

Short breaks toolkit

for parent carer forums



*improving
services*



teamwork

Information for parent carer forums – England

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About this toolkit

This toolkit has been created by Contact for the Short Breaks Partnership.

It provides an overview of the legal framework relating to developing and providing short breaks services. We have also included case studies from parent carer forums showing some of the ways they are engaging with their local authority short breaks' commissioning planning and delivery.

Findings from Contact's SEND survey of parent carer forums provide a perspective on how short breaks policy and provision meets legal requirements. Parent carer forums can use this, along with the SENDirect research when considering the availability, quality and sufficiency of short breaks in their local area.

This guide sits alongside other guidance and resources produced by the Short Breaks Partnership:

- Council for Disabled Children has produced guidance for short breaks commissioners.
- Action for Children has produced guidance for short breaks providers.
- Kids have produced guidance for children and young people, including a video showing their experiences of short breaks services.

Each set of guidance, including this toolkit, is supported by e-Learning modules.

The Short Breaks Partnership

The Short Breaks Partnership is a consortium of charities made up of Contact, the Council for Disabled Children, Action for Children and KIDS. The consortium has received funding from the Department for Education to develop guidance on the importance of short breaks services for parent carer forums, children and young people, local authorities and commissioners and short breaks providers.

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Particular thanks go to Steve Broach, Barrister at Monckton Chambers, for providing legal guidance on each of the areas covered by this toolkit.

Steve is co-author of *Disabled Children: A Legal Handbook* (Legal Action Group, Second Edition, 2016) and *Children in Need: local authority Support for Children and Families* (Legal Action Group, Second Edition, 2013).

The Short Breaks Partnership Bulletin

During 2015/16, the Short Breaks Partnership published quarterly bulletins, which included information, advice and guidance on short breaks services. Much of the information in this toolkit has been sourced from these bulletins, which are also available at

 www.contact.org.uk/pcp/shortbreaks



Introduction

Short breaks were one of the central areas for development as part of the 'Aiming High for Disabled Children' programme, alongside parent participation, Disabled Children's Access to Childcare (DCATCH) and transition. Whilst parent carer participation has gone from strength to strength, many areas are seeing short breaks slip down the agenda. Contributing factors to this include how local authorities receive funding for short breaks, high turnover in statutory authority workforce and a broader focus on the special educational needs and disabilities (SEND) reforms.

The requirement to provide short breaks services is not new. The law requires local authorities to provide services designed to:

'minimise the effect on disabled children within their area of their disabilities; to give such children the opportunity to lead lives which are as normal as possible; and to assist individuals who provide care for such children to continue to do so, or to do so more effectively, by giving them breaks from caring.'

(Children Act 1989, schedule 2, para 6)

In 2011 the Breaks for Disabled Children Regulations came into effect. They added to the legal duties set out within the Children's Act 1989 and Children and Young People's Act 2008. They set out a number of requirements adding detail as to how short breaks can help families. This includes education, training or any regular leisure activity; meeting the needs of other children in the family more effectively; or carrying out day-to-day household tasks. (The Breaks for Carers of Disabled Children Regulations 2011, part 3)

An area of good practice also established during the 'Aiming High for Disabled Children' programme was the provision of short break services for disabled children and their families which offered support in the right way at the right time, without the requirement of a formal assessment.

'Responsive services should be easily accessible for all disabled children and their families who need them, designed around the child and family, and delivered in a coordinated and timely manner.'

(Aiming High for Disabled Children: Better Support for Families)

We know that short breaks services offer both a valuable lifeline for families, and give disabled children and young people opportunities to enjoy different experiences, make friends and realise their plans and ambitions in life. There is compelling evidence that providing short breaks results in positive outcomes for children, young people and their families and statutory authorities alike:

- disabled children and young people experience increased choices, wider social networks and are growing in confidence and independence
- parents experience more choice and control of family life, develop supportive peer relationships, and their expectations and aspirations of what their children may achieve are raised
- local authorities see less need for social care interventions, a decrease in costly out-of-area placements and a fall in the number of disabled children entering the looked after system.



However, despite the wealth of evidence demonstrating the importance of short breaks, and the fact that local authorities are legally bound to provide a range of short breaks services, we know that the quality of provision remains patchy. While there are many examples of great short breaks services that are being developed around the country, there are also far too many disabled children and young people and their families who continue to miss out due to lack of appropriate local provision.

Short breaks provision works best when parent carers, and children and young people work in partnership with professionals to design, develop and improve services. This means that families receive services which meet their needs, and professionals do not commission services that families do not want or value, resulting in less complaints and wasted resources. Furthermore, co-production is an underlying principle of the Children and Families Act (section 19), and local authorities have a legal duty to consult with parent carers when developing their short breaks provision and service statement.

Of course, developing participation and co-production is not easy. It often involves a big commitment and often a huge culture change for professionals at all levels. It makes huge demands on everyone's skills, time, energy and enthusiasm... but the rewards are worth it. We also appreciate that the current financial climate can present challenges to local authorities and health services, with important decisions to be made about all service provision, including that of short breaks services.

The Short Breaks Partnership came together in an effort to support these challenges. Building on the work of the Short Breaks Network, and many other partners across the sector, we have been working to help local authorities and commissioners, providers of short breaks, parent carers and children and young people understand the value of short breaks, and share examples of great practice in commissioning planning and delivery of short break services.

Working with families helps professionals to understand what needs to happen to develop services that meet families' needs. Meanwhile families gain an understanding of the complexities involved and the challenges faced by the professionals who have to bring about changes to services. Working together, recognising each other's expert knowledge, families and professionals are able to find creative solutions and reach informed decisions that make effective use of resources and deliver the best possible outcomes for disabled children and families.

We hope that this toolkit will help your forum to build on the relationships you already have at a local level, and to develop new partnerships, in order to make sure that all families in your area are able to access the short breaks provision they need.

“For some parents the provision of short breaks simply means the difference between being able to cope with their disabled child, and not being able to cope.”



Short breaks – the general duty

This section describes the legal duties that local authorities have in relation to short breaks. A case study showing how Hampshire Parent Carer Network has been working with the local authority to develop their short breaks provision is at the end.

Legal and Policy

Short breaks at home or in the community must be provided to a disabled child under section 2 of the Chronically Sick and Disabled Persons Act 1970, when they are necessary to meet that child's needs.

The 'short breaks duty' was introduced by section 25 of the Children and Young Persons Act 2008. It amended the schedule to the Children Act 1989 (para 6) to include a new duty:

'to assist individuals who provide care for [disabled] children to continue to do so, or to do so more effectively, by giving them breaks from caring.'

Detailed requirements are imposed on local authorities by the regulations made under the duty – The Breaks for Carers of Disabled Children Regulations 2011. Regulations are law and must be followed in the same way as an Act of Parliament. The short break regulations do three important things.

1 Requires local authorities to have regard to the needs of carers:

(a) at crisis point, and

(b) who would be able to provide care for their disabled child more effectively if breaks from caring were given to them to allow them to:

(i) undertake education, training or any regular leisure activity,

(ii) meet the needs of other children in the family more effectively, or

(iii) carry out day to day tasks which they must perform in order to run their household'

(Regulation 3)

2 Expand the scope of the duty, so that local authorities are required to:

'provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or to do so more effectively'

(Regulation 4)

This range of services must include:

- ***day-time care in the homes of disabled children or elsewhere***
- ***overnight care in the homes of disabled children or elsewhere***
- ***educational or leisure activities for disabled children outside their homes***
- ***services available to assist carers in the evenings, at weekends and during the school holidays.***



3 Require the production of a ‘short breaks services statement’ (Regulations 5) setting out:

- ***the range of services provided***
- ***any eligibility criteria***
- ***how the range of services is designed to meet the needs of carers in [the] area.***

The statement must be published and kept under review, which implies that it must be updated when necessary, for example when any eligibility criteria change. The statement must be published on the website as part of the ‘local offer’ introduced under section 30 of the Children and Families Act 2014.

The following are some key points of interpretation in relation to each of the duties imposed by the regulations.

Regulation 3

Creates a purpose for the provision of short breaks. As well as crisis care, short breaks should:

- ***enable family carers to study or undertake leisure activities***
- ***meet the needs of other children***
- ***carry out household tasks.***

What is missing from this list is work, because the service designed to assist family carers of disabled children to work is childcare, which has its own statutory scheme. Given the wider duties of local authorities to safeguard and promote children’s welfare, it is also essential that every short break is a positive and safe experience for the disabled child.

Regulation 4 – the sufficiency duty

This is very important. For a local authority to comply with this duty, it must know:

- ***the population of disabled children in its area and the level of need in that population, and***
- ***the level of service currently available to meet that need.***

Informed by this evidence the local authority must exercise its judgment as to whether the range of services is:

‘sufficient to assist carers to continue to provide care or to do so more effectively.’

Regulation 5 – short breaks services statement

This is an important aid to transparency and fairness in the allocation of short breaks. Through the statement, families should know:

- ***what breaks are available, and***
- ***what criteria need to be met to access them.***

The statement must also show that the sufficiency duty imposed by Regulation 4 has been met – by setting out:

‘how the range of service is designed to meet the needs of carers in [the] area.’



To step back from the detail, the scheme imposed by the short breaks duty and the accompanying regulations establishes short breaks as a vital statutory service. There is no doubt that under the duty every local authority must have a range and level of short breaks available which it considers sufficient to meet the needs of families in its area. That judgment on sufficiency must be properly informed by all the evidence.

However, the duty falls short of giving any individual disabled child or family a right to a short break service. That right may be found elsewhere in the statutory scheme affecting disabled children, most often the Acts below:

The Chronically Sick and Disabled Person's Act 1970

Sets out a range of services to individual disabled children, for example:

- ***leisure facilities (this could mean outings or a placement at a day centre)***
- ***travel and other assistance, like travel to and from a day centre***
- ***holidays.***

The Children Act 1989

Sets out a range of support services including the right to permanent or temporary residential accommodation, if a child needs it. It forms the legal basis for residential short breaks. Section 20(1) relates to residential short breaks where families are at crisis point. If a child needs this service, it should be provided. If there are no suitable facilities locally, a local authority can look outside its local area. Some examples of services listed under the Children Act 1989 are:

- ***occupational, social, cultural or recreational activities***
- ***home help***
- ***assistance to enable a child and family to have a holiday***
- ***travel assistance.***



Case Study 1

How the views of parent carers are informing short breaks provision in Hampshire

Sharon Smith, Hampshire Parent Carer Network

Hampshire County council provides a range of short breaks services which have been developed in partnership with parents and carers, and which over 5,000 families access. These services have proven to be hugely successful in helping children and young people with additional needs and disabilities to take part in positive activities, and in providing their parents and carers with a much-needed short break from their caring role.

These services meet the needs of a wide range of children and young people, and include:

- buddy schemes
- supported access to mainstream groups, and
- the provision of specialist activities and play schemes.

Parents and carers pay a contribution that covers the cost of the activity, and funding is made available by Hampshire council to provide the support required to enable children with additional needs and disabilities to access these services.

The Hampshire 'Gateway' short breaks service offers a range of short breaks to all disabled children and young people aged 0-19 who live, or attend school in Hampshire (excluding Portsmouth, Southampton and the Isle of Wight). The service is mainly open-access, with the exception of support provided through the Disabled Children's Team following a social care assessment of needs.

Follow the links below to see what the service looks like:

- Hampshire Gateway Card
- Hampshire Gateway Website
- Short breaks services statement

In 2014 over 5,100 Gateway Card holders were able to access a short break from caring. This is an increase of 46% year on year from 2013 (3,500) and 325% compared to 2012 (1,200).

Steve Crocker, Deputy Director, Children and Families says:

“There's every reason for local authority officers to engage effectively with parents' groups. As well as their experiences of parenting disabled children, parents have a range of valuable experiences, ideas and skills which can help shape future service provision, even in the most difficult of circumstances.”

The 'Gateway' short breaks service has been developed through a high level of engagement with two local organisations: Parent Voice and Hampshire Parent Carer Network, the local Parent Carer Forum. Decisions on how funds are allocated to short breaks services are made at grant funding panels that include parents, carers and local authority officers. Parent Voice and Hampshire Parent Carer Network representatives are also involved in the short breaks strategy working group that co-produced Hampshire council's short breaks service statement.



Parent feedback on the 'Gateway' short breaks service is very positive! This highlights the importance of these services, for both them and their children.

'Great activities for my son and such a lifeline for me. A short break allows me to keep going through the really tough times.'

'This is the only way we can have a break from caring. It is a lifeline service.'

'Parents and carer of these young people need time to recharge their batteries and the young people benefit from time spent with other young people.'

'This is the only time my son can attend an activity without me, it is my only break.'

'Short breaks enable my disabled son to play with his friend, and his siblings to have a bit of normality, they are vital!'

Despite financial pressures on statutory services in recent years, the local authority had made a commitment to protect short breaks services in Hampshire by maintaining funding at a consistent level. However, due to the number of children accessing short breaks services increasing, the amount of available funding per child was effectively less.

Through effective partnership working, the grant funding panels and parent representatives were able to work with providers to achieve the same level of services for families in despite these challenges.

In January 2014, a report was presented to Hampshire councils' Children and Families Select Committee, which set out the budget for children's services in 2014/15 and options for the 2015/16 budget. This report included a proposal to reduce the children with disabilities budget from £3.5m to £2.5m by cutting provision in residential care, respite and short breaks services.

Hampshire Parent Carer Network knew how important this provision was because they had been involved in the development of the 'Gateway' short breaks service, which greatly benefited many families. They also recognised the impact on families if these services were cut, namely that they would likely end up in crisis. Because of these factors, Hampshire Parent Carer Network felt it necessary to initiate discussion with the local authority to understand their reasoning behind the proposals, to ensure the value of short breaks was fully appreciated and to explore the potential for workable alternatives.

Gail Bedding, chair of Hampshire Parent Carer Network says:

"Maintaining our relationship with the local authority is key to our work, we are involved with many other work streams that will make a difference to many families and it is very important that we are respected."

This area of participation, lasting over a year, involved the local parent carer participation representatives, Hampshire Parent Carer Networks' participation co-coordinator and much support from many of the families living in Hampshire. The work was all-encompassing and took a great deal of time, energy and commitment. In addition, there was the added emotional aspect felt in understanding how important these services were, and the devastation families would experience if they were cut.



Despite these challenges Hampshire Parent Carer Network were proactive in ensuring that the positive relationships with the local authority and other partners was maintained, and that this would shape their approach with the activities undertaken.

As part of the programme of participation activities, legal advice was sought on what options there may be to support the provision of short breaks services and to query the process around reducing these services. This enabled Hampshire Parent Carer Network to engage with the local authority in an informed manner, and to be able to understand and articulate the value of short breaks services alongside the legal duties and responsibilities for statutory authorities.

Wider areas of activity included:

- the launch of a short breaks survey to gain the views of parents and carers, providers and other stakeholders, and presenting these findings and further reports to the Children and Families Select Committee
- making deputations to the executive lead member for children's services
- the establishment of a cross-party councillor-led Task and Finish group to review short breaks provision
- encouraging families to highlight the personal value of short breaks services to their local councillor,
- supporting families to engage in the local authorities' consultation process in an informed manner.

Kieran Lyons, disability services manager says:

“Hampshire Parent Carer Network has worked with Hampshire County council on shaping our short breaks services for the future. Although this has been a challenging and difficult process, the recognition that parent involvement often leads to better outcomes has meant we have been able to acknowledge our differences while agreeing the route for the future.”

In January 2015, councillor Mans announced that the Hampshire County council would use funding from their reserves as a one-off payment to protect the budget for short breaks services in 2015/16. Looking to 2016/17 and beyond, a new partnership working group has been established with representatives from Hampshire Parent Carer Network, Parent Voice and from short breaks providers. This group will consider what range of short breaks services could be delivered on a significantly reduced budget.

Hampshire Parent Carer Network spent months working alongside short breaks providers and Hampshire County council to explore the real impact of substantial cuts, with a series of meetings and workshops taking place from March 2015 onwards. Listening to the collective voice of its 500+ members and the 1,500 others who responded to Hampshire's survey with their views, it was clear that cutting short breaks would destroy the lives of many families, and in October 2015, the council announced that it would not be cutting budgets for short breaks services in 2016/17.



Gail Bedding, CEO of Hampshire Parent Carer Network, welcomed councillor Perry's decision, saying:

***“Parent carers have been influential in the development of the short breaks programme over the past five years. Their local knowledge and their advice in the allocation of grants has been invaluable in meeting the needs of children and young people with a wide range of great activities. Hampshire Parent Carer Network knows that short breaks are vital for our families. I am delighted that now we can continue to help shape the service as it moves forward into 2017.*”**

“Hampshire’s excellent short breaks programme provides play and leisure opportunities for disabled children and young people. They have fun, learn new skills, and gain independence. Exhausted families get some respite, which can save them from going into crisis. The landmark decision not to cut budgets for 2016/17 leads the way in signaling how short breaks improve the lives of disabled children.”



Short breaks and the local offer

This section describes how short breaks fit into the 'local offer'. Every local authority must develop a local offer that enables parents and young people to see what services are available in their area and how to access them. You can also find a case study example of how Wiltshire Parent Carer council has shaped both the local offer and Wiltshire's short break scheme.

Legal and policy

The local offer introduced by section 30 of the Children and Families Act 2014 is fundamental to the special educational needs (SEN) and disability reforms. It is intended to benefit all disabled children and young people in a local authority's area, not just those with Education, Health and Care plans.

The *Special educational needs and disability code of practice: 0 to 25 years* states (para 4.2) that the local offer has two key purposes:

- to provide clear, comprehensive, accessible and up-to-date information about the available provision and how to access it, and
- to make provision more responsive to local needs and aspirations by directly involving disabled children and those with special educational needs (SEN) and their parents, and disabled young people and those with SEN, and service providers in its development and review.

Considering these objectives in the context of short breaks, every local authority must therefore have a local offer which:

- provides high quality information on available short break provision and how this can be accessed, and
- helps ensure that short break provision is responsive to the needs and aspirations of disabled children and young people and families in their area.

The first of these aims relating to information is linked to the duty to have in place a 'short breaks services statement' (see Short breaks – the general duty on page 5).

Paragraph 4.44 of the *Special educational needs and disability code of practice: 0 to 25 years* makes clear that the short breaks services statement will 'form a core part of the local offer'.

The duty to include information on social care and health services, including short breaks, in the local offer is found in schedule 2 to the Special Educational Needs and Disability Regulations 2014 ('the 2014 Regulations'). Paragraphs 12 and 13 of the schedule state that the following information must be included in every local offer.

Paragraph 12 states:

'Health care provision for children and young people with special educational needs or a disability that is additional to or different from that which is available to all children and young people in the area...'

It is important to note that para 12 specifically requires the local offer to include:



- services for early years' providers (and schools and post-16 institutions) to assist them in supporting children and young people with medical conditions
- arrangements for making universal services accessible to children and young people with special educational needs and disabled children and young people.

The second point in particular should help make universal services that provide a form of short break more accessible to disabled children with health needs.

Paragraph 13 states:

'Social care provision for children and young people with special educational needs or a disability and their families...'

This includes short break services, as these are 'services provided in accordance with section 17 of the Children Act 1989', see para 13(a).

Paragraphs 12 and 13 require that information about:

- all short breaks provision which is expected to be available both inside and outside the local authority's area
- is published in local offers
- whether this is provided or funded by health or social care.

There is to date only one High Court judgment considering the requirements of the local offer, *R (L and P) v Warwickshire CC [2015] EWHC 203 (Admin)*. In that case, the claimants' solicitor identified that the local offer was only compliant with seven of the 23 paras in schedule 2. The Judge held that 'the proposed offer needs a good deal more work before it is issued in final (but variable) form' (para 79). The Warwickshire judgment emphasizes that every local offer must comply with all the requirements of schedule 2 – including the requirements that it must contain health and social care provision for disabled children and young people, such as short breaks.

The second part of the purpose of the local offer is to:

'make provision more responsive to local needs and aspirations.'

Local authorities are required to publish comments on the local offer (regulation 56 of the 2014 Regulations). These comments can be made not only on the accessibility of the local offer and the process by which it was developed and reviewed but also on:

'the content of its local offer, including the quality of the provision that is included and any provision that is not included.'

Local authorities have a positive duty to 'seek' comments from disabled children, young people and parents on short break provision, as well as all the other provision covered in the local offer (regulation 56(1)). Comments must be published at least annually (regulation 56(3)) and on an anonymised basis. Given that the local offer duty came into force on 1 September 2014 all local authorities should by now have published at least the first set of comments.



Why do local offer comments matter? The answer to this comes from section 27(2) of the Children and Families Act 2014, which requires local authorities to keep local provision under review and consider the extent to which it is sufficient to meet local needs.

If a local authority is told in comments on the local offer that its short break provision is inadequate, it will have a duty, under section 27 of the Children and Families Act 2014 to review this and determine whether further investment in short breaks is required.

This reinforces the sufficiency duty on short breaks imposed by the short breaks regulations covered in Section 2: Short breaks, the general duty.

For local authorities to determine whether short break services are sufficient they will need to gather information beyond the local offer comments. A decision on sufficiency will require the local authority to understand the size and needs of its population of disabled children and young people and review this against the level and quality of available services. In carrying out this exercise, local authorities will need to have regard to a range of data sources, including its Joint Services Needs Assessment (JSNA) and its disabled children's register – the Warwickshire case emphasises that the duty to maintain a register under para 2 of schedule 2 to the Children Act 1989 remains in force.

It will also be necessary for local authorities to work with children, young people and families when commissioning the services, to meet their sufficiency duties. This is the fundamental purpose of the requirement in section 19 Children and Families Act 2014:

for local authorities to have regard to the views, wishes and feelings of children, young people and parents in everything they do under part 3 of the Children and Families Act 2014.

It is also central to the joint commissioning arrangements required under section 26 of the Children and Families Act:

to secure the necessary education, health and care provision in each area.

This in turn requires the local authority and its partners to consider the JSNA and the joint health and wellbeing strategy, which again disabled children, young people and families should have the opportunity to influence, including through parent forums.

Section 116 A (5) (b) of the Local Government and Public Involvement in Health Act 2007 requires:

'the people who live or work in [the] area' to be involved in the production of every joint health and wellbeing strategy.

In March 2011, the Department for Education published departmental advice titled '*Short breaks for carers of disabled children*'. This advice supported the implementation of the Breaks for Carers of Disabled Children Regulations 2011 discussed in Section 2: Short breaks, the general duty.

The 2011 advice also described 'key areas of good practice'. The first of these was that:

'a 'local offer' is considered in order to provide families with access to some short breaks services without any assessment'



This good practice never found its way into legislation or statutory guidance. However, there is a clear steer in the 2011 advice that it is desirable for local authorities to allow access to short breaks on a non-assessed basis, to meet relatively low-level needs. As the advice notes, this approach is supported by the duty to work in partnership to safeguard and promote children's welfare found in section 10 of the Children Act 2004.

It is essential however, that where unassessed short breaks are available:

- the criteria for access to those breaks is set fairly – examples given in the 2011 advice at para 4.6 of unfair criteria are special school attendance or receipt of higher rate Disability Living Allowance.
- there is a straightforward route for disabled children, young people and families to access an assessment under the Children Act 1989 (for those under 18) or the Care Act 2014 (if over 18) if there is a possibility that the unassessed short breaks local offer may be insufficient to meet the child or young person's needs – or if the family simply want a formal assessment to take place. There is a duty to assess every child 'in need' under the Children Act 1989, and all 'disabled' children are 'in need' – see sections 17 (10) (c) and (11).

While local authorities are legally required to publish information on short break services and how to access them, there is no statutory requirement to provide access to short breaks on an unassessed basis – although there is a clear steer that such an approach is in line with the government's policy and complies with good practice.

As such, the new local offer requirement dovetails with the requirements of the short breaks duty covered in Section 2: Short breaks, the general duty. The local offer mandates publication of information about available services and supports the review of the quality and sufficiency of that provision generally. The short breaks duty, and in particular the regulations made under it set the specific requirement for a sufficient level of high quality short breaks to be available. Compliance with both sets of legal duties should result in short breaks being made available to those disabled children, young people and families who need them.



Case study 2

Co-produced and co-designed from the beginning

Stuart Hall, Wiltshire Parent Carer Council

Founded in 2008, Wiltshire Parent Carer Council is an independent forum for parent carers of children with special educational needs or disabilities aged 0-25. Wiltshire Parent Carer Council works as a strategic partner with those responsible for planning and providing services, ensuring the views, wishes and feelings of children and families are central to all decision-making processes.

An area of good practice established during the 'Aiming High for Disabled Children' programme was the provision of short breaks services for disabled children and their families which offered support in the right way at the right time, without the requirement of a formal assessment.

'Responsive services should be easily accessible for all disabled children and their families who need them, designed around the child and family, and delivered in a coordinated and timely manner.'

(Aiming High for Disabled Children: Better support for families)

Prior to Aiming High, fewer than 100 families across Wiltshire (excluding Swindon) were able to experience the benefit that regular access to a short break provided. Families receiving this type of support tended to be those who had children with the most complex needs. Where short breaks were being provided, this generally consisted of an offer of 'respite' following a social care assessment of needs.

Through the endeavors of Wiltshire Parent Carer council, its members and the local authority a culture change is becoming embedded where families, commissioners and providers actively work together in participation and coproduction. As a result of these positive relationships, there is an increased understanding of the respective challenges that face families, local authorities and providers. Services are developed with a focus on:

'what works for children, young people and families, informed by their individual experiences.'

Consequently, around 1,200 families are now able to access vital support through Wiltshire's short breaks scheme. Wiltshire Parent Carer Council has representatives on all service review boards providing feedback on parent carers' experiences of services. As a result, a short breaks service which had poor feedback at the outset has been supported to achieve a 98% customer satisfaction rate of good or better.

Susan Tanner, head of commissioning at Wiltshire council said:

"Co-produced and co-designed, from the beginning. You can't look at a 98% service satisfaction rate and not go: 'Wow, that's amazing!', and the reason is because we worked together. Together we make better decisions, it is just that simple!"



Many of these developments formed part of Wiltshire council's strategic vision for the future of short breaks. This was developed at the beginning of 'Aiming High' and was based on a series of consultation events held during 2008/09. The vision emphasizes how important short breaks are for families, and sets out how Wiltshire council and its partner organisations, including Wiltshire Parent Carer Council intend to improve the provision of all short break services in Wiltshire

To achieve the vision, we agreed to:

- work together (the local authority would work with parent carers and other local partners).
- fully involve parent carers and disabled children and young people in all aspects of short break planning and delivery. Specific attention was given to engaging with those who were not currently receiving services
- develop the market by working closely with providers and potential providers to ensure that we commissioned services that are of the highest possible quality, that met the needs identified, at the most efficient cost, as identified through engagement with parent carers
- regularly monitor and report on progress. This requirement was built into all tender agreements and includes the Wiltshire Parent Carer Council as an important partner in the process and relationship.

As part of the cycle of continuous improvement, feedback from families, including their views, wishes and feelings, proves to be of central importance to ongoing development of the short breaks scheme. This ensures that short breaks services are:

- of the highest quality
- focused on meeting the needs of families and
- they demonstrate excellent value for money.

During the initial consultation for the short breaks scheme families outlined a set of priorities they viewed as being fundamental to the development and delivery of short breaks services.

Parent carers told us they wanted:

- clear and easy to understand eligibility criteria
- they wanted experiences
- activities to be accessible, take place in a safe environment, be easy to access wherever they live across the county, and take place at times that work for the child, young person and family
- to be flexible and person-centered, and aim to meet the individual needs of children and young people, and their families
- a range of options and choice
- a break from their caring responsibilities.

These priorities reflect many of the requirements for local authorities for the provision of short breaks services as set out in the Breaks for Carers of Disabled Children Regulations 2011 including the publication of a short breaks services statement. This needs to give details of:

- the range of services provided
- any eligibility criteria for those services, and
- how the range of services is designed to meet the needs of parent carers in their area.



An area that has seen sustained participation result in excellent outcomes is the offer of support for settings for the development of inclusive practice. As a result of this:

- universal services have become more accessible
- families have greater confidence, and
- disabled children and young people are better able to enjoy community activities with their friends.

Through ongoing participation activities, the 'short breaks scheme' remains responsive to the needs of all eligible families living in Wiltshire. Examples include:

- extending the scheme to support children and young people aged 5-18 (to their 19th birthday)
- providing families with more choice of support by widening the range of commissioned services available.

One parent carer said:

“This isn’t about new services, it’s about enabling our children to access and enjoy what is already out there.”

In September 2014, when the Children and Families Act 2014 came into effect, Wiltshire Parent Carer Council was able to use their excellent relationship with the local authority to complete a programme of participation and coproduction activities to shape Wiltshire council’s local offer. In addition, they continue to work with the local authority to ensure that all services for children and young people with special education needs and disabilities and their families are developed within the ‘culture of coproduction’.



Short breaks and personal budgets

A personal budget is an amount of money identified by a local authority or other public body to deliver agreed provision. For disabled children and young people, this provision may often include short breaks. This section gives an overview of the legal context for personal budgets, and describes how in Middlesbrough, Parents4Change have enabled more families to have choice and control through an increased offer of personal budgets for short breaks services.

Legal and policy

Where local authorities or NHS bodies are responsible for meeting a disabled child or young person's needs for short breaks, this responsibility is now often discharged through a 'personal budget'. A personal budget sets out the amount of money that is available to spend on support for a child, to meet their assessed needs.

Personal budgets can be delivered in a variety of ways:

- direct payments - this is where the money to buy the service is transferred to the disabled person or family, who then commission or arranges the required service themselves
- a 'notional budget', which means it is held by the public body (NHS or local authority) who commission the service, in partnership with the disabled person or family, or
- a personal budget may be wholly transferred to a third party, for example a local voluntary organization to manage on the family's behalf.

In whatever format they are delivered, the purpose of personal budgets is to achieve greater choice and control over service provision for disabled children, young people and families.

Personal budgets are particularly relevant to children and young people who have Education, Health and Care plans (EHC plans), see Children and Families Act 2014 section 49. The Special educational needs and disability code of practice: 0 to 25 years states at para 3.38.

Young people and parents of children who have EHC plans have the right to request a personal budget, which may contain elements of education, social care and health funding. Partners must set out in their joint commissioning arrangements their arrangements for agreeing personal budgets. They should develop and agree a formal approach to making fair and equitable allocations of funding and should set out a local policy for personal budgets that includes:

- a description of the services across education, health and social care that currently lend themselves to the use of personal budgets
- the mechanisms of control for funding available to parents and young people
- clear and simple statements of eligibility criteria and the decision-making processes that underpins them.



To make this happen, the Special Educational Needs and Disability Code of Practice (para 3.39) imposes a number of process requirements on local authorities and partners, including:

- that there is a personal budget pathway developed within the EHC needs assessment and plan development process locally, and that
- partners 'identify how the new joint commissioning strategies will support greater choice and control year on year, as the market is developed and funding streams are freed from existing contractual arrangements'.

Personal budgets are also achieving greater prominence for children and young people with complex health needs. Since October 2014, disabled children and young people who are eligible for continuing care have had a right to have a personal health budget. There is detailed guidance from NHS England on how this right should be realised.

There may be 'exceptional circumstances' (guidance p15) where a personal health budget can be refused. The guidance suggests this could be:

'due to the specialized clinical care required or because a personal health budget would not represent value for money as any additional benefits to the individual would not outweigh the extra cost to the NHS'

From the perspective of disabled people and families, two important questions often arise in relation to personal budgets:

- can the funding be accessed as a direct payment?
- at what level should the personal budget be set?

The answer to the first question depends on which statutory agency is responsible for funding the service. In relation to short breaks, which are provided by the local authority under its social care duties, it is likely that there will be a right to have the personal budget amount paid as a direct payment.

The statutory scheme governing local authority direct payments for disabled children derives from Children Act 1989 section 17A and has been fleshed out by regulations and detailed guidance. Under regulation 7 (1) (c) of the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009, local authorities are under a duty to make a direct payment where:

- the parent appears to the authority to be capable of managing a direct payment by themselves or with such assistance as may be available to them
- the parent consents to the making of a direct payment (local authorities cannot insist that a person has a direct payment)
- the authority is satisfied that the person's need for the relevant service can be met by securing the provision of it by means of a direct payment, and
- the authority is satisfied that the welfare of the child will be safeguarded and promoted by securing provision by means of a direct payment.

Importantly, direct payments cannot be used to buy prolonged periods of residential respite care (being capped at a maximum of four consecutive weeks in any period of 12 months). Otherwise, there should be no restriction on the type of services and support that can be purchased using a direct payment, so long as it is meeting the eligible assessed needs of the child or young person.



In relation to short breaks funded by NHS bodies (typically Clinical Commissioning Groups (CCGs)) however, there is no right to have the personal budget paid as a direct payment. Guidance from NHS England sets out illustrative examples (at para 33) of why a CCG might decide not to provide someone with direct payments – for example, because ‘the benefit to that individual of having a direct payment for healthcare does not represent value for money’.

The second question is the amount of any personal budget or direct payment. A personal budget or direct payment must be fixed at an amount that is sufficient to meet the eligible, assessed needs. Public bodies are entitled (and arguably required) to meet needs in the most cost-effective way. However, fixed direct payment rates – for example on an hourly basis – will not be lawful if it is not possible to meet the assessed needs within those rates.

Public bodies need to be careful in using ‘resource allocation systems’ or ‘Raises’ when determining the amount of a personal budget or direct payment.

In *R (JL) v Islington LBC [2009] EWHC 458 (Admin)*, the Judge observed (at [39]) that she found it:

“hard to see how a system such as this one, where points are attributed to a standard list of factors, leading to banded relief with a fixed upper limit, can be sufficiently sophisticated to amount to a genuine assessment of an individual child’s needs.”

Raises should only be used as a starting point to generate an ‘indicative’ amount, which may then need to be altered upwards (or potentially downwards) to ensure the eligible needs are met - see *R (KM) v Cambridgeshire CC [2012] UKSC 23 at [28]*.

Any personal budget set in relation to an EHC plan (and arguably any personal budget for a disabled child or young person at all) must be set in compliance with Children and Families Act 2014 s 19. Section 19 states:

- the views, wishes and feelings of the child and his or her parent, or the young person, and
- the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.

This must be kept in mind when decisions are taken on (for example) the amount of a personal budget and whether to make the funds available by way of a direct payment.

Where direct payments are made, it is vital that parents are given proper support so they are able to access them. These are addressed in detail in the guidance for social care direct payments issued in 2009 and amended in October 2010. See in particular the section headed ‘Specific delivery issues’ at pages 47-54.

Written contracts should be provided for any support staff employed to deliver support via direct payments, and the guidance sets out the essential terms of these contracts at para 137. The guidance states at para 139 that:

‘councils may wish to include a payroll service, which will take responsibility for administering wages, tax and National Insurance for the direct payment recipient.’



Guidance is also given on the need for criminal records checks for anyone employed to deliver care via a direct payment. A further important consideration is now the potential requirement for direct payment workers to be enrolled onto a workplace pension scheme.

Local authorities will need to advise parents and young people in relation to this complex issue via their direct payments support services.

The guidance also deals with the question of local authority responsibilities to fund additional costs associated with direct payments:

114. In estimating the reasonable cost of securing the support required, councils should include associated costs that are necessarily incurred in securing provision, without which the service could not be provided or could not lawfully be provided. The particular costs involved will vary depending on the way in which the service is secured, but such costs might include recruitment costs, National Insurance, statutory holiday pay, sick pay, maternity pay, employers' liability insurance, public liability insurance and VAT. Some councils have found it helpful to include a one-off start-up fund within the direct payments to meet these costs as well as other forms of support that might be required, such as brokerage, payroll services and Criminal Records Bureau checks on employees.

A major area of concern for some direct payments recipients is the level of scrutiny afforded by the public body as to how the direct payments are used. The guidance on local authority direct payments states that:

- monitoring arrangements should be consistent both with the requirement for the council to be satisfied that the person's needs can and will be met, and with the aim of promoting and increasing choice and independence (para 220).
- councils should focus on achieving agreed outcomes, rather than on the service being delivered in a certain way (para 221).
- councils should aim to ensure that the information that the direct payment recipient is asked to provide is straightforward and the least onerous possible, consistent with monitoring requirements (para 222)
- the fact that the council is making direct payments rather than arranging services itself does not affect its responsibility to review an individual's care package at regular intervals (para 225)
- the frequency of monitoring will be dictated by the length of time the person has managed direct payments... and their particular circumstances. For children... reviews may be necessary more often so that the council remains satisfied that the direct payments promote and safeguard the welfare of the child (para 226).



In the light of the Children and Families Act, there is an obvious need for education, social care and health to join up funding in a coordinated personal budget, with some or all of the funds paid by a direct payment. In this regard the *Special educational needs and disability code of practice: 0-19* states at para 9.111 that:

'Local authority commissioners and their partners should seek to align funding streams for inclusion in personal budgets and are encouraged to establish arrangements that will allow the development of a single integrated fund from which a single personal budget, covering all three areas of additional and individual support, can be made available. EHC plans can then set out how this budget is to be used including the provision to be secured, the outcomes it will deliver and how health, education and social care needs will be met.'



Case Study 3

Increasing choice and control

Parents4Change, Middlesbrough

An essential principle to supporting disabled children and young people and their families is respect. Where individual 'views, wishes and feelings' are fully recognised and valued, services and outcomes are meaningfully personalised to 'aspirations'. Choice and control is a significant aspect of this, not least in relation to personal budgets.

“The [Children and Families] Act places the views, wishes and aspirations of children, parents and young people at the heart of the system and requires a culture change in the ways in which professionals work with families and with each other.” Edward Timpson, minister for children and families”

The experiences of the parent carer forum in Middlesbrough provides an example of how the 'views, wishes and feelings' of children, young people and families have been effective in influencing policy and practice.

The parent carer forum, Parents4Change have developed positive working relationships with council officers, local politicians and Members of Parliament. They have proactively engaged with council work-streams and focus groups, and arranged regular conferences to increase awareness around disability and represent the views of families.

Following a conference with families, Parents4Change produced a report that highlighted a number of areas where families felt that the availability of short breaks locally did not fully meet their needs. The report highlighted that provision appeared to be led by 'resources' rather than 'needs'; and featured complex processes and eligibility criteria that made it difficult for families to access support.

The key points raised by families were:

- eligibility criteria - criteria should be needs-led, not resource-led and the amount of red tape needed to access services needs to be greatly reduced
- short breaks should be made available for the whole family so everyone can go away together, for example on activity holidays and for weekends away with other families who have disabled children.
- there needs to be more education of the general public about disability and additional needs to increase tolerance, understanding and eradicate ignorance
- there should be pro-active access to, and availability of information and support, for example a directory given to each individual that includes all the relevant information a family needs
- a keyworker who families can call up for information and take up the individual needs of a family to save parents lots of time and energy finding information out for themselves
- it would be helpful if there was more promotion and expansion of all current services. There is recognition that there is a lot out there but families need to know where services are and also be able to access them.



Middlesbrough Borough council were committed to improving services and held a 'visioning' day bringing together more than 80 parents and professionals to consider short break provision. At this event the aim was put forward that:

'disabled children, young people and their families are involved in developing a range of flexible and easily accessible, high quality short break services and activities.'

As an outcome of the visioning day, a short breaks focus group was established in partnership with Parents4Change. One of this group's main achievements was the review and subsequent change to the eligibility criteria for short breaks. This demonstrated how the views of children and families can result in positive changes to policy and practice.

At the next conference, families had the opportunity to express their view on how support for disabled children should be prioritised. This feedback helped shape the 'multi-agency strategy for children with disabilities'. This strategy included the appointment of a short breaks facilitator and tendering of a new short breaks service.

The conferences were beginning to show real impact in gathering the 'views, wishes and feelings' of families, presenting these to strategic decision makers and enabling participation and co-production of services. Achievements include:

- a new short breaks 'text service'
- improvements to the key worker service
- greater flexibility for short break personal budgets.

The increased offer of personal budgets for short breaks was implemented following a successful pilot programme with families. Examples of how these have provided families with greater 'choice and control' include those of Amy and Ruth. Amy is mum to a little boy with complex disabilities who requires 24-hour care. Having a short breaks personal budget has enabled them to buy a travel bed to allow the family to take trips together. She said the flexibility and choice they had received through the personal budget was 'fantastic!'

Ruth is mum to a young man who has autism and Tourette's. They use their short breaks personal budget to go on holiday as a family and to pay for a season ticket so he can watch Middlesbrough Football Club, which he loves.

Ruth said:

"It's a good service – it's getting him out of the house as well as giving us a chance to do more as a family together. The holiday is great as we have a break and can relax as he does more on his own getting a level of independence in a safe place where he feels comfortable – life is a lot better now with a personal budget!"



Recently Middlesbrough Borough council has been involved with a successful pilot scheme to develop the personal budgets outcome and evaluation tool (POET). This is expected to be of great value to councils and health services in demonstrating how personal budgets can enable disabled children and young people achieve their ambitions in life.

There is no question that the relationships the parent carer forum has been able to develop with council officers, local politicians and Members of Parliament have proven to be of great value. The conferences too have been significant catalysts for change. The success is demonstrated by the increase of short breaks for families, which has risen from 28,090 to 49,593. In addition, the overall number of short breaks provided has also increased from 300 to 508 with continued improvements expected.

The forum continues to work closely with the council including the CEO of Middlesbrough Borough council; key political figures and the Mayor to ensure that the 'views, wishes and feelings' of children, young people and families remain central to all decision making in Middlesbrough.

Key Learning

Events

Regular conferences increase public awareness around disability and represent the views of families to council decision-makers.

Reports

Families experiences are gathered and used to inform the forum's annual report which provides an evaluation of needs in the area

Communication

Open and honest communication has fostered good relationships and provided a conducive environment for co-production.

Relationships

Positive relationships with local politicians and members of parliament increase public support and enable effective participation.



Short breaks for children with complex needs

Legal and policy

The overriding obligation on local authorities and NHS bodies, particularly Clinical Commissioning Groups (CCGs), is to work together to ensure children's needs are considered and addressed. This duty is expressed in a number of places throughout the statutory scheme – for example:

- Children Act 2004 section 10, which requires local authorities and health bodies to co-operate to safeguard and promote the welfare of children in their area
- NHS Act 2006 section 82, which requires NHS bodies and local authorities to co-operate to advance the health and welfare of their populations
- Children and Families Act 2014, which imposes a range of duties in relation to co-operation including a requirement for joint commissioning arrangements to be in place in every area (section 26).

It is particularly important that CCGs play a full part in the commissioning and development of short break services in their area, as there will be some children with needs of such complexity that they fall outside the scope of the duties owed by local authorities. This is shown by the important case of *R (T, D and B) v Haringey LBC* [2005] EWHC 2235 (Admin), concerning a three year old child with a tracheostomy.

The issue was whether either the local authority or the NHS body had a duty to provide child D with additional short break care. The Judge held that on the facts of that case the care required fell outside of the scope of the duties in the Children Act 1989 (para 68). A local authority cannot act as 'substitute or additional NHS for children' (also para 68). Therefore high levels of medical care (including nursing care) for children will be the responsibility of CCGs, not local authorities.

The key duty on CCGs is found in section 3 of the NHS Act 2006, as amended by the Health and Social Care Act 2012. This requires each CCG to arrange for the provision of a wide range of services

'to such extent as it considers necessary to meet the reasonable requirements of the persons for whom it has responsibility.'

This duty is drafted in very broad terms and does not create any specific right to health services for a particular person. This is one of the reasons why the imposition of duties on NHS bodies under the Children and Families Act 2014 is so important.

New advice for CCGs, health professionals and local authorities was published by central government in February 2016. In particular, under the Children and Families Act, where a disabled child with complex needs has an Education, Health and Care plan, the CCG must

'arrange the specified health care provision for the child or young person' see section 42(3)

Education, Health and Care plans are, however, reserved for children with significant special educational needs.



CCGs must also work with local authorities to contribute to the 'Local Offer' of services available, but there is no right to any particular level or type of services under the Local Offer. Paragraph 12 schedule 2 to the Special Educational Needs and Disability Regulations 2014 mandates that every Local Offer must include

'Health care provision for children and young people with special educational needs or a disability that is additional to or different from that which is available to all children and young people in the area.'

It is important to note that paragraph 12 specifically requires the Local Offer to include arrangements for making universal services accessible to children and young people with special educational needs and disabled children and young people, which may reduce the need for specialist short breaks.

The guidance which applies to all children with complex needs is the National Framework for Children and Young People's Continuing Care, which has recently been reissued (February 2016). The National Framework is for children whose needs are 'so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community' (para 2). Although the National Framework is said merely to provide 'advice' to CCGs, it sets out a detailed process by which eligibility for continuing care should be determined. Any CCG which departs significantly from the National Framework may therefore have to justify this if challenged in court.

The National Framework sets out a three stage process:

- assessment, led by a nominated children and young people's health assessor and leading to a recommendation as to whether the child has continuing care needs
- decision making, by a multi-agency forum or panel considering the recommendation and deciding whether or not the child has continuing care needs. The aim should be for a decision to be given to the child or young person and their family within six weeks (para 50).
- development of a package of care. The National Framework states that:

'Commissioners will decide how the continuing care will be provided, what proportion and level of resource is required to deliver it and how much needs to be specially commissioned.'

Importantly, the National Framework states that:

'Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care.'

This is plainly correct, albeit that the social care input must not require the local authority to act as a 'substitute NHS'. The National Framework recognises this by reference to the Haringey judgment, see para 26 and Annex C.

Guidance as to which children may have continuing care needs is provided in a 'decision support tool'. The National Framework states (para 148) that:

'A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care.'

Importantly one of the domains is 'behaviour'. As a consequence the National Framework states (para 28) that:

'Assessment of a child's needs should consider the extent to which a child with a learning disability, or autism may have a continuing care need due to challenging behaviour.'

There is undoubtedly an expectation under the National Framework that children assessed as eligible for continuing care will receive a bespoke package of support, which may include short breaks. The National Framework states (para 95) that:

'The package of care must be shaped by the child or young person's support needs, rather than by what is offered by providers.'

In deciding what level of services, including short breaks, are required by a child with complex needs, the CCG must take into account:

- the NHS Mandate for 2016-17, which states that vulnerable children 'should receive high quality, integrated services that meet their health needs'. The current NHS Mandate (2015-16) states that 'One area where there is a particular need for improvement, working in partnership across different services, is in supporting children and young people with special educational needs or disabilities'.
- the NHS Constitution, which contains a number of statements of 'rights', including that 'You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences' and 'You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary'.

CCGs will also need to consider disabled children's rights to health, including those in article 25 of the UN Convention on the Rights of Persons with Disabilities and article 24 of the UN Convention on the Rights of the Child, which will be relevant when decisions are made which engage the rights protected under the Human Rights Act 1998. Both the UN Conventions describe disabled children's rights to the 'highest attainable standard of health'.

At para 101, the National Framework states:

'Decisions about residential care and other social care support must of course be made by the local authority, as lead commissioner for social care, with health working alongside to identify how the child/young person's health needs can be met.'



That may well be true generally, but following the Haringey judgment the CCG will need to take the lead or act as the sole commissioner where the child's health needs are such that they fall outside the scope of the local authority's duties. These issues need to be addressed and resolved by local authorities and CCGs as soon as they arise in the light of the co-operation duties summarised above to avoid any detriment to the child.

Furthermore the National Framework states (para 54) that:

'Children and young people who require fast-track assessment because of the nature of their needs (such as a palliative care need) should be identified early and the child or young person's needs met as quickly as possible. The continuing care process should not restrict access to end-of-life care for children and young people who require immediate support over a shorter period, and should not result in any delay to appropriate treatment or care being put in place.'

In all decisions made in relation to children's health needs time will be of the essence. As the Working Together to Safeguard Children guidance says in relation to children's social care needs:

'For children who need additional help, every day matters' (para 10, p7). The response to children's assessed health needs must therefore always be made in a reasonable time. Where children are eligible for continuing care, the National Framework states that arrangements to deliver the package of care should be in place 'as soon as possible.'

As set out in the previous chapter, children with complex health needs will generally be entitled to a personal budget, and can receive a direct payment. There is however no right to direct payments in health – it will be up to the CCG in each case to decide whether the child's needs should be met that way if it is what the family want, subject to the usual public law requirements of fair, rational and reasonable decision making.



Case Study 4

The need for health support in universal settings and continuing care

Ben Palmer, Parent Carer Participation Associate, Contact

While many of the duties to provide short breaks sit with local authorities, health authorities have legal responsibilities to support children with special educational needs and disabilities (SEND) and their families.

The Special Educational Needs and Disability Regulations 2014 requires those responsible for health services, to make provision for:

‘services for relevant early years providers, schools and post-16 institutions to assist them in supporting children and young people with medical conditions’; and to make: ‘arrangements for making those services which are available to all children and young people in the area accessible to children and young people with special educational needs or a disability.’

Clinical Commissioning Groups (CCGs) also have a legal responsibility for securing, to a reasonable extent, the health care that a person needs, where their needs are so complex that they ‘cannot be met by universal or specialist health services’.

The National Framework for Children and Young People’s Continuing Care, along with recent legislation, has created a new integrated approach to the provision of services for children with SEND. However, there have many been difficulties for families where their child’s needs encompass health and social care. This case study shows how West Sussex County Council have addressed some of these issues in their area, by successfully working with the West Sussex Parent Carer Forum throughout the decision making process.

The situation that presented itself was the planned closure of two residential short break homes. A review of services was undertaken, which included feedback from the parent carer forum. Whilst feedback at a strategic level was sought, health providers did not speak directly to parents using the service. Previously, in November 2011, the council had worked along with the parent carer forum to co-produce their Short Breaks Services Statement. While this was not directly linked to the issue at hand, it proved to be instrumental in creating a positive working relationship.

When it came to the closures of the short break homes, the council worked alongside the forum to gather the views of those families who used the services. When health providers held an official consultation, the forum supported those directly affected to get involved, and offered a strategic view of the wider impacts of the closures. Following on from this, the forum worked closely with families, listening to their views, and providing support so that these views were paramount to this process.



As a consequence, a number of strategies were developed to make the transition following the agreed closures as smooth as possible, including:

- providing a space throughout the year at an alternative residential short break home
- the arrangement for specialist transport to the residential short break home
- increased training and support for foster carers
- improvements to other residential short break homes to allow them to support children with complex health needs.

The result is that the majority of families have made a transition to the new arrangements. This shows the clear benefit of participation, and highlights the value of coproduction with the parent carer forum in the review and development of services. This also shows that in order to successfully review services, it is necessary to engage with both the parent carer forum, and all other children and families directly, or indirectly affected.

The parent carer forum has also been involved in the improvement of GP services within the local area. As a result of this, one surgery has been awarded a Pathway to Pacesetter award for its improved services.

The practice in question have 114 patients under 16 on their register who have complex needs. Many of them found the experience of accessing services through the practice to be stressful and overly complicated. Parents frequently had to recount their child's complex health needs with each practitioner they met. A working party was created with parents from the forum to consider these issues.

This coproduction approach has resulted in a broad number of changes within the GP practice, which has affected the culture, ways of working and patient experience. These changes have made a truly significant difference to the lives of children and families, and include:

- the introduction of a 'Medical Passport' providing essential information to help clinicians and other staff to understand, and support appropriately each child with complex needs and their family. This includes their preferred method of communication, behaviours they may display and important medical information
- introduction of a 'flagging' system for parents of children with complex needs so when they telephone the surgery, the system displays the best practice for that particular patient. This means families do not have to provide lengthy explanations each time they call, and the reception staff are better equipped to carry out their roles
- improvements to facilities including 'Where's Wally?' posters, toys and books and a quiet area for children who find the environment overwhelming
- photo boards with staff member's roles have been added to the practice to help children and families easily identify those supporting them.
- a Facebook page has been created to allow parents of children with SEND to share their experiences and provide to feedback to the practice so communication is an ongoing and effective process.



Parents have been delighted with these improvements:

***'The surgery is now more flexible, they've changed their perception of parent carers and conversations are easier. [They] genuinely wanted to help us.'* Lindsey**

***'Since the medical passport we generally see the same nurse or doctor. This is so much calmer. My son needs to spin three times on the chair before the appointment can start and now everyone knows and accommodates this. They really care – the care they give makes a huge difference to us as a family.'* Zoe, parent of an autistic child**

Staff members have also seen these positive benefits:

***'The medical passports are a great innovation because staff can now prepare themselves before a consultation. There is definitely a better understanding between professionals and families.'* Debbie Elcome, Practice Coordinator**

West Sussex Parent Carer Forum have successfully been able to support improvements in both short breaks and other important services. However, the availability of short breaks for children with complex needs and their families is patchy, and not universally accessible. Much can be learned from the coproduction approach the forum in West Sussex have taken, the excellent outcomes achieved and the principles that can be applied where services for children with SEND are developed.

Key principles

The importance of widespread commitment from all parties to engage with parents, accompanied by the recognition that to be effective, this will require support and investment.

Acting upon and responding to issues raised by parents. Where parents feel their views are taken seriously they can see that they can genuinely contribute to decision-making processes.

Expectation to respond to parents' needs. A commitment to participation needs to be understood and reflected in the approach of all involved, reflecting the changing attitude from a 'can't do' to a 'together we can do' approach.



Understanding the current state of short break services

Having read the previous sections of the toolkit, parent carer forums will have an understanding of the legal responsibilities that local commissioners have in relation to short breaks, and be able to give examples of how parent carer forums in some local areas have been engaging with commissioners and providers to ensure these legal duties are met.

However, we know that the quality of short breaks provision, and indeed the extent of parent carer participation in commissioning planning and delivery, varies from area to area. The purpose of this section of the toolkit is to equip parent carer forums with national evidence on the current state of short breaks provision, and criteria describing what good practice in commissioning planning and delivery should look like, which you can use to have conversations with commissioners and other stakeholders in your area.

In addition to the national evidence, parent carer forums can also use the Short Breaks Partnership Statement Review Tool, published alongside this toolkit, to analyse the quality of short breaks provision in your area and the extent to which your local authority is meeting its legal duties in relation to short breaks. The Statement Review Tool contains a self-evaluation tool form with a series of questions to consider in relation to key areas of short breaks provision. Parent carer forums may want to work through the markers independently, and present the findings to local commissioners and providers as evidence for what is working well in short breaks provision and where improvements are needed. Alternatively, you may want to arrange to meet with local commissioners and providers and use the markers as a tool to assess progress together.

Why short breaks matter: key statistics

The overwhelming positive impact of short breaks on outcomes for disabled children and their families, and the resulting cost saving for local authorities has been well-established through a range of national studies. Below are some key statistics that you may want to use as evidence when engaging with commissioners – alongside any feedback from parent carers in your area about the difference that short break services make to them and their families.

- 76 per cent of parent carers experience stress or depression
- 72 per cent suffer from lack of sleep
- 80 per cent of parent carers of children with learning disabilities say they have reached or are close to reaching 'breaking point'
- disabled children make up ten per cent of children in care, compared to five per cent in the general population
- there is a direct relationship between the level and range of short breaks and 'lower levels of psychological distress, higher levels of life satisfaction and better health'
- parent carers cite short breaks as the single most important factor in helping their relationship and avoiding marital breakdown
- short breaks could save the state up to £174 million annually if all eligible children received them. This saving is based on decreased cost of long-term residential care, decreased cost to health services from reduction in parents', families' and carers' stress and decreased cost to schools of educating siblings with behavioural and emotional difficulties.



Recent research on short breaks

There is a range of evidence available from different organisations and research studies which considers the extent to which local authorities are meeting their legal duties in regard to short breaks and good practice in commissioning planning and delivery is spreading across the country.

Key findings from two recent pieces of research carried out by Contact and the National Network of Parent Carer Forums are summarised below. Parent carer forums may wish to use this national evidence in conversations with local authorities, alongside your knowledge of specific issues and good practice locally.

Links to other potential sources of national evidence for parent carer forums can be found in the resources section. In particular the Every Disabled Child Matters report *Short breaks, an uncertain future* contains statistics which you may find useful.

SENDirect Short breaks report, March 2016

SENDirect is an online service which allows parents and professionals to see what choices and services are available to them, to get information about their legal rights and to help create suitable new services where currently there are none. The service also provides guidance and information to help families to tell if an activity or service might be worth trying for their child.

SENDirect carried out an audit of local authorities' short breaks statement and local offer website pages and analysed responses to Freedom of Information (FOI) Requests to understand whether local authorities are carrying out their legal obligations relating to short break services. In addition to the audit and analysis of FOI responses, the team also looked at feedback from families gathered through SEN Direct surveys, engagement on social media and through blogging, as well as searches on the SENDirect website. SENDirect's research found that the majority of local authorities proved to be aware of the importance of consulting with families of disabled children, as well as the range of services offered locally and the difference between them. However, it also identified the following issues and problems with short break services:

Availability of information

Only the 60% of the local authorities have their short breaks statement on their local offer website page and 11 local authorities do not have the statement clearly visible even on the local authority website, which is a violation of the law.

Inaccuracy of the information available to families

37% of Statements are incomplete in terms of:

- range of services provided
- how these services meet the needs of carers and families
- evidence of reviews of the statement
- evidence of consultation of families during review.

Difficulty with accessing short breaks

Four local authorities are acting in contrast with the law since they are refusing short breaks to children without a formal assessment because they do not meet the eligibility criteria: 32 children have been illegally refused in the last 12 months.




Lack of consultation

78% of families consulted said that they have not been asked to feedback about short breaks planning.

The report recommends that local authorities develop their practice in three key areas:

- understanding what families want and the value that they place on short breaks provision
- ensuring that the short breaks services statement is easy for families to find and contains accurate information about the full range of services that may be available to them, and
- supporting families to be involved with service development and negotiate effectively to obtain what they want.

The full SENDirect *Short breaks report* will be available to view on the SENDirect website. For further details visit  www.sendirect.org.uk

SEND Survey 6, November 2015

In November 2015 the sixth *SEND survey* was carried out with local authorities and parent carer forums to gauge how effective they feel the implementation of the SEND reforms is in their local areas, and to identify challenges, support requirements, and examples of good practice that might be replicated in other areas.

A total of 104 parent carer forums across England responded to the survey (representing a 68.4% return). 69% of responses to the survey had four or more forum members completing the survey, highlighting that responses contained a cross-section of views. A third of parent carer forums discussed their responses to the survey with their local authority. The sixth SEND survey included questions asking parent carer forums' views on short breaks in their local area. It found that:

- 29% of forums feel that their local authority and CCG understand the needs of parent carers very well, or extremely well, in relation to short breaks. Only 15% feel that they measure the impact in assisting parent carers 'to continue to care or do some more effectively', very or extremely well.
- just 18% of the forums who responded feel that their local authority and CCG design short breaks based upon an understanding of their needs very well, or extremely well.
- of the forums who responded, 24% feel that their local authority and CCG work very well, or extremely well with their parent carer forum on the short breaks service statement and local offer. A further 29% report working moderately well.
- just 15% of forums believe that the short breaks service statement and local offer are very well, or extremely well based on the needs of families, a further 29% agreeing that they are moderately well based on needs.
- very low numbers of forums report that their short breaks statement or local offer meet the requirement to contain up to date information on eligibility criteria, or how services meet the needs of parent carers very well, or extremely well, just 14% and 13% respectively.
- 54% of forums report that their local authority is making changes to their short breaks provision during 2015/16 or have changes planned in 2016/17. However, 41% of forums don't know if their local authority will be making any changes to provision, and just over two thirds of forums don't know whether the budget will increase, or decrease. However, 0% of forums who do know their area's planned short breaks budget stated that the budget in their local area will increase.

A summary report of the sixth *SEND survey* results is available at

 www.contact.org.uk.summaryreport.pdf.

Once published, a full report of the survey will also be available on the Contact website.



Further resources

Short Breaks, an Uncertain Future, by Every Disabled Child Matters

This report, based on freedom of information requests submitted to local authorities across England in summer 2015, as well as focus groups and surveys of parent carers, found that more than half of local authorities (58%) had cut spending on short breaks for families with disabled children since 2011/12. It sets out the risk this poses in terms of undermining outcomes for disabled children and the successful implementation of the Special Educational Needs and Disability (SEND) reforms and the impact of reduced spending for disabled children and families. The report highlights the need for continued investment in short breaks provision, and for local authorities to publish data on the level of short breaks provision in their area.


 www.contact.org.uk/short-breaks-in-2015-an-uncertain-future-final.pdf

Challenging cuts to short breaks services by Every Disabled Child Matters

This legal resource aims to help families to challenge cuts to short break services in your area. It:

- explains what short break provision families with disabled children should expect to be available in their area
- explains the legal framework around short break services
- includes template letters to families with disabled children to help challenge decisions by local authorities
- signposts families to sources of legal support.

The full resource can be downloaded at:

 www.contact.org.uk/challenging-cuts-to-short-break-services-final.pdf

The template letters can also be downloaded in Word format at:

 www.edcm.org.uk/Template-letter-1.doc

 www.edcm.org.uk/Template-letter-2.doc

Webinar – Using the law to challenge cuts to short break service by Steve Broach, Barrister at Monckton Chambers

This webinar recording covers the background to funding for short breaks from the Aiming High for Disabled Children programme onwards, legal duties relevant to the provision of short breaks services, and relevant legal issues to consider in relation to proposals to cut services. It sets out potential avenues of challenge for parent carer forums in relation to proposed cuts to short break funding.

 www.youtube.com/usingthelawtochallengecuts

Disabled Children: A Legal Handbook 2nd edition by Steve Broach, Luke Clements and Janet Read

Authoritative, accessible guide to the legal rights of disabled children and their families in England and Wales. The authors navigate the many, often overlapping, sources of law, explaining the difference between what public bodies must do to support disabled children and that which they may do.



The handbook aims to empower disabled children and their families through a greater understanding of their rights and entitlements. It is essential reading for the families of disabled children, their advocates and lawyers, voluntary and statutory sector advisers, commissioners, managers and lawyers working for public authorities, education, social and health care professionals, students and academics.

Each chapter has been adapted into a PDF for you to download for free on the Council for Disabled Children's website. It includes chapters on:

- Legal fundamentals
- Children's services
- Education
- Health
- Housing
- Decision-making: The legal framework
- Carers
- Equality and non-discrimination
- Transition to adulthood
- Remedies.

📄 www.councilfordisabledchildren.org.uk/disabled-children-a-legal-handbook

The handbook is also available to purchase in hard copy at

📄 www.lag.org.uk/bookshop

You can also download the handbook on the kindle store.

Short breaks for carers of disabled children: Departmental advice for local authorities, Department for Education, March 2011

This advice was produced to help local authorities understand how to fulfil their duties under the Children Act 1989 and the Breaks for Carers of Disabled Children Regulations 2011. It is non-statutory, which means that it is not binding on local authorities, but parent carer forums may wish to signpost local authorities to this document to support them in developing good practice.

📄 www.gov.uk/Short_Breaks_for_Carers_of_Disabled_Children.pdf

Parent Carer Participation - an overview by Contact/National Network of Parent Carer Forums

This guide, written for commissioners and service managers, describes good practice in developing parent carer participation, and may be useful for parent carer forums to share with their local authority.

📄 www.contact.org.uk/pcp_overview.pdf

If you have any questions about this toolkit, or how to engage with your local authority to improve short breaks services, please get in touch with:

Contact regional advisor 📄 www.contact.org.uk/pcp

NNPCF representative 📄 www.nnpcf.org.uk/who-we-are



Support Contact

From cake sales, to running marathons, or signing up to be a regular giver – there are many ways you can help us continue to provide information, advice and support to ALL families with disabled children in the UK. Find out more:

www.contact.org.uk/fundraising

020 7608 8786

fundraising@contact.org.uk

Or why not get involved in our campaign work across the UK?

<http://www.contact.org.uk/campaigning>

Get in contact with us

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 www.facebook.com/contactafamily

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 helpline@contact.org.uk

Free family linking service

 www.makingcontact.org

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