000$).

¹⁶ Population estimate for 2008 from Office for National Statistics for children resident in England below the age of 18.

¹⁷ These are referred to as groups A and B in the LAIMP returns. The incidence of short breaks for children with complex needs is examined in Appendix 2.

¹⁸ Carlin J, Stanley N and Manthorpe J (ND) *Meeting complex needs: a study of decisions, services and perceptions*. Unpublished manuscript provided by J. Carlin in private correspondence.

The impact calculation

We now describe the basis of our impact calculation, using the population and outcome incidence rates outlined earlier. The three long-term outcomes that constitute a benefit to the state identified in the theory of change are:

1. Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home.
2. Decreased cost to health service from reduction in parents', families' and carers' stress.
3. Decreased cost to schools of educating siblings with behavioural and emotional difficulties.

Decreased cost of long-term residential care

The impact map suggests that efficient delivery of short breaks services enables parents with disabled children to cope better with their situation, which may in turn prevent some long-term residential care placements. We consider this outcome in terms of the cost of a residential school placement.¹⁹

The latest available data, stemming from an analysis carried out in 2005, suggests that there are 'about 13,300 disabled children in long-term residential placements in education, social care and health settings in England'.²⁰ **Assuming our 67% rate of DLA to all disabled children ratio, this equals 8,911 disabled children (for which short breaks services could be beneficial).**

While it must be acknowledged that some of these placements may be unavoidable, it is possible that efficient delivery of short breaks services can contribute to reducing the proportion of disabled children in such placements. Estimating the savings is difficult. A recent cost-benefit analysis of short breaks services assumed that all children who did not have complex needs (47%) would not have been placed in care if sufficient short breaks services had been available.²¹ We feel this is too generous in the case of long-term residential placements, given that 35% of those in long-term residential care have behavioural, emotional and social difficulties (BESD).²² Such problems may make it more difficult to keep the child at home, as dealing with the actual disability and potentially violent behaviour is a difficult combination. **We therefore make the more conservative assumption that 30% of such placements could be prevented.**²³

¹⁹ While there are other types of placement available, e.g., foster care, residential school placements are assumed to be a better proxy for children with complex needs.

²⁰ Pinney A (2005) *Disabled children in residential placements*. Report commissioned by the Disabled Children's team in the Department for Education and Skills (London: DfES).

²¹ Capps J and Heady L (2008) *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families* (London: New Philanthropy Capital).

²² Pinney (2005) *op. cit.* p 3.

²³ 65% of the 47% not having complex needs.

We feel this conservative assumption is well-supported by studies of parents of disabled children. A study of 73 parents of severely learning-disabled children with challenging behaviour who were in 52-week residential schools showed that factors other than complex levels of disability are at play – in particular, inability to cope with challenging behaviour by both schools and the parents themselves:

*Respondents gave a range of reasons (many more than one) for their child leaving their previous school and going to a 52-week residential school. Forty per cent stated that 52 week/24 hour care was needed for reasons such as **consistency of management**, 33 per cent reported that they were **no longer able to cope with their child's behaviour at home**, 27 per cent referred to the **severity of their child's challenging behaviour**, and 26 per cent reported that their **child had been excluded from school** because of disruptive behaviour. The social and educational reasons underlying placement can be illustrated: 'no school to meet his needs...excluded from the two schools identified by the council'; 'we couldn't cope with him anymore...I had a breakdown and ended up in a mental ward'.²⁴*

This is further corroborated in a study that surveyed parents of young people and younger adults under 40 with complex needs who are living at home (n=67), where roughly half of the respondents were parents of a child under 18. They asked what sort of support the carers would need in order for their son/daughter to remain at home in five years' time. Only 40% cited short breaks/respite care.²⁵ From this study, **we therefore assume an attribution rate of 40% of preventable placements resulting from short breaks.**

We assume a cost of £2,428 per child per week for a residential placement, based on data from a recent report by the NHS on the cost of looking after children in children's homes.²⁶ The reliability of this figure is enhanced by the fact that it is broadly in line with data provided by a recent Audit Commission report on the cost of residential schools for children with special educational needs (SEN)²⁷ and with data used in a recent cost-benefit analysis of short breaks services.²⁸ We acknowledge that a residential placement for a disabled child with complex health needs may be more expensive than this average figure, but published data to support such an assumption is not presently available.

²⁴ McGill P, Tennyson A and Cooper C (2006) Parents whose children with learning disabilities and challenging behaviour attend 52 week residential schools. *Br J of Social Work* 36(4): 597–616.

²⁵ Carlin J, Stanley N and Manthorpe J (ND) Meeting complex needs: a study of decisions, services and perceptions. Unpublished manuscript provided by J. Carlin. p10.

²⁶ The NHS Information Centre, Social Care Statistics (2009) *Personal Social Services Expenditure and Unit Costs England, 2007/08*. The Health and Social Care Information Centre, Table 6.2.

²⁷ Audit Commission (2008) *Out of authority placements for special educational needs*. London: Audit Commission.

²⁸ Copps, J. and Heady, L. (2008) *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families*. London: New Philanthropy Capital.

Based on these assumptions, estimated savings to the state stemming from prevented residential (school) placements at current levels of service provision amounts to £640,710 per year. The calculation is presented in Table 4.1.

Table 4.1: Annual savings on cost of residential placements.

Calculation element	Value
Number of disabled children (that could benefit from short breaks services) in long-term residential placements	8,911
Percentage of placements that could be prevented	30%
Percentage of preventable placements attributable to short breaks services	40%
Number of placements that could be prevented in a given year	1,069
Cost per child per week for a residential placement	£2,428
Number of weeks	52
Total potential savings per year	£135,008,065
Outcome incidence rate (percentage of children actually receiving short breaks services)	21%
Potential savings to state at current level of provision	£28,351,693

The estimated current savings to the state from prevented residential placements attributable to short breaks services amount to £28,351,693 per year. However, increased service provision (i.e., an increase in the outcome incidence rate) will boost the savings to the state.

Decreased costs to health services

Our impact map suggests that efficient delivery of short breaks services reduces the level of stress experienced by parents/carers and their disabled children. A reduction in stress is likely to result in fewer GP visits and lower sickness absence from the workplace. Carers who experience a reduction in stress may also have better long-term health outcomes, but calculating the impact of this is beyond the scope of this report.

Cost savings stemming from reduction in GP visits

We assume that almost all people caring for a disabled child experience stress, and to higher levels than other people, and that the stress of caring adversely affects

their physical health.²⁹ We further assume that 20% of the general population suffer from stress,³⁰ and that therefore 20% of carers would have been stressed anyway. As the general population includes parents of disabled children, however, this results in double-counting. **We therefore assume that 75% of the stress experienced by carers of disabled children is attributable to their caring activities.**³¹

Stress among caregivers is linked with increased ill-health, both in terms of subjective self-reports and objective health measures. Pinquart and Sörensen conducted a meta-analysis of 176 studies to explore the link between caring and health problems, and found that:

*Poor health of caregivers may be due to (a) the effects of physical exertion that produces muscle strain, skeletal injury, aggravation of chronic illness such as arthritis, or other sources of physical discomfort and pain; (b) negative changes in health-related activities, such as diet and exercise; (c) physiological effects of psychological distress, such as depression, which increase susceptibility to infectious agents; and (d) changes in sympathetic arousal and cardiovascular reactivity that increase the risk for hypertension and cardiovascular disease (e.g., Shaw et al., 1997).*³²

Carers are more than twice as likely to be in poor health themselves in comparison to parents who do not have a disabled child, and we assume some of this ill-health to be stress-related.³³ A meta-analysis conducted in 2003 showed that carers had 23% higher levels of stress hormones than non-carers.³⁴ We therefore assume they are at least 25% more likely to visit their GP in any given year,³⁵ which translates into **one extra visit per year.**³⁶ In 2007/2008, the average **cost of a GP surgery consultation with prescription was £76.**³⁷

²⁹ Pinquart M and Sorensen S (2007) Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological Sciences* **62b(2)**: 126–137. See also http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822

³⁰ Cops J and Heady L (2008) *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families* (London: New Philanthropy Capital) p 15.

³¹ The 5% difference (80–75%) is accounted for by the 4.8% of the child population that is made up of disabled children.

³² Pinquart and Sorensen (2007) *op. cit.* p 126.

³³ Buckner L and Yeandle S (2006) *Managing more than most: A statistical analysis of families with sick or disabled children* (Leeds: University of Leeds) Commissioned by Carers UK, p 6.

³⁴ Vitaliano PP, Jianping Z and Scanlan JM (2003) Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin* **129(6)**: 946–972.

³⁵ Cops and Heady (2008) *op. cit.* p 15.

³⁶ Office for National Statistics (2006). *Use of services: Home visits fall to 4% of GP consultations.* <http://www.statistics.gov.uk/cci/nugget.asp?id=1335>

³⁷ Curtis L (2008) *Unit costs of health and social care 2008* (Canterbury: PSSRU at Kent) http://www.pssru.ac.uk/pdf/uc/uc2008/uc2008_s08.pdf Table 8.8b; including direct care staff costs and excluding qualification costs. Prescription cost is based on net ingredient cost.

A statistical analysis of the 2001 Census found that approximately 462,000 families in England and Wales have at least one child with a 'limiting long-term illness',³⁸ and that these households 'contain 305,000 carers, of whom 65% are women'.³⁹ As this number of families is fairly close to our own estimate of the disabled child population (459,000) we use the figure of 305,000 carers as a proxy for the number of people caring for a disabled child. As we only focus on those children that claim DLA, we reduce this figure by 33%.⁴⁰

Based on these assumptions, we estimate that current savings to the State stemming from prevented GP visits amount to £2,446,069 per year. The calculation is shown in Table 4.2.

Table 4.2: Annual savings stemming from reduced number of GP visits.

Calculation step	Value
Proportion of extra stress attributable to caring for a disabled child	75%
Number of people affected	204,350
Number of extra GP visits per year	1
Average cost of GP surgery consultation with prescription	£76
Total potential savings per year	£11,647,950
Outcome incidence rate (percentage of children actually receiving short breaks services)	21%
Potential savings to state at current level of provision	£2,446,069

Cost savings stemming from reduction in sickness absence

We saw earlier that there are 462,000 families with a disabled child. If we assume that each of those household contains 1.64 adults,⁴¹ there could be 757,680 adults potentially at work. However, 34% of such households have no one in paid work.⁴² If we assume that of the other 66% of households, at least one person is in work, approximately 500,000 people are working. Not all of them will work full-time, however, so assuming that 75% work full-time, this equates to 375,000 full-time

³⁸ Buckner L and Yeandle S (2006) *Managing more than most: A statistical analysis of families with sick or disabled children* (Leeds: University of Leeds) Commissioned by Carers UK, p 5.

³⁹ Ibid, p 5.

⁴⁰ $67\% \times 305,000 = 204,350$

⁴¹ Cops J and Heady L (2008) *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families* (London: New Philanthropy Capital) p 15.

⁴² Buckner and Yeandle (2006) *op. cit.* pp 5 and 2 respectively.

employees taking additional sick days. **Adjusting for our DLA to all disabled children ratio of 67%, this comes to 251,250 full-time employees.**

Using these assumptions about stress, we assume that working parents of disabled children are 25% more likely to take sick days than other parents. Given that the average person takes 8 sick days per year,⁴³ we assume that a parent of a disabled child who is in full-time work will take an **extra 2 sick days per year**. In 2008, the average cost to employers of a sick day was £83.25.⁴⁴

The final part of the calculation involves identifying what proportion of the cost to the employer results in a cost to the state. If we assume that the cost to the employer is a reduction in profit (turnover falls but costs remain static as a result of the sick day taken), and that corporation tax is 19%, then **the reduction in corporation tax intake for the state for every £83.25 (in lost profit) is £15.82.**

Based on these assumptions, we estimate that current savings to the state stemming from sick days prevented amounts to £1,252,054 per year. The calculation is presented in Table 4.3.

Table 4.3: Annual savings stemming from reduced sick days.

Calculation step	Value
Proportion of extra stress attributable to living in a household containing a disabled child	75%
Number of people affected	251,250
Number of extra sick days per year	2
Average cost of lost corporation tax per sick day	£15.82
Total savings per year	£5,962,163
Outcome incidence rate (percentage of children actually receiving short breaks services)	21%
Potential savings to state at current level of provision	£1,252,054

Taken together, the current savings to the state from prevented GP visits and sick days amounts to £3,698,123 per year. It should be noted that we have not considered issues of attribution, e.g., the extent to which other services provided to

⁴³ Chartered Institute of Personnel and Development (2008) Absence Management, Annual Survey Report 2008. Cited in Leaker D (2008) Sickness absence from work in the UK. *Economic & Labour Market Review*. 2(11).

⁴⁴ Ibid, p 22.

disabled children and their parents/carers play a role in preventing placement in long-term residential care. The actual saving is therefore likely to be lower than the cited figure. However, increased service provision (i.e., an increase in the outcome incidence rate) will boost the savings to the state.

Decreased cost of educating siblings with behavioural and emotional difficulties

The impact map suggests that short breaks services enable parents to spend more time with, and caring for, the disabled child's siblings. We assume this has a positive impact on these siblings, and that this will make them less likely to display EBSD. A reduction in EBSD, in turn, results in savings to the educational system.

Research indicates that having a disabled sibling doubles the chance of a child displaying EBSD,⁴⁵ and the most recently available data suggests that 4.3% of all children display EBSD⁴⁶. As the general population includes siblings of disabled children, however, this results in double-counting. We therefore assume that an extra 4.0% of siblings may develop EBSD (as opposed to 4.3%).

We assume that each disabled child has, on average, 0.8 siblings.⁴⁷ This equates to 247,800 siblings who are potentially at risk of EBSD.⁴⁸ We further assume that half of these siblings are in primary education and half are in secondary education, and that these education systems bear additional costs in meeting the needs of these children.

We use Ofsted estimates for the cost of educating children with EBSD in primary and secondary schools, which are £1,078 and £3,234 respectively.⁴⁹

Based on these assumptions, we estimate that current savings to the State amount to £4,487,757 per year. The calculation is presented in Table 4.4.

If we take the four cost savings identified in Tables 4.1–4.4, we arrive at a saving to the state of £36,537,573. That is based on current levels of outcomes incidence (that only 21% of the available number of disabled children receive short breaks services) and might therefore benefit in the ways presented in the impact map.

⁴⁵ Copps J and Heady L (2008) *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families* (London: New Philanthropy Capital) p 16.

⁴⁶ Office for National Statistics (2004) Mental Health: Mental disorders more common in boys. <http://www.statistics.gov.uk/CCI/nugget.asp?ID=853&Pos=2&ColRank=2&Rank=1000>. Note this is based on 1999 data.

⁴⁷ *Ibid*, p 14.

⁴⁸ Based on our estimated DLA adjusted disabled child population of 309,750, children.

⁴⁹ Ofsted (2003) *Pupils with emotional, behavioural and social difficulties in mainstream schools*. Cited in Copps and Heady (2008) *op. cit.* p 16.

Table 4.4: Annual savings stemming from reduced EBDC expenditure by schools.

Calculation step	Value
Increase in EBSD in siblings (i.e., doubling of baseline rate)	4.0%
Extra cost to a primary school per year per pupil	£1,078
Cost to primary education system (assumes 123,900 extra cases of EBSD)	£5,342,568
Extra cost to a secondary school per year per pupil	£3,234
Cost to secondary education system (assumes 123,900 extra cases of EBSD)	£16,027,704
Total savings per year	£21,370,272
Outcome incidence rate (percentage of children actually receiving short breaks services)	21%
Potential savings to state at current level of provision	£4,487,757

The potential savings to the state from provision of short breaks, plus the associated activities listed at the beginning of this Section, for all disabled children, for whom short breaks are appropriate, would amount to approximately £174 million.

How can the value of short breaks services be maintained?

A key variable in estimating impacts is how long they last over time. The ‘benefit period’, as it is known, can act as a multiplier on any savings. We therefore aim to establish the benefit period of effective short breaks services provision, i.e., how *enduring* the impact is.

Despite more than two decades worth of research into the impacts of short breaks and respite provision, methodological shortcomings make it impossible to describe the durability of their impact with any certainty. In their very recently completed literature review, which encompassed 50 studies on the subject conducted between 1999 and 2009, Robertson *et al.* conclude that the quality of research into short breaks provision has not improved in recent years:

A decade on, the evidence base for the impact of short breaks on carer well-being has increased but many of the shortcomings noted by McNally et al. (1999) in relation to studies of all carers do still apply to the evidence base

*concerning the impact on the well-being of carers of disabled children. Methodological problems include small sample sizes, lack of control groups, single and short post-respite follow-ups, and interviewers not being blind to the study conditions.*⁵⁰

The authors cited in the above paragraph, McNally *et al.*, concluded that ‘...there was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers’ well-being’.⁵¹ Robinson *et al.* come to the same conclusion:

...there is still no evidence on whether the initial impact of short breaks on carer well-being translates into a long-term reduction in outcomes such as carer stress, or whether in fact these return to baseline levels once the ‘honeymoon period’ of short breaks fades.

*The evidence also suggests that short breaks enable carers to carry out what are relatively mundane activities, such as sleeping and social contact. The importance of such fundamental aspects of human functioning cannot be overemphasised, but as has been noted in this review, short breaks are limited to such fundamentals and cannot be seen as a panacea in the absence of other forms of support. Short breaks are unlikely to impact on many other areas of carer well-being such as their informal support networks, or address, for example, the difficulties inherent in caring for a child with severe behaviour problems.*⁵²

The only study that looked at the impact of holistic service provision for families of disabled children found that short breaks only had a positive impact one year after provision if they were part of a package of measures that included, e.g., training on coping skills and a volunteer to work with the child.⁵³

We must therefore conclude two things:

1. First, any savings to the state arising from effective short breaks service provision can be applied only in the financial year in which the service is provided. There is no evidence to support the view that short breaks services have a more enduring impact on disabled children and their parents/carers after they stop receiving them.
2. Secondly, any savings to the state arising from effective short breaks provision cease very soon after the level of provision is curtailed.

⁵⁰ Robertson J, Hatton C, Emerson C, Wells E, Collins M, Langer S and Welch V (2009) *The impacts of short break provision on disabled children and families: An international literature review.* (Lancaster: Centre for Disability Research (CeDR), Lancaster University) p 10.

⁵¹ *Ibid*, p 5.

⁵² *Ibid*, p 28.

⁵³ *Ibid*, p 28.

5. Conclusions

This study is not designed to provide a comprehensive analysis of the impact of the short breaks programme. Nor can it provide more than an indicative guide to the type and level of cost savings the state receives from the provision of short breaks services.

It has, however, identified a number of key conditions surrounding the provision of short breaks services. These are:

- The type of impacts identified in this report cannot be achieved by short breaks alone. It is an imperative that short breaks services are provided as part of a holistic range of services that support families with disabled children (see list at beginning of Section 4).
- Based on the lack of evidence of enduring benefits beyond the lifetime of the programme's activities, current service levels need to be maintained in order to maintain savings to the state.
- There are other compelling reasons for maintaining a higher level of service provision.
 - This report has not quantified the social benefits arising from effective provision of short breaks services, i.e., outcomes benefiting disabled children and their families rather than the state. Doing so would be a worthwhile exercise, however, as the investment by AHDC in transforming short breaks services provision may well show a good return.
 - Our analysis of Pathfinder data returns shows that access to services is still limited, with currently only an estimated 14% of disabled children receiving short breaks services, despite massive investment in short breaks amongst Pathfinder authorities.

Given the savings to be made, this makes a compelling argument for continuing and strengthening efforts to broaden access. This comes with a caveat however; given the amount of money invested so far, LAs simply must do better in terms of both broadening access and collecting data based on nationally understood definitions.

Appendix 1: Numbers of disabled children with complex needs

Estimating the population of children with complex needs is difficult. First, any attempt to estimate is hampered by the use of different definitions by different authorities and service providers. For instance, PCTs, disability teams and schools all see complex needs from the perspective of what they need to do in order to meet these needs. Secondly, our interviews indicate that despite AHDC guidance and TDC requirements to gather data on children with ASD and complex physical needs, not all LAs appear to agree with these definitions of complex need. Our interviews resulted in the following definitions of complex needs, some of which have no bearing on the Full Service Offer:

- Children requiring specialist skills from care services providers.
- Children with complex health needs, e.g., technology dependent.
- Transition periods e.g. from childhood to teenage years.
- Complex family situations e.g., lack of a support network, mental health, relationship breakdowns, etc. – basically anything that makes for a stressful environment that could potentially impact on the family’s ability to cope.
- Families with more than one disabled child.

For purposes of simplicity, we have opted to use the number of children entitled to the ‘Higher Rate’⁵⁴ DLA as a proxy. It is a useful proxy because it is not means-tested, as some other programmes are (e.g., the Family Fund Trust), and because very recent data are available. We acknowledge that this may result in a slight under-count, as some children with high levels of special educational needs may not be included.

In February 2009, a total of 362,890 children under 18 were entitled to DLA; of these, 132,140 were entitled to the Higher Rate DLA.⁵⁵ In other words, our calculation assumes there are 132,140 children with complex needs. This implies that roughly 29% of disabled children can be considered to have complex needs.⁵⁶

⁵⁴ This is the highest rate available.

⁵⁵ Based on the DWP Tabulation Tool available at <http://83.244.183.180/100pc/tabtool.html>, by selecting “all entitled caseloads” as a sample and displaying to show “Care Award Type” by “Age of Claimant”.

⁵⁶ Based on our estimated disabled child population of 459,000 children.

Appendix 2: Outcome incidences for disabled children with high support needs

Looking at incidence of provision to disabled children with complex needs, if we make the conservative assumption that 29% of disabled children can be considered to have complex needs, there are roughly 734 such children in this Pathfinder authority's area. Based on the LAIMP data, we estimate that 86% of short breaks services were provided to children with complex needs,⁵⁷ which suggest these LAs provided short breaks services to an average of 456 children with complex needs.⁵⁸ This suggests that roughly 62% of disabled children with complex needs received short breaks services in these Pathfinder LAs.

⁵⁷ Groups A and B in the LAIMP returns. however the structure of the return does not provide an overall figure for the number of children in Groups A and B. We have therefore used a proxy based on provision of *overnight* short breaks. Please see Appendix 2 for the calculations of averages.

⁵⁸ i.e. 86% of the 549 children served.

Appendix 3: LAIMP return averages

Table A4.1: Proportion of disabled children in receipt of short breaks services

	LA 1	LA 2	LA 3	LA 4	LA 5	Average
Total child LA population	43,527	138,800	157,916	69,000	42,652	90379
Estimated disabled child population (4.8%)	2,089	6,662	7,580	3,312	2,047	4338
Number of disabled children served	398	327	1,202	559	260	549
% of disabled children served	19%	5%	16%	17%	13%	14%

Table A4.2: Disabled children in receipt of overnight short breaks services.

	LA 1	LA 2	LA 3	LA 4	LA 5	Average
Total disabled children served	67	62	473	81	135	164
Groups A & B children served	55	62	375	81	91	133
% of A&A children as proportion of total served	82%	100%	79%	100%	67%	86%